EFFECTS AND MODIFIERS OF EXPERIENCED STIGMA AMONG PEOPLE LIVING WITH DRUG-RESISTANT TUBERCULOSIS IN LAGOS, NIGERIA.

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Thesis submitted in fulfilment of the requirements for the Doctor of Philosophy in Health Sciences in the Faculty of Health Sciences at the Durban University of Technology

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DECLARATION

I, Adejumo Adedeji Olusola, hereby certify that the work presented in this thesis is my own in its entirety, and where the work of others has been used, the appropriate citations have been included. This thesis has not been previously submitted to any institution and is being submitted to the Durban University of Technology in fulfilment of the requirements for the Doctor of Philosophy in Health Sciences degree.

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DEDICATION

This work is dedicated to God, the giver of life, wisdom, and grace. I thank God for His mercies and help in my difficult and challenging times. All that I am and have come from you, God. There is nothing I have that I did not receive from you. To God my Saviour, who alone is wise, be glory, majesty, praise, and honour. Amen.

ACKNOWLEDGEMENTS

I want to thank God Almighty for all His blessings and for making this study possible. It can only be him. Thank you, Jesus.

I want to acknowledge my family, my wife Esther and my three daughters, Oluwatosin, Toluwanimi and Mororeoluwa, for their support and encouragement. God bless you all.

I want to express my warmest gratitude to the following people for their contributions in completing this thesis:

To my supervisors, Prof. Firoza Haffejee, Prof. Olusoji Daniel and Prof. Champaklal Jinabhai, for their guidance, supervision, dedication, and sincere and valuable feedback, which is highly appreciated. You all made it easier for me to complete this work. I am grateful.

To Dr. Ellen Mitchell, my mentor, who inspires me to improve. You suggested long ago that I undertake this program. Thank you for the counsel and support. You gave valuable advice and provided direction when I was conceiving this study.

To Dr. Shallie Philemon, I would not have done this program at DUT without you. Thank you for the initial contacts you made on my behalf.

To Dr. Olusola Sokoya, the Lagos State TB, Leprosy, Buruli Ulcer Control Officer, and Mrs. Tunrayo Martins, the DR-TB focal person. Thank you for your assistance, especially during the data collection.

To the medical directors of Mainland Hospital, General Hospital Alimosho, and General Hospital Ikorodu, thank you for allowing us to use your facilities for the study.

To Mr Balogun, Mrs Adekoya and Mrs Ogundipe, the TB local Government supervisors of Ojo, Ajeromi and Ikorodu, respectively. Thank you for your assistance in contacting and organising participants for the interviews.

Thank you to all the research assistants for helping with data collection and transcription.

To Adedoyin Adams, thank you for being a special friend, for all the encouragement and support, and for all you have added to my life in a very short time. Thank you.

To Edochie Chenelo Serah, thank you for celebrating the smallest achievements, reading the manuscripts, and making vital suggestions.

To Nnenna Karen Ihezie, my special friend, thank you for the company. You helped with some of the transcription, and thank you for offering to help anytime I needed assistance.

To all the participants in this study, thank you for taking the time and effort to share your experiences. Your contributions are very valuable.

ABSTRACT

Background:

Tuberculosis (TB) continues to be a disease of public health concern in Nigeria despite current efforts to increase notification rates in the country. In 2024, Nigeria recorded its highest TB notification and a treatment coverage rate of 79%. Despite these efforts, the country is yet to reach the global elimination targets due to several factors, including the effect of stigma on TB notification and treatment adherence. Previous studies have reported a high prevalence of TB-related stigma, mainly because of the close relationship between TB and HIV. People living with drug-resistant TB (PwDR-TB), however, experience more stigma compared to drug-sensitive TB patients because of the longer duration of DR-TB treatment. TB-related stigma is associated with decreased self-esteem, poor quality of life, anxiety, feelings of guilt, isolation, loneliness, and depression. In addition, People with TB (PWTB) experience abuse, neglect, shame and social seclusion at home, work, community, or healthcare facilities. TB-related stigma undermines TB screening efforts and negatively impacts the disclosure of status, healthcare-seeking behaviours, care delivery, treatment adherence, and outcomes.

Despite the importance of TB-related stigma on TB control and the quality of life among PwDR- TB in Nigeria, there is a paucity of literature on the subject. This study intends to contribute to the body of knowledge on TB-related stigma in Nigeria to understand the prevalence, effects, and modifiers of stigma among PwDR-TB in Nigeria.

Aims & Objectives

This study aims to assess the effects of experienced stigma among DR-TB patients in Lagos, Nigeria.

Objective 1

To determine the prevalence of stigma experienced by PwDR-TB in Lagos, Nigeria.
Objective 2

To determine the prevalence of loneliness, anxiety, depression, and good treatment adherence and their association with experienced stigma.

Objective 3

To determine the association between experienced stigma and quality of life among PwDR-TB in Lagos, Nigeria

Objective 4

To determine the association (if any) between the protective effect of social support, resilience, and temporal discounting on stigma among PwDR-TB in Lagos, Nigeria.

Objective 5

To explore the stigma experiences of PwDR-TB in Lagos, Nigeria.

Methods

A mixed-method design (explanatory sequential design) was used. A descriptive cross-sectional study was conducted among 203 PwDR-TB on treatment for at least eight weeks recruited across five treatment centres in Lagos, Nigeria. Validated scales, such as the Redwood DR-TB Stigma Scale, Generalised Anxiety Disorder-7, Patient Health Questionnaire-9, UCLA Loneliness Scale Version 3, and Morisky Medication Adherence Scale, were used to assess experienced stigma, anxiety, depression, loneliness, and adherence, respectively. Additionally, the Multidimensional Scale of Perceived Social Support, Brief Resilience Scale, Deferment of Gratification Scale, and Functional Assessment of Chronic Illness Therapy-Tuberculosis were used to assess social support, resilience, temporal discounting, and health-related quality of life. The scales were combined in a questionnaire administered by five research assistants at the outpatient clinic of the selected hospital sites. Five focus group discussions (FGDs) were conducted for the qualitative study, one in each of the selected facilities. Some participants who took part in the survey were randomly invited to the focus group discussions. Each focus group consisted of 9 – 12 participants and lasted 60 – 75 minutes. A total of 53 participants took part in the FGD. Student ‘t’ tests, one-way ANOVA, partial correlations, logistic regression, and hierarchical multiple regression were conducted using IBM SPSS Statistics version 26, while Thematic analysis was employed for the qualitative study.

Findings

The findings have been reported in six manuscripts.

The prevalence of TB stigma was 65.5%. Being male, not earning an income, substance use (alcohol or cigarette smoking, and the duration of the DR-TB diagnosis were associated with stigma among PwDR-TB. HIV-negative participants experienced TB stigma 2.4 times more (crude OR 2.4 [95% CI 1.14 to 5.04], p=0.021) than HIV-positive participants, although the relationship was not sustained in the multivariate analysis. Anxiety, loneliness, and depression were reported by 148 (72.9%), 114 (56.2%) and 128 (63.1%) of the 203 participants, respectively. TB-related stigma was positively associated with depression, anxiety, and loneliness. Social support was negatively associated with depression, anxiety, and loneliness. The mean overall health-related quality of life (HRQoL) was 41.1 ± 12.9 among people with DR-TB. The HRQoL score of the physical domain was the lowest (25.8 ± 13.8). Participants who were young, male, single, with higher education, and who were HIV-negative had higher HRQoL than their counterparts ($p<0.05$). Stigma was negatively associated with HRQoL, while social support was positively related, collectively explaining 57.6% of the variance. In the final model, social support contributed more (B=0.576) to predicting HRQoL than did stigma (B=−0.414). Treatment adherence differed among the participants, with most (73.4%) having a medium adherence rate. The prevalence of low and high treatment adherence was 20.7% and 5.9%, respectively. Adherence was positively associated with social support, resilience, and temporal discounting and negatively associated with stigma. Stigma was negatively correlated with adherence ($r = -0.628$, $p < 0.01$), resilience ($r = -0.386$, $p<0.001$), and temporal discounting ($r=-0.364$, $p<0.001$). Temporal discounting significantly contributed more to predicting adherence than social support, resilience, and stigma. Qualitative findings revealed poor attitudes of the healthcare workers (HCWs) towards people with TB. Participants described the behaviour of HCWs as rude, hostile, and demeaning. These attitudes led some participants to consider abandoning treatment, while others wished they knew where to lodge complaints against the HCWs. Participants felt humiliated, and some described the feeling as worse than the DR-TB symptoms. The

counselling by HCWs about the use of separate cutlery and self-isolation at home evoked feelings of loneliness, which was disapproved of by many participants.

Conclusion

This study revealed that the prevalence of stigma among PwDR-TB was high. Also, the prevalence of anxiety, depression and loneliness was higher among PwDR-TB who experienced stigma. Stigma negatively impacted the health-related quality of life and adherence among PwDR-TB. Social support reduced the effects of stigma on anxiety, loneliness, and health-related quality of life. Resilience and temporal discounting improved adherence to treatment but were negatively associated with stigma. The qualitative study showed that the health facilities were a significant source of stigma for PwDR-TB. To address stigma in Nigeria, there is a need to build resilience among PwDR-TB. Community engagement is necessary to provide an avenue for people with TB to advocate for change in the social norms that reinforce stigma. Healthcare workers need to be trained on self-awareness of their implicit bias towards PwDR-TB and engage in stigma reduction training. The policymakers should push for policies that reduce barriers to TB care within and outside the hospital environment, such as supporting infrastructure that optimises infection control and boosts the confidence of HCWs to care for their patients effectively. More research is needed on stigma reduction strategies that can be adopted by the TB programme, which will leverage the successes of other settings in Africa and domesticating such to address stigma among people with TB in Nigeria.

Keywords: Drug-resistant tuberculosis, Stigma, Social support, Resilience, Temporal discounting, Health-related quality of life.

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LIST OF ABBREVIATIONS

ANOVA	Analysis of variance
AOR	Adjusted odds ratio
BRS	Brief Resilience Scale
CI	Confidence Interval
COR	Crude odds ratio
DGS	Deferment of Gratification Scale
DR-TB	Drug-resistant tuberculosis
FACCIT	Functional Assessment of Chronic Illness Therapy
FGD	Focus Group Discussion
HCWs	Healthcare Workers
HIV/AIDS	Human immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
HBM	Health Belief Model
HRQoL	Health-Related Quality of Life
HSDF	Health Stigma and Discrimination Framework
IC	Infection control
LCDAs	Local Council Development Areas
LGAs	Local Government Areas
MMSPSS	Multi-dimensional Scale of Perceived Social Support
PHQ-9	Patient Health Questionnaire-9
PLWHA	People Living with HIV/AIDS
PLWTB	People Living with tuberculosis
PwDR-TB	People with drug-resistant tuberculosis

PWTB	People with tuberculosis
SPSS	Statistical Package for Social Sciences
TB	Tuberculosis
TPB	Theory of Planned Belief
UCLA	University of Los Angeles, California
UI	Uncertainty interval
USD	United States Dollars
WHO	World Health Organization

LIST OF PUBLICATIONS

Published Articles

1. **Article title:** Stigma Experienced by People with Drug-Resistant Tuberculosis in Lagos, Nigeria: A Cross-Sectional Study.

   Authors: Olusola Adedeji Adejumo, Champaklal Jinabhai, Olusoji Daniel, Firoza Haffejee.

   Journal: Transactions of the Royal Society of Tropical Medicine and Hygiene.

   Publication date: March 2025

2. **Article title**: Association between experienced stigma, anxiety, depression and loneliness among people with drug-resistant tuberculosis in Lagos, Nigeria: The moderating role of social support.

   Authors: Olusola Adedeji Adejumo, Firoza Haffejee, Champaklal Jinabhai, Olusoji Daniel.

   Journal: Tropical Medicine and International Health.

   Publication date: October 2024.

3. **Article title**: The effects of stigma and social support on the health-related quality of life of people with drug-resistant tuberculosis in Lagos, Nigeria.

   Authors: Olusola Adedeji Adejumo, Champaklal Jinabhai, Olusoji Daniel, Firoza Haffejee.

   Journal: Quality of Life Research.

   Publication date: February 2025.

4. **Article title:** Treatment Adherence among People with Drug-Resistant Tuberculosis in Lagos, Nigeria: The Effects of Stigma, Resilience, Social Support, and Temporal Discounting.

   Authors: Olusola Adedeji Adejumo, Olusoji Daniel, Champaklal Jinabhai, Firoza Haffejee.

Journal: International Journal of Mycobacteriology.

Publication date: March 2025.

Manuscript under review

5. **Manuscript title:** 'The way they treat us is worse than the disease': A qualitative study of the experiences of people with drug-resistant tuberculosis at healthcare facilities in Lagos, Nigeria.

   Authors: Olusola Adedeji Adejumo, Firoza Haffejee, Olusoji Daniel, Champaklal Jinabhai,

   Journal: BMC Health Services Research

   Status: Under Review

   Submission ID: 015b2764-da8d-438f-80da-33876fd12f66.

   Date of submission: 4th April, 2025.

6. **Manuscript title:** The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study

   Authors: Olusola Adedeji Adejumo, Olusoji Daniel, Firoza Haffejee, Champaklal Jinabhai,

   Journal: Stigma and Health

   Status: Under Review

   Submission ID:

   Date of submission: 1st May, 2025

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 Introduction

Tuberculosis (TB) is a stigmatised disease because it disproportionately affects people of low socioeconomic class, the vulnerable and marginalised groups, such as the poor, prisoners, and refugees (Ashaba *et al*., 2021). It is often associated with HIV/AIDS because of the similarity of presenting symptoms, such as weight loss. Consequently, the negative characteristics of promiscuous sex, which are often associated with HIV/AIDS, are also assumed in people with TB (PWTB) (Chen *et al*., 2021a). TB-related stigma is one of the social factors affecting TB control globally. It manifests through social seclusion, avoidance, shaming, abuse, and neglect. It is characterised by unfavourable social discrimination, which may be perceived, anticipated, or experienced by PWTB and can occur at home, in the workplace, in the community, and health facilities (Nofalia *et al*., 2020; Teo *et al*., 2020; Kapyolo *et al*., 2023). TB-related stigma is driven by wrong perceptions of the curability and contagiousness of TB during treatment (Chen *et al*., 2021a).

According to Goffman, stigma is “an attribute that is deeply discrediting, which spoils a person’s social identity or sense of self” (Goffman, 1963). It is a discrediting attribute that makes a person socially unacceptable; it leads to loss of social status, rejection, or exclusion and is a significant factor in the emergence of power structures that devalue certain social groups, thereby contributing to social inequality (Kilic *et al.*, 2025; Yan *et al.*, 2018). Stigma is a social health determinant contributing to mortality, morbidity, and health inequalities (Addison *et al.*, 2023). It has been described as a ‘hidden burden of disease’ (World Health Organization, 2001) and is characterised by cognitive, emotional, and behavioural components (Kane *et al.*, 2019).

The prevalence of TB-related stigma varies depending on the socio-cultural environment, interpersonal relations, and health institutions’ culture (Datiko *et al*., 2020). There is

sparse evidence of the prevalence of TB-related stigma among people with drug-resistant tuberculosis (PwDR-TB). However, studies among people with drug-sensitive TB from high TB-burdened countries such as Uganda, India, Tanzania, Ethiopia, and Nigeria reported TB-stigma prevalence of 52%, 26%, 20.6%, and 38.7%, respectively (Ashaba *et al*., 2021; Baskaran *et al*., 2023; Kapyolo *et al*., 2023; Datiko *et al*., 2020; Abioye *et al*., 2011). The prevalence of TB-related stigma is suggested to be higher among PwDR-TB than those with drug-sensitive TB because of the longer duration of treatment, the prolonged isolation and the shame associated with treatment failure (Baskaran *et al.,* 2022).

Prohibition of stigma and discrimination against PWTB is a thrust of the 'End TB Strategy' (World Health Organization, 2019). Discrediting PWTB is counterproductive to TB care and elimination efforts because of the possible negative impacts on healthcare-seeking, care delivery, adherence, and recovery. Indeed, perceptions about how PWTB are treated in the community and healthcare facilities can influence the timing, location, and quality of care. It also impacts resilience and health outcomes and undermines TB screening efforts in the community (Kilic *et al.,* 2025; Sommerland *et al*., 2017; Duko *et al.*, 2015). It hinders the disclosure of disease status to significant others and is associated with decreased self-esteem, poor quality of life, anxiety, feelings of guilt, isolation, loneliness, and depression (Chen *et al.*, 2021a).

These discriminatory attitudes include, hindrance of educational opportunities, fear of divorce, inability to marry, inability to share meals and utensils with family members, being subjected to gossip, shame, and ridicule within the family and community, loss of employment, or inability to get a job (Ashaba *et al*., 2021; Kamble *et al*., 2020). Social stigma can negatively affect the treatment-seeking behaviours, symptoms disclosure, TB treatment adherence and treatment outcomes of PWTB (Ashaba *et al*., 2021; Kamble *et al*., 2020). It also undermines TB screening programs, thus increasing the risk of further transmission of TB in the community and TB under-reporting (Kamble *et al*., 2020). Stigma may also negatively impact patients' social capital, resilience to disease, and household-level well-being (Dodor *et al.*, 2009; Deshmukh *et al.*, 2017). Social support is crucial in controlling TB, as it promotes treatment adherence, buffers psychological distress,

enhances self-efficacy, and fosters positive attitudes (Baniqued *et al.,* 2020). With adequate social support, PWTB experience less stigma, have better health-seeking behaviour, show enhanced illness adaptation and reduced risk of anxiety, depression, and loneliness (Zhang *et al*., 2023; Wang *et al*., 2022). Furthermore, it improves treatment adherence, treatment loss-to-follow-up and quality of life (Wen *et al*., 2020; Zhang *et al*., 2020).

PwDR-TB often face multidimensional challenges that the health system cannot solve, and resilience is one person-centred approach that has not been fully explored but is crucial in mitigating these challenges (Nagarajan *et al*., 2024). Resilience is the psychological ability to overcome negative feelings and adapt to adversity in a way that enhances mental well-being and quality of life (Cal *et al*., 2015). The association between resilience and mental illness has been documented. It is associated with a reduced risk of suicide (Harris *et al*., 2020), improved quality of life, good self-esteem, high spirituality, and reduced hopelessness among people with bipolar disorder (Mizuno *et al*., 2016; Lee *et al*., 2017). Resilience is protective against self-stigma and positively impacts the long-term outcomes of chronic diseases (Post *et al.*, 2021).

Temporal discounting is another concept not well-researched in TB control. Temporal discounting is an intellectual process that compares the value of immediate and delayed rewards (Bahrami and Borhani, 2023). It explains why individuals who persevere to complete a prolonged treatment course have a brighter future (Duan *et al*., 2017). Adherence is crucial to TB control and could be daunting, especially for PwDR-TB, because of the long treatment duration, the adverse effects of the medication, and personal behavioural and socioeconomic factors (Alipanah *et al.,* 2018). Non-adherence to long-term therapies has been linked with failure to prioritise the future, as patients are often more attracted to immediate rewards (Sapkota *et al*., 2015).

TB continues to be a disease of public health threat in Nigeria. According to the World Health Organization (WHO), Nigeria is a high-burden TB, TB/HIV, and drug-resistant TB (DR-TB) country. In 2023, the TB incidence rate for Nigeria was estimated at 219 (95% UI 143 – 311) per 100,000 population (World Health Organization, 2024). Studies from Nigeria reported that the high prevalence of stigma is a significant factor affecting TB

control programs in the country (Junaid *et al.*, 2021; Oladele *et al*., 2020). Studying the prevalence, severity, modifiers, and consequences of TB stigma among PwDR-TB is crucial to TB control in Nigeria. Unfortunately, it is understudied despite the reported high level of TB-related stigma and poor TB care, restricting the diagnostic and treatment process as well as sabotaging the health and rights of PWTB (Kuyinu *et al.,* 2016; Oladele *et al.,* 2020). There is scarce evidence concerning the prevalence of stigma among PwDR-TB, which is one of the gaps this study intends to cover. This thesis investigates the prevalence, effects, and modifiers of stigma among PwDR-TB patients in Lagos, Nigeria.

1.2 Research problems

PwDR-TB are uniquely disadvantaged by stigma compared to persons with drug-susceptible TB because they are more exposed to stigma due to the longer duration of DR-TB treatment and the assumed perception that DR-TB is caused by poor treatment adherence, which often tempts health workers to blame individuals for their disease (Thomas *et al.,* 2016). Crucially, little is known about the scope, prevalence, and effects of stigma, such as poor quality of life, loneliness, anxiety, depression, and poor adherence among PwDR-TB in Lagos, Nigeria. The role and the effects of resilience, social support, and temporal discounting on stigma among PwDR-TB are poorly understood in Nigeria.

This study hypothesises that stigma is associated with anxiety, depression, loneliness, and poor quality of life among PwDR-TB; however, social support, resilience, and temporal discounting have a negative relationship with stigma among PwDR-TB in Lagos, Nigeria.

1.3 Aim and objectives

Aim**:** To assess the effects of experienced stigma among DR-TB patients in Lagos, Nigeria.
Objective 1: To determine the prevalence of stigma experienced by PwDR-TB in Lagos, Nigeria.

Objective 2: To determine the prevalence of loneliness, anxiety, depression, and good treatment adherence and their association with experienced stigma. Objective 3: To determine the association between experienced stigma and quality of life among PwDR-TB in Lagos, Nigeria

Objective 4: To determine the association (if any) between the protective effect of social support, resilience, and temporal discounting on stigma among PwDR-TB in Lagos, Nigeria.

Objective 5: To explore the stigma experiences of PwDR-TB in Lagos, Nigeria.

1.4 Structure of the Thesis

This thesis is structured in a publication format. It consists of an introduction, including aims and objectives, in Chapter One and a literature review in Chapter Two. Chapters three to seven comprise a manuscript, and Chapter eight provides an overall discussion, recommendations, and conclusion. The first objective is addressed by the manuscript in Chapter Three; the manuscript in Chapters Four and Six answered the second objective, while in Chapter Five, the manuscript addresses the third objective. The manuscripts in Chapters four, five and six answer the fourth objective. The fifth objective is answered by the manuscripts in Chapters Seven and Eight.

Chapter One: Introduction

Chapter Two: Literature review

Chapter Three: Published article 1.

Stigma Experienced by People with Drug-Resistant Tuberculosis in Lagos, Nigeria: A Cross-Sectional Study. (Published in Transactions of the Royal Society of Tropical Medicine and Hygiene; March 2025).

Chapter Four: Published article 2.

Association between experienced stigma, anxiety, depression, and loneliness among people with drug-resistant tuberculosis in Lagos, Nigeria: The moderating role of

social support (Published in Tropical Medicine and International Health; October 2024).

Chapter Five: Published article 3

The effects of stigma and social support on the health-related quality of life of people with drug-resistant tuberculosis in Lagos, Nigeria (Published in Quality of Life Research; February 2025).

Chapter Six: Published article 4.

Treatment Adherence among People with Drug-Resistant Tuberculosis in Lagos, Nigeria: The Effects of Stigma, Resilience, Social Support, and Temporal Discounting (Published in International Journal of Mycobacteriology; March 2025).

Chapter Seven: Manuscript under review 1.

'The way they treat us is worse than the disease': A qualitative study of the experiences of people with drug-resistant tuberculosis at healthcare facilities in Lagos, Nigeria. (Manuscript under review, submitted to BMC Health Services Research; 7th April, 2025)

Chapter Eight: Manuscript under review 2.

The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study (Manuscript under review, submitted to BMC Research Notes; 21st April, 2025)

Chapter Nine: Discussion, recommendations, limitations, and conclusion.

CHAPTER TWO

LITERATURE REVIEW

Tuberculosis has been afflicting humans for many years and is said to have originated some 150 million years ago (Daniel, 2006). TB is a chronic bacterial infection caused by *Mycobacterium tuberculosis*, the most common species, *M bovis* or *M africanus*. The bovine strain primarily affects cattle and other animals but can be transmitted to humans by drinking unpasteurised milk. *M avium* and *M intercellulare* can cause human disease, which often mimics TB, but are usually not communicable (Müller *et al*., 2013). Over 80% of TB infections affect the lungs (pulmonary TB), while extra-pulmonary TB is non-infectious and can affect any body part except the lungs. (World Health Organization, 2024).

2.1 Epidemiology of TB

TB is contagious and airborne. It is transmitted through airborne spread of infectious droplets, nuclei, which are generated when infected persons cough, sneeze, talk or spit. Other routes of transmission are uncommon and of no epidemiologic significance. Exogenous factors determine the risk of acquiring TB infection (Glaziou *et al*., 2014). An individual's risk of infection depends on the probability of having contact with an infected person, the degree of infectiousness of the case, the concentration of the droplet nuclei in contaminated air, the length of time the individual is exposed to the contaminated air, the shared environment where contact takes place, and the susceptibility of the individual to the infection which is linked to the standard of living, the nutritional level of the exposed person and presence of immune-suppression which result from

HIV and steroids (Glaziou *et al*., 2014; Raviglione *et al*., 1993). TB is a disease of poverty that thrives where social and economic determinants of ill health prevail. It also primarily affects young adults living in the developing world in their most productive years (World Health Organization, 2013).

2.1.1 Signs and symptoms:

Persons infected with TB usually present with prolonged cough, weight loss, fever, night sweats, extreme fatigue, and bloody sputum (World Health Organization, 2018). Without treatment, each person with active TB will infect 10 - 15 people each year, and 50% of the PWTB may die (World Health Organization, 2024).

2.2 Host factors predisposing to TB

2.2.1 Age and sex:

TB can affect anyone regardless of age and sex. Globally, the incidence of TB is higher in males than in females. The WHO reported that 55% of the global TB burden was among adult males, 33% among adult females, and 12% among children in 2023 (World Health Organization, 2024). Men are less likely than women to access diagnostic and treatment services for TB and are more likely to transmit the bacteria in the community for a much more extended period (Horton *et al*., 2020)

2.2.2 Heredity/Immunity

It has been suggested that genetic factors play a significant role in innate resistance to infection with *M. tuberculosis*. This resistance exists due to differing susceptibility to TB in different populations. About a quarter of the population is globally estimated to be infected with latent TB (World Health Organization, 2018). The risk of developing TB is about 5% within two years after infection (World Health Organization, 2024). However, people with comorbid conditions such as HIV, people with a compromised immune system due to the prolonged use of steroids, diabetics, people with severe malnutrition, renal pathology and silicosis have a higher chance of developing TB disease (Glaziou *et al*., 2014).

2.2.3 Nutrition:

During World War 11, TB rates increased in European countries affected by the war, particularly in some special groups such as the German camps (Cochrane, 1948) and in

the Warsaw ghetto (Schechter, 1953). Improving sanitation status may alter the probability of those infected from developing clinical TB and decrease the breakdown rate from infection to disease (Jamison *et al*., 2006). In low-income countries, TB and undernutrition are closely linked, with each exacerbating the other. Undernutrition increases the risk of developing active TB from a latent infection, while TB can lead to further malnutrition, creating a vicious cycle. Addressing this dual challenge is crucial for effective TB control and improved patient outcomes (Semba *et al*., 2010). Undernutrition can impair the body's immune response, leading to bacterial multiplication and severe TB infection. Also, TB infection causes an inflammatory response, which could deplete essential nutrients, creating a vicious cycle that hinders recovery and treatment outcome (Mueller-Wieland, 1961). Studies have demonstrated the association between undernutrition and increased TB incidence, severity, unfavourable treatment outcomes, and mortality (Sinha *et al*., 2021). A study from Ethiopia demonstrated that the prevalence of undernutrition was 43.9% among PWTB, family size, household average income, type of TB, and positive HIV status predicted undernutrition among PWTB (Shifera and Yosef, 2024). Another study from a low-income country reported that undernourished PWTB had a twofold higher risk of having unsuccessful treatment outcomes compared to well-nourished PWTB (Wagnew *et al*., 2024).

2.2.4 HIV Infection:

Human immunodeficiency virus (HIV) predisposes one to TB. The risk of TB is higher among people living with HIV and is strongly associated with the level of immunodeficiency (Goletti *et al*., 2023). There is a 2-5-fold higher risk of TB disease soon after HIV infection compared to HIV-negative individuals. However, the risk further increases to at least 20-fold more compared with the general population with progression to HIV-induced severe immunodeficiency (Goletti *et al*., 2023). HIV fuels the TB epidemic; it promotes progression to active TB both in people with recently acquired diseases and those with latent *M tuberculosis* infections. HIV is the most potent known risk factor for reactivation of latent TB infection to active disease. HIV-infected people are more susceptible to being infected when they are exposed to *M tuberculosis* (World Health

Organization, 2003). The annual risk of developing TB in people living with HIV/AIDS who are co-infected with TB ranges from 5 to 15%. In Kinshasa, Zaire, HIV- positive women had a 26-fold increased risk of developing TB compared with HIV seronegative women after a median follow-up of 32 months (Braun *et al*., 1991).

2.2.5 Treatment of TB:

The treatment of TB has evolved. Before the era of anti-TB drugs, TB patients were managed in sanatoria. Treatment was expensive, but half of the patients died from the disease (World Health Organization, 1999). The development of streptomycins in the 1940s revolutionised TB treatment and reduced the case fatality to about 5% (World Health Organization, 1999). Thioacetazone and para-aminosalicylic acid were later discovered in 1948, and Isoniazid in 1952 paved the way for combination chemotherapy to prevent resistance. The initial regimen for TB treatment was 18 months, but the discovery of rifampicin transformed the treatment of TB. The rifampicin-containing regimens known as the short-course therapy became the standard of care for the global TB control strategy called directly observed treatment short-course in 1993 (Seung *et al*., 2015).

The WHO-recommended treatment for drug-susceptible TB consists of a two-month intensive phase of Rifampicin, Isoniazid, Pyrazinamide, and Ethambutol as a fixed-dose combination, followed by a four-month continuation phase of Rifampicin and Isoniazid as a fixed-dose combination (World Health Organization, 2019). The second-line regimen depends on the presentation, comorbidities, resistance pattern, and sensitivity test results. The WHO approved all 6–9-month oral shorter regimens for MDR-TB/RR-TB, consisting of Bedaquiline, Pretomanid, Linezolid, and Moxifloxacin. In Pre-XDR (where there is resistance to fluoroquinolones, i.e. Moxifloxacin or Levofloxacin), Bedaquiline, Pretomanid, and Linezolid are administered for 6-9 months. The treatment duration for XDR-TB is 18 months, consisting of six months of Delamanid, Linezolid, Clofazimine, and Cycloserine, and 12 months of Clofazimine, Cycloserine, and Linezolid (for patients resistant to Bedaquiline). However, for XDR-TB patients resistant to Linezolid, the treatment duration is 18 months, consisting of 6 months of Bedaquiline, Delamanid,

Clofazimine, and Cycloserine, followed by 12 months of Clofazimine, Delamanid and Cycloserine (Federal Ministry of Health, 2023).

2.3 The economic impact of TB

TB has a profound economic impact on PWLTB because it primarily affects people in the lower socio-economic ladder. Direct and indirect costs are associated with TB diagnosis, treatment and lost productivity. These costs are particularly devastating for families in high-burden TB countries where TB disproportionately affects the working class and can lead to job loss and financial crisis. Ending catastrophic costs in TB-affected households is one of the central thrusts of the end-TB strategy (World Health Organization, 2024)

The WHO defines catastrophic TB costs as the direct and indirect costs of TB diagnosis and treatment above 20% of the household's annual income (World Health Organization, 2015). Direct costs include non-medical (food, transportation, and nutritional supplements) and medical (registration, consultation, laboratory investigation, hospitalisation, and medication). Indirect costs include loss of income due to loss of productivity, missed work, opportunity cost, time loss of revenue, and caregiving work (Lönnroth *et al*., 2014). TB-affected households have had to borrow money, sell household assets, and sometimes take children out of school to cope with the financial burden imposed by TB care (Madan *et al.,* 2015).

Many families fall into poverty because of the high direct and indirect costs of medical treatment and can consequently not utilise health care services (Onazi *et al*., 2015). A Nigerian study reported that many households with PWTB often become poor because of the cost of treatment and indirect costs such as job losses and opportunity costs imposed by TB care (Ukwaja *et al*., 2013). The catastrophic cost associated with DR-TB is thought to be higher than that of drug-susceptible TB due to the longer duration of treatment and the need for expensive second-line medications (Jang and Chung, 2020). A Nigerian Study estimated the average direct household costs for drug-sensitive TB to be 157 USD, and the incidence of catastrophic payment was 44%. About 70% and 15% of the poorest and richest household income quartiles experience catastrophic activity,

respectively (Ukwaja *et al*., 2013). A systematic review involving studies from several countries reported that the cost of treatment of PwDR-TB ranges from 2423 USD in Peru to 14,657 USD in Russia (Fitzpatrick and Floyd, 2012). A WHO report highlighted that the pooled percentage of TB-affected households facing catastrophic costs in 35 countries was 49% World Health Organization, 2024),

The economic impact of DR-TB is severe on the families of patients. It could result in extreme poverty because of out-of-pocket expenses and income loss during diagnosis and treatment (van den Hof *et al*., 2016). The considerable financial losses PwDR-TB face before, during and after treatment have been documented (Lim *et al*., 2021; Daftary et al., 2021). Factors associated with the burden of catastrophic cost include sociodemographic factors, diagnostic delay, length of hospital stay, household wealth status, distance from health facilities, number of household members, healthcare setting, pre-TB expenditures, and hospitalisations (Wang *et al*., 2020).

2.4 Prevalence of TB

The incidence of TB has been increasing steadily. In 2023, an estimated 10.8 million people (95% uncertainty interval [UI]: 10.1–11.7 million) had TB, which is an increase from 10.7 million (95% UI: 10.0–11.5 million) in 2022, 10.4 million (95% UI: 9.7–11.1 million) in 2021, and 10.1 million (95% UI: 9.5 10.7 million) in 2020 (World Health Organization, 2024). Most people who developed TB in 2023 were from South-East Asia (45%), Africa (24%), and the Western Pacific (17%). The Eastern Mediterranean (8.6%), the Americas (3.2%), and Europe (2.1%) had lower proportions of incident TB cases in 2023 (World Health Organization, 2024) (See Figure 1). The global TB incidence rates vary widely among countries. The high-income countries, such as Canada, the United States of America, Australia, New Zealand, and most countries in Western Europe, have the lowest rates, less than 10 cases per 100,000 population. Most countries in the Americas have rates below 50 per 100,000 population, while the countries with remarkably high incidence rates are mainly in Africa. In 2023, an estimated 1.25 million deaths (95% UI: 1.13–1.37 million), including 1.09 million among HIV-negative individuals (95% UI: 0.98–1.20

million) and 161,000 (95% UI: 132,000 – 193,000) among people living with HIV (World Health Organization, 2024).

DR-TB continues to be a public threat, and of great concern is the resistance to the most effective first-line drugs: Rifampicin and Isoniazid. Globally, among the 410,000 (95% UI: 370,000–450,000) individuals who develop MDR-TB or RR-TB each year, 62,000 (95% UI: 52,000–72,000; 15%) reside in Africa (World Health Organization, 2024). Five countries, namely India (27%), the Russian Federation (7.4%), Indonesia (7.4%), China (7.3%), and the Philippines (7.2%), accounted for more than half of the estimated global number of DR-TB cases (World Health Organization, 2024). Approximately 20% of people with MDR-TB die despite treatment, and the treatment success is less than 65%. Diagnostic delays, comorbidities such as HIV and diabetes, prolonged delay at treatment initiation, and high rates of loss-to-follow-up and relapse are factors that undermine the therapeutic success of DR-TB treatment (Naidoo *et al*., 2024).

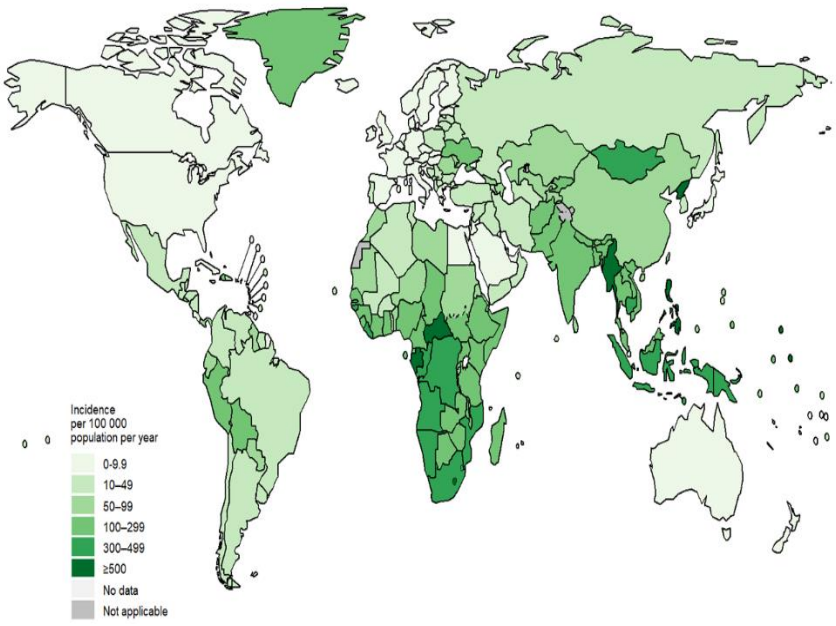

Figure 1: Estimated TB incidence rates, 2023

2.5 Drug-resistant tuberculosis

DR-TB continues to be a public health threat and is one of the urgent and complex challenges affecting TB control globally (World Health Organization, 2024). Early in the DR-TB epidemic, resistance occurred primarily within individuals due to genetic mutations and poor adherence to the TB regimen. However, in most high-incidence settings, community transmission of drug-resistant strains is the primary transmission driver and depends on population factors such as social mixing, migration patterns, and early diagnosis and treatment (Swain *et al.,* 2020*;* Naidoo *et al*., 2024). Studies have demonstrated that about 80% of MDR-TB or XDR-TB cases are due to community spread rather than intra-host acquisition of resistance (Brown *et al*., 2019; Manson *et al*., 2017). Therefore, the narrative that DR-TB resistance is due to unrestrained rates of acquired resistance in poorly treated or non-compliant individuals is no longer valid in settings with high DR-TB prevalence (Naidoo *et al*., 2024).

The WHO has defined different categories of DR-TB: mono-resistance refers to resistance to one first-line anti-TB drug; rifampicin resistance (RR) refers to resistance to rifampicin alone; poly-drug resistance refers to resistance to more than one first-line anti-TB drug, excluding both isoniazid and rifampicin. Multi-drug-resistant TB (MDR-TB) represents resistance to both isoniazid and rifampicin, and extensive drug-resistant TB (XDR-TB) is the resistance to any fluoroquinolone (such as moxifloxacin, levofloxacin) and at least one second-line injectable drug (capreomycin, kanamycin, and amikacin), in addition to multidrug resistance (World Health Organization, 2019)

2.6 Prevalence of TB in Nigeria

TB continues to be a public health threat in Nigeria. According to the WHO*,* Nigeria is a high-burden TB, TB/HIV and DR-TB country. In 2023, the TB incidence rate for Nigeria was estimated at 219 (95% UI 143 – 311) per 100,000 population (World Health Organization, 2024*).* Of the estimated 492,743 TB cases in 2023, Nigeria reported

371,019 cases (75.3%) (Federal Ministry of Health, 2023). In addition, 43% of the 408,500 people diagnosed globally with DR-TB in 2022 were enrolled for treatment. Nigeria and nine other countries (eight in Asia and one in Europe) accounted for 70% of the treatment enrolment gap (World Health Organization, 2024). Nigeria (4.6%) is among the eight countries [India (26%), Indonesia (10%), China (6.8%), the Philippines (6.8%), Bangladesh (3.5%) and the Democratic Republic of Congo (3.1%)] accounting for more than two-thirds of the global TB burden (World Health Organization, 2024). Studies from Nigeria reported that high prevalence of stigma as a significant factor affecting the TB control program in the country (Junaid *et al.*, 2021; Oladele *et al*., 2020).

2.7 Stigma

Stigma is a social determinant of health and a key factor in health disparities contributing to mortality, morbidity, and health inequalities (Hatzenbuehler *et al*., 2013). It can be described as a 'hidden' burden of disease characterised by cognitive, emotional, and behavioural components (World Health Organization, 2001; Kane *et al*., 2019). According to Goffman, stigma is "an attribute that is deeply discrediting, which spoils a person's social identity or sense of self" (Goffman, 1963). Stigma can result in exclusion, discrimination, and marginalisation (Goffman, 1963). It begins with identifying a person's undesirable or disvalued trait and progresses to the individual's adoption of a sense of disvalue, leading to feelings of shame, disgust, and guilt. This may make the stigmatised individual hide the stigmatised trait, withdraw from interpersonal relationships, or increase risky behaviour (Courtwright and Turner, 2010). The perception also makes a person feel socially unacceptable (Yan *et al*., 2018).

Stigma is a trait that deviates from the norm, initiating a judgmental process through which others interpret other aspects of the individual's life (Jones *et al*., 1984). Other authors opined that stigmatised people are believed to have some qualities or traits that suggest a social characteristic that is debased in a particular context (Crocker *et al*., 1998). Link and Phelan described stigmatisation as a process that includes branding, profiling, discrimination, separation, and loss of status that co-exist in the context that permits them (Link and Phelan, 2001). Stigmatisation is a complex phenomenon involving inter and

intrapersonal attitudes, institutions, and communities. It is a discrediting attribute that leads to loss of social status, rejection, or exclusion. Stigma is a significant factor in the emergence of power structures that devalue some social groups, thereby leading to social inequality (Cremers *et al*., 2015).

2.7.1 Categories of stigma

Conceptually, stigma is classified into four categories: perceived stigma is an individual's understanding of how others may think, feel, or behave towards a person with a particular trait or identity (Zelaya *et al*., 2012). Anticipated stigma refers to the future expectation of experiencing stigma (Earnshaw *et al*., 2013; Nofalia *et al*., 2020). Experienced or enacted stigma is the experience of discrimination in the past or present due to certain conditions (Catona *et al*., 2016; Nofalia *et al*., 2020), while internalised stigma is the awareness, acceptance, and endorsement of negative feelings, beliefs and behaviours associated with the stigmatised condition and applying it to self (Earnshaw *et al*., 2013; Nofalia *et al*., 2020). Another school of thought classifies stigma into community stigma (public stigma) and self-stigma (Sewilam *et al*., 2016). Community or social stigma consists of labels, biases, and discrimination that lead to negative assessments, differentiating individuals based on conventional or specific attributes. Self-stigma is a negative perception of oneself as not socially desirable, leading to withdrawal and fewer interactions within social spaces (Sewilam *et al*., 2016). Stigma is multidimensional: it may involve labelling of differences in traits, stereotyping a negative trait, marginalisation of individuals with an unwanted trait, loss of status, discrimination, and the feeling of disgrace in the stigmatised person to the repulsion of the stigmatisers (Link and Phelan, 2001).

2.7.2 TB-related stigma

TB is a quintessential social disease. It is most common among people with compromised immune systems and those who live or work in poor, overcrowded conditions. TB-related stigma exists because it is aided and fostered through social and cultural norms, which, in the long run, brands organised discriminatory practices (Pearce *et al*., 2012; Pescosolido and Martin, 2015). TB-related stigma is one of the social factors affecting TB control

globally. It is characterised by unfavourable social discrimination, which may be perceived, anticipated, or experienced by PWTB (Daftary *et al*., 2018; Teo *et al*., 2020). TB is a global disease that impacts family and social relationships, resulting in undesirable health and economic consequences (Chang and Cataldo, 2014). It is considered a stigmatising disease because it majorly affects vulnerable groups such as the poor, prisoners, refugees, and people living with HIV/AIDS (PLWHA) (Sulis *et al*., 2014; Ashaba *et al*., 2021).

Studies from different African settings have shown hereditary factors, promiscuity, witchcraft, smoking, HIV, and poverty as some of the negative stereotypes connected with TB (Cremers *et al*., 2015; Ashaba *et al.*, 2021). These have frequently affected the social relationships of PWTB with community members and caregivers (Sommerland *et al*., 2017). TB-related stigma is essentially the result of an exaggerated fear of contracting the infection. This is due to wrong perceptions of the curability and contagiousness of TB during treatment (Dodor *et al*., 2008; Chen *et al*., 2021a). In addition, TB is often associated with HIV/AIDS because of the similarity of presenting symptoms, such as weight loss. Consequently, the negative characteristics of promiscuous sex, which are often associated with HIV/AIDS, are also assumed in PWTB (Chen *et al*., 2021a). A systematic review showed that TB-related stigma manifests through social seclusion, avoidance, shaming, abuse, and family neglect (Nofalia *et al*., 2020).

2.7.3 Prevalence of TB-related stigma

The prevalence of TB-related stigma varies depending on the socio-cultural environment, interpersonal relations, and health institutions' culture (Datiko *et al*., 2020). Studies from high-burden countries such as Zambia, South Africa, India and Kenya show that PWTB are stigmatised and discriminated against by family members, neighbours and healthcare workers (Mason *et al*., 2015; Nyblade *et al*., 2019; Somma *et al*., 2008; Thomas and Stephen, 2021). In another study, TB-related stigma was intertwined with traditional beliefs about the disease, gender roles and relationships (Miller *et al*., 2017). Studies among people with drug-sensitive TB from high TB-burden countries such as Uganda, India, Tanzania, Ethiopia, and Nigeria reported TB-stigma prevalence of 52%, 26%,

20.6%, and 38.7%, respectively (Ashaba *et al*., 2021; Baskaran *et al*., 2023; Kapyolo *et al*., 2023; Datiko *et al*., 2020; Abioye *et al*., 2011).

The prevalence of TB-related stigma is suggested to be higher among PwDR-TB than those with drug-sensitive TB because of the longer duration of treatment, the prolonged isolation and the shame associated with treatment failure (Thomas *et al*., 2016). TB-related stigma is experienced at home, in the workplace, in the community and in health facilities (Kapyolo *et al*., 2023). A Tanzanian study reported that 50% of the stigma experienced by PWTB was within the family, while the community and workplace contributed 36% and 10% to the stigma, respectively (Kapyolo *et al*., 2023). The leading driver of TB-related stigma is the fear of contagion, and PWTB becomes profiled as dangerous and labelled as worthy of exclusion (Mahbub *et al*., 2024).

2.7.4 Gender and TB-related stigma

There is a gender difference in the socio-economic and psychological consequences of TB-related stigma mediated by cultural beliefs (Miller *et al*., 2017). Four factors associated with the gender differences in TB-related stigma have been postulated: the financial dependence of women on men to obtain treatment, the low priority given to women's health, the social isolation of women and decreased marital prospects among women made women worried more than men about the social consequences of TB-related stigma (Chang and Cataldo, 2014).

A study that compared gender and TB-related stigma in Bangladesh, India, Malawi, and Colombia posited that women were affected more by TB-related stigma (Sommer *et al*., 2008). Contrary to this, other studies have suggested that the prevalence of TB-related stigma may be higher among men because of the interaction between culture, masculinity, and the biological predisposition of men to have TB (Horton *et al*., 2016). Traditionally, men are expected to be financially capable of providing for their families and may feel inadequate when they cannot fulfil their roles (Akanle and Nwaobiala, 2020). TB and TB-related stigma collectively threaten their survival as many stopped working for social and physical reasons, contributing further to financial distress, which may erode

their breadwinner status and their value within the broader community (Sommer *et al*., 2008).

2.7.5 Misconception of TB and TB-related stigma

The knowledge of the causes of TB varies across countries and cultures (Chang and Cataldo, 2014). A systematic review showed varied knowledge of TB's causative factors across Africa and Asia. TB is believed to be caused by germs in Vietnam (Long *et al*., 1999) and Rwanda (Ngang *et al*., 2007) and transmitted through the air in Tanzania (Mangesho *et al*., 2007), India (Sharma *et al*., 2007), and Malaysia (Koay, 2004). It is also believed to be due to exposure to cold air in Ethiopia (Legesse *et al*., 2010) and Kenya (Liefooghe *et al*., 1997). Smoking is implicated as the cause of TB in South Africa (Promtussananon and Peltzer, 2005), Uganda (Buregyeya *et al.*, 2011), Malawi (Weiss *et al*., 2008), and Kenya (Liefooghe *et al*., 1997). In Haiti (Coreil *et al*., 2010), Rwanda (Ngang *et al*., 2007), and Peru (Baldwin *et al*., 2004), TB is believed to be caused by poor nutrition and poor living conditions in Morocco (Ottmani *et al*., 2008).

In many settings, unsubstantiated ideas regarding TB transmission were associated with negative attitudes towards PWTB. In Uganda, Peru and among Mexican Americans in the United States, PWTB were banned from sharing utensils with family members because TB was believed to be a foodborne disease (Buregyeya *et al*., 2011; Baldwin *et al*., 2004; Joseph *et al*., 2008). In Malawi and India, PWTB were perceived to be promiscuous because TB was associated with sexual contact (Weiss *et al*., 2008; Atre *et al*., 2004). TB was associated with hereditary conditions in Kenya, Uganda, and Vietnam (Liefooghe *et al*., 1997; Buregyeya *et al*., 2011; Long *et al*., 1999). Whereas in Pakistan, TB was attributed to infertility, which reduced the chances of marriage (Khan *et al*., 2006). TB was associated with hard labour in Kenya, Rwanda, and Vietnam (Liefooghe *et al*., 1997; Ngang *et al*., 2007; Long *et al*., 1999). In Asian countries such as Pakistan, India and Vietnam, TB was associated with stress, worry, anxiety and trauma (Khan *et al*., 2006; Nair *et al*., 1997; Long *et al*., 1999).

2.8 Consequences of TB-related stigma

2.8.1 Social and health consequences

PWTB often experience discrimination, social isolation, and rejection, which may be at home, work, health facilities and the community (Ashaba *et al*., 2021). These discriminatory attitudes include hindrance of educational opportunities, fear of divorce, marriage restrictions, inability to share meals and utensils with family members, being subjected to gossip, shame, and ridicule within the family and community, loss of employment, or inability to get a job (Ashaba *et al*., 2021; Kamble *et al*., 2020). Social stigma can negatively affect the treatment-seeking behaviour, symptoms disclosure, TB treatment adherence and treatment outcomes of PWTB (Ashaba *et al*., 2021; Kamble *et al*., 2020). It also undermines TB screening programs, thus increasing the risk of further transmission of TB in the community and TB under-reporting (Kamble *et al*., 2020). A study reported that sputum delay was about 6-fold more common among PWTB who experienced high-level stigma (Chakrabarty *et al*., 2018).

TB diagnosis can result in a reluctance to seek medical care because of the consequences of the stigma (Murray *et al*., 2013). TB-related stigma affects health-seeking behaviours such as utilisation of TB services and completion of TB treatment (Murray *et al*., 2013). Similarly, stigma has been associated with lower testing levels in other infectious diseases, such as HIV, and has been perceived as an impediment to testing and treatment (Haffejee *et al*., 2018). Thus, the utilisation of TB services may also be diminished due to stigma, which should be tackled to improve the utilisation of services and improve treatment outcomes.

2.8.2 Psychosocial effects of TB-related stigma

TB is a socio-medical condition accompanied by social and economic stressors. Although an infectious disease, it is also a biological manifestation of social inequality (Moshin, 2014). The social stressors for PwDR-TB include stigma, lack of social support, family

separation, loneliness, and rejection, often not addressed during TB care (Alene *et al*., 2018; Shringarpure *et al*., 2016). TB-related stigma often manifests in discriminatory behaviours, which include hindrance of educational opportunities, fear of divorce, marriage restrictions, inability to share meals and utensils with family members, being subjected to gossip, shame, and ridicule within the family and community, loss of employment, or the inability to get a job (Ashaba *et al*., 2021; Kamble *et al*., 2020), often resulting in loneliness, low self-esteem, poor quality of life, anxiety, and depression (Chen *et al*., 2021b).

In addition, the lifestyle changes imposed by the long course of DR-TB therapy and illness/sequelae often result in psycho-social distress, isolation, and lack of participation in everyday routines, which may result in low self-worth, low self-esteem, and depression (Morris *et al*., 2013). A study reported that having dependent children was associated with anxiety and stress because of the inability to perform their parental role (Vega *et al*., 2004). Stigma reduces social interaction between PWTB and others, impacting the patient's mental life (McArthur *et al*., 2016). Studies have shown that stigmatised PWTB are eleven times more likely to be depressed than those not experiencing stigma (Duko *et al*., 2015; Lee *et al*., 2017).

2.9 Prevalence of anxiety, depression, and loneliness

Anxiety, depression, and social isolation (loneliness) cause psychological distress, which is common among PWTB (Xavier and Peixoto, 2015). A meta-analysis review reported the prevalence of depression among people with MDR-TB at 53.2% (Duko *et al*., 2020). Previous studies from Nigeria showed the prevalence of depression among people with drug-sensitive TB to be 28%-48.6% (Amole *et al*., 2020; Umar Shittu *et al*., 2019). Similarly, studies have shown that the prevalence of depression is higher among PwDR-TB compared to those with drug-sensitive TB (Duko *et al*., 2020), type 1 and 2 diabetes (Roy and Lloyd, 2012) and HIV (Wang *et al*., 2023).

In a study from Indonesia, the prevalence of anxiety among people with MDR-TB was 86.3% (Susanto *et al*., 2023), higher than the 54% and 66% obtained among people with MDR-TB and XDR-TB in India, respectively (Srinivasan *et al*., 2021). The cause of the

high prevalence of depression and anxiety among PwDR-TB is still uncertain. While some authors believe it is due to the course of the illness and the side effects of cycloserine, one of the second-line TB drugs (Theingi *et al*., 2021), however, recent studies have shown that there was no association between depression and cycloserine (Tornheim *et al*., 2022; Court *et al*., 2021). A study from Indonesia demonstrated that the prevalence of anxiety and depression was 86.3% and 68.6%, respectively, among people with MDR-TB who were yet to commence the second-line drugs (Susanto *et al*., 2023).

2.9.1 TB-related stigma and isolation

Humans are social beings; connection with others is needed for health and well-being. Social isolation (loneliness) can increase morbidity, reduce treatment adherence, and reduce social support (Leigh-Hunt *et al*., 2017). Isolation during disease is a complex phenomenon that could outlast the initiating condition. Isolation has many dimensions, such as the person imposing the isolation (either the patient not interacting with society or others ignoring the patient), the type of isolation (social or physical isolation) and the duration of isolation (short-term or long-term) (Redwood *et al*., 2022).

Physical isolation is often required during the initial treatment of TB for infection control purposes until they no longer continue to be public health threats, typically the first two weeks of drug-susceptible TB treatment and after one to three months of treatment for DR-TB (Ritchie *et al*., 2007; Dharmadhikari *et al*., 2014). However, family and friends extend this isolation for a considerable period, which may predispose PWTB to loneliness and depression (Alene *et al*., 2018). With no clinical advice for the duration of physical isolation, PWTB could be trapped in endless physical and social isolation (Petersen *et al*., 2017). In Vietnam, a study showed that PwDR-TB practised isolation after being informed they were no longer infectious because of the fear of infecting others, fear of stigma and preserving the family reputation.

The intense desire of PwDR-TB to be seen as moral citizens by the community further encourages this behaviour (Redwood *et al*., 2022). A study from Ghana showed that health workers perpetrated prolonged isolation by educating the patients to isolate themselves even when they were no longer infectious (Dodor *et al*., 2009). It opined that

community members often mirrored healthcare providers' isolation and exclusionary practices, which may be responsible for the diagnostic delay, low-case findings, and poor adherence (Dodor *et al*., 2009).

2.9.2 TB-related stigma and Health-related quality of life

Health-related quality of life (HRQoL) assesses the impact of disease and its treatment on a person's daily perception of physical, mental, and social well-being (Ahmad *et al*., 2016). It is essential because people with chronic diseases often prioritise their cognitive and social well-being over physical health (Sherbourne *et al*., 1999). Patients are not concerned about bacteriological cures alone; their well-being, functional capacity, and experiences of illness are equally important (Conrad and Barker, 2010).

TB is one of the diseases that can adversely undermine the HRQoL (Dujaili *et al*., 2015). It can be influenced by several patient, disease, and treatment-related factors in PWTB because of the multi-drug therapy, side effects of medications, social impacts, social support, social stigma, and possible complications (Brown *et al*., 2015). Generally, HRQoL is lower in PWTB compared with healthy populations (Dixit *et al*., 2024) but higher among people with drug-sensitive TB compared with their counterparts with DR-TB due to a complex interaction between physical illness, psychological consequences of the disease and the financial burden (Araia *et al*., 2021).

One of the most critical factors affecting HRQoL among PwDR-TB is stigma. Studies from India and Indonesia showed that TB-related stigma was negatively related to HRQoL (Kaur *et al*., 2016; Fuady *et al*., 2024). A systematic review from South Africa evaluating HRQoL among PWTB suggested that psycho-social burdens such as stigma and social isolation impact HRQoL more than clinical symptoms (Kastien-Hilka *et al*., 2017). TB-related stigma predisposes to depression, low self-efficacy, anxiety and ultimately poor HRQoL (Courtwright, 2010). PWTB have a poorer quality of life than the general population (Datiko *et al*., 2020), and stigma has been associated with poor quality of life among PWTB (Tadesse, 2016). Psychological distress is a significant factor affecting PWTB, with a prevalence between 51.9% and 81% (Ayana *et al*., 2019). Psychological distress among PWTB in sub-Saharan African countries was estimated to be 42.3%

(Duko *et al*., 2020). They may interfere with patients' immune response, affect drug adherence and increase mortality from TB (Ambaw *et al*., 2018).

2.10 TB-related stigma and the healthcare workers

Healthcare workers are integral to the patient-centred care required for therapeutic efficiency, equity, and safety of DRTB treatment. This care is needed to alleviate psycho-social and economic issues such as poverty, poor access to treatment and social stigma that worsen DR-TB treatment (Liboon *et al*., 2023). TB is a stigmatised disease, and TB-related work is viewed as "dirty work" (Craig *et al*., 2018). Consequently, health workers delivering care for TB are discriminated against by colleagues not working in TB clinics (Craig *et al*., 2018). TB-related stigma causes a vicious cycle. Stigmatised patients are reluctant to get diagnosed, seek, and complete treatment; stigmatised healthcare workers also display undesirable attitudes and behaviours towards their patients and co-workers (Nyblade *et al*., 2019).

Stigma in healthcare facilities negatively impacts individuals seeking healthcare services (Nyblade *et al*., 2019). The manifestations of stigma in healthcare facilities range from denial of care, provision of sub-standard care, subjection to long waiting times, and physical or verbal abuse (Hamann *et al*., 2014; Dodor *et al*., 2009) which could deprive clients' access to diagnosis, treatment, and successful health outcomes (Tudor *et al*., 2013). Common drivers of stigma within health facilities include fear of infection, cultural beliefs about TB, poor knowledge of the disease, inability to manage the disease and established organisational practices (Chang and Cataldo, 2014). Due to fear of infection, health workers in some African countries exhibit attitudes and practices that promote TB-related stigma. They may avoid, blame, or impose prolonged isolation on patients, which promotes TB stigma (Chang and Cataldo, 2014).

Health workers' attitudes can reinforce the stigma attached to a disease. In a study from Ghana, community members identified five interrelated ways the attitudes of health workers expose PWTB to further stigma in the community. The isolation and exclusionary practices of health workers, including the isolation of TB patients from other

patients and the use of face masks and gloves when attending to TB patients, were emulated by the community. Though these measures are part of the standard of care, the community leverage these actions to stigmatise PWTB. Secondly, the attitudes of health workers towards PWTB, such as shouting at TB patients, isolating TB patients from other patients and moving away when TB patients approach them. The inaccurate health information disseminated by health workers, such as avoidance of utensils and not touching items used by TB patients, food hygiene safety practices, and prohibition of burial rites, encouraged stigmatisation of TB patients in the community (Dodor *et al*., 2009). A South African study reported that negative attitudes towards the provision of grants, information and treatment contributed to TB stigmatisation (Cramm and Nieboer, 2011). In Ethiopia, TB-related stigma in public health facilities was responsible for patients approaching private health facilities for TB treatment, which caused a delay in treatment initiation (Sagbakken *et al*., 2008). In India, an unfriendly attitude of health workers during treatment was responsible for a high percentage of lost to follow up (Shringarpure *et al*., 2016).

2.11 Modifiers between TB-related stigma and health outcomes

2.11.1 Social support

For decades, social support has been recognised as an essential element in the control of TB (Murray *et al*., 2016). The WHO's framework for social support is divided into four subtypes. The first is informational, emotional, companionship and material support (World Health Organization, 2014). Social support refers to the apparent and genuine care received from friends, relatives, significant others, and/or the community (Li *et al*., 2014). When these are inconsistent, they suggest societal stigma (Zarova *et al*., 2018). Social support buffers adverse life events and improves TB treatment outcomes (Deshmukh *et al.*, 2018). When adequate, social support improves self-confidence and life fulfilment (Qiu *et al*., 2018). It enhances crisis adaptation and reduces the pressure on the patients, reducing the risk of psychological distress (Qiu *et al*., 2018; Masumoto *et al*., 2014). Studies from Ethiopia and China have shown that experiencing stigma is associated with psychological distress (Ayana *et al*., 2019; Xu *et al*., 2017).

People with good social support are likely to have a better quality of life and are less likely to be lonely, anxious, stigmatised, or discriminated against (Tadasse, 2016). Adequate social support increases people's life fulfilment and self-confidence. It enhances crisis adaptation and reduces the pressure on PWTB, hence reducing the risk of psychological distress such as loneliness, anxiety, and depression (Qiu *et al*., 2018; Masumoto *et al*., 2014). Social support has been shown to moderate the effect of stigma on depression and anxiety. Studies have shown that at high social support, the effect of the association between stigma was reduced, contrary to the exacerbated effect seen at low social support. Adequate social support reduces the impact of stigma and increases patient life fulfilment and self-confidence. It fosters patients' adaptation and reduces the risk of psychological distress (Zhang *et al*., 2023; Wang *et al*., 2022).

There is a complex relationship between TB stigma, social support, and HRQoL. Studies have shown that HRQoL is high among PWTB who experienced a lower level of stigma; however, in contrast, social support has the opposite effect (Faudy *et al*., 2024; Zhang *et al*., 2020). Patients with high social support are more likely to initiate diagnosis and treatment early (Deshmukh *et al*., 2018), and experience less stigma (Kastien-Hilka *et al*., 2016), leading to better HRQoL (Deshmukh *et al*., 2018). Institutional support from implementing partners and government agencies (Bamidele *et al*., 2024) and support in the workplace from healthcare providers and families positively influence the HRQoL of PwDR-TB (Laxmeshwar *et al*., 2019). Social support and TB stigma had opposite effects on HRQoL. Many studies have documented the effects of stigma and social support on HRQoL among PWTB; there is a need for further studies to ascertain which of the factors has a higher impact on HRQoL.

Social support is associated with treatment adherence. Qualitative studies among PwDR-TB from Nigeria and Armenia showed that social support from family, friends, the healthcare system, and the community were crucial to treatment adherence and success (Adagba *et al*., 2023; Grigoryan *et al*., 2022). Having someone observe drug intake, free treatment, provision of financial support for transportation, support from health workers, friends and the care and respect from family members were motivators for adherence (Adagba *et al*., 2023; Grigoryan *et al*., 2022). Systematic reviews and meta-analyses

showed that social support is necessary to improve treatment loss-to-follow-up and adherence among PwDR-TB (Law *et al*., 2019; Wen *et al*., 2020).

2.11.2 Resilience:

People with chronic diseases often experience repeated psychological distress, social isolation, and low self-esteem due to the pressure of continuous self-care, which, when combined, could result in depression. To reduce this susceptibility, there have been calls for patient-strength-oriented interventions reinforcing positive factors while downplaying the negative ones (Dias *et al*., 2015). The literature has applied resilience to describe the diverse approaches to overcoming difficulties. It is linked to better psychosocial and physical outcomes given the individual and community challenges (Vanderbilt-Adriance and Shaw, 2008). The challenges of PwDR-TB are multidimensional, and health provider services are limited in their ability to address them. Resilience is one of the person-centred approaches not fully explored but crucial in mitigating these challenges (Nagarajan *et al*., 2024).

Resilience refers to the various efforts to overcome difficulties through resource allocation, psychological coping skills, and enhancing social structures and interactions (Woodward *et al*., 2017; Waugh & Koster, 2015). It is a psychological ability to diminish negative feelings and improve adaptation during a predicament that motivates patients to remain psychologically healthy, helping them cope with anxiety and depression associated with chronic diseases and hence improving their quality of life (Cal *et al*., 2015). Resilience reinforces patients' strengths and empowers them to overcome crises and return to their original state (Rutter *et al*., 2008). Wagnild and Young defined resilience as a positive trait that relieves the adverse consequences of stress and promotes adjustment (Wagnild and Young, 1993), while Dias *et al*. (2015) define resilience as a dynamic interaction between internal and external risk factors and adaptive factors during a crisis (Dias *et al*., 2015).

The link between resilience and health benefits may not be simple, as many PWTB struggle for survival in the context of diverse difficulties (Cremers *et al*., 2018). Resilience is dynamic change over time and is inconsistent across all domains. PWTB may show resilience in one domain but not another (Cremers *et al*., 2018). Some researchers view

stigma as a stressor in the environment, and some individuals have developed psychological resilience to manage these stressors (Shih, 2004). Stigmatised individuals can build resilience through compensation by being more assertive or persistent. They may also refine or monitor their social interaction with others or adopt an attitude that helps them to distance themselves from being judged with prejudice (Shih, 2004). Though strategies to develop resilience may differ from one individual to another, stigmatised individuals draw from existing resources (inner strength), which can be actively developed and sustained to create a sense of self-efficacy (Boardman *et al*., 2011). A qualitative study from India found that the interaction of participatory care, self-adaptation, and self-efficacy, aided by caregiver and health system support, led to resilience among PwDR-TB (Nagarajan *et al*., 2024).

Resilience has been linked with adherence to TB treatment (Nagarajan *et al*., 2024). Qualitative studies from Nigeria and Armenia have shown resilience exhibited through a sense of family responsibility, willpower, and determination to improve, which enhances adherence (Adagba *et al*., 2023; Grigoryan *et al*., 2022). Though resilience has long-term health benefits, an ethnographic health study from South Africa demonstrated that some manifestations of resilience, such as delaying intake of TB drugs when lacking food to avoid psychosis and alcohol consumption to better cope with therapy, may interact to undermine the health outcomes (Cremers *et al*., 2018).

PwDR-TB often develops self-driven solutions and resilience to overcome the multi-dimensional challenges and consequences of DR-TB medications. There is a need for TB programs to adopt a resilience-building approach that leverages the strengths and vulnerabilities of PWTB and their communities (Cremers *et al*., 2018). A study that assessed mental health stigma and resilience showed that participants noted that the relationship between stigma and resilience is complex. Some participants opined that resilience caused less stigmatisation if it occurred first, while others suggested that stigmatisation decreased their ability to be resilient (Crowe *et al*., 2016). The authors, however, suggested that knowledge of this relationship is crucial for counsellors, as it allows them to determine whether the patient is resilient or whether stigmatisation is reducing the client's resilience (Crowe *et al*., 2016).

The role of resilience in mental illness has been well-researched. It is associated with a reduced risk of suicide (Harris *et al*., 2020) and favourable long-term outcomes among people with schizophrenia (Torgalsboen, 2012). It is associated with improved quality of life, good self-esteem, high spirituality, and reduced hopelessness among people with bipolar disorder (Mizuno *et al*., 2016; Lee *et al*., 2017). Low resilience was associated with high impulsiveness and an increased number of depressive episodes among patients with bipolar disorders (Choi *et al*., 2015). These findings suggest that resilience plays a protective role in the degree of self-stigma patients perceive, positively impacting the long-term outcomes of chronic diseases. It may play a crucial role in building resistance to stigma. (Post *et al.*, 2021).

2.11.3 Temporal discounting

Temporal discounting refers to an individual's ability to value an expected future outcome more than the present reality (Duan *et al*., 2017). Temporal discounting is an intellectual process that compares the value of immediate and delayed rewards (Bahrami and Borhani, 2023). Temporal discounting is a key factor in impulsivity, as achieving long-term goals often requires delaying gratification (Bahrami and Borhani, 2023). The extent to which the future can be discounted is associated with environmental factors and varies across individuals and situations (Odum and Baumann, 2010). Individuals who persevere to complete a prolonged treatment course tend to perceive a brighter future. An individual with low temporal discounting believes that efforts made in the present are necessary to have gains in the future (Duan *et al*., 2017). The link between TB and self-control is robust, and low or steep temporal discounting is associated with low impulsivity and higher intelligence (Bahrami and Borhani, 2023).

Temporal discounting is a complex phenomenon encompassing cognitive and affective processes (Bahrami and Borhani, 2023). It is affected by time perception and risk-taking (Wittmann and Paulus, 2008; Peters and Büchel, 2009). Time perception is associated with impulsivity in temporal discounting (Rubia *et al*., 2009). Research indicates that individuals with high temporal discounting tend to overestimate time-based intervals (Rubia *et al*., 2009; Jokic *et al*., 2018). A recent study examining the relationship between

social exclusion and temporal discounting found that participants socially excluded showed a steeper discounting of future rewards compared to those included (Bahrami and Borhani, 2023). A mixed-methods study from Nigeria, which compared adherence to DR-TB treatment among hospital-based and community-based patients, showed that hope for a future cure motivated adherence (Adagba *et al*., 2023). A systematic review opined that non-adherence to long-term therapies may result from failing to prioritise the future, as patients are often more attracted to immediate rewards (Sapkota *et al*., 2015).

2.12 TB-related stigma interventions

Stigma could manifest as perceived, anticipated, internalised, enacted, or experienced stigma. Practical and robust interventions are needed to reduce health-related stigma by targeting the drivers, the myths and misconceptions surrounding the disease and the blame attributed to those infected (Stangl *et al*., 2019). To mitigate harm and change the paradigm of negative attitudes and behaviours, interventions after stigma has been linked to a disease should tackle the manifestations of stigma in the family, community, and health care facilities (Stangl *et al*., 2019). To achieve this, the driver targeted by the intervention must be defined (Macintyre *et al*., 2017).

A scoping review that analysed interventions designed to reduce TB-related stigma showed a significant gap in the literature on the evaluations of TB-related stigma interventions, as none of the identified stigma reduction interventions were designed to reduce the effects of stigma among PWTB. All interventions were in the pilot phase and were diverse in their approach to measurement and implementation. Most of the interventions reviewed employed diverse strategies targeting stigma at the individual, interpersonal and organisational levels; none targeted structural or policy-level changes (Foster *et al*., 2022).

Despite the global importance of addressing TB-related stigma, reviews have shown that there is a paucity of studies evaluating the interventions to reduce TB-related stigma (Foster *et al.*, 2022; Nuttall *et al.*, 2022). The available interventions were limited and often lacked adequate design and implementation methods and practical evaluation strategies

(Nuttall *et al*., 2022). The need to assess TB-related stigma in diverse populations, use validated tools to quantify the impact at different points in the TB cascade and the paucity of interventions to address TB-related stigma in health facilities is paramount (Foster *et al*., 2022). A reliable and validated stigma measurement tool ensures accurate and consistent stigma measurement. It also enables the comparison of the impact of evaluating these interventions across studies and contexts (Nuttall *et al*., 2022).

In their review, Foster *et al*. (2022) opined that counselling individuals or support groups may address internalised and anticipated stigma. However, information-based interventions targeted at the household and community levels are appropriate for individuals experiencing stigma (Foster *et al.*, 2022). To do this will require a deep understanding of the local context and the cultural environment, while noting that what works in one community may be inappropriate in another because of variability in the community's sociocultural characteristics (Foster *et al*., 2022). Nuttall *et al*. (2022) noted in their review that PWTB experienced stigma from the public, TB healthcare workers and other healthcare workers; therefore, interventions targeted towards more than one key population at the same time will be more effective.

2.13 Theoretical framework

Many health behaviour models can be applied to understand and design interventions to address TB-related stigma. These models highlight how individual beliefs, social influences and environmental factors contribute to stigmatising behaviours. These models include the Health Belief Model (HBM), the Theory of Planned Behaviour (TPB), Social Cognitive Theory (SCT) and the Health Stigma and Discrimination Framework (HSDF) (Alyafei and Easton-Carr, 2024).

The HBM is a psychological framework used to understand and predict health-related behaviours. It focuses on how individual perceptions of health threats influence their behaviour. In the context of stigma, it could explain why individuals avoid or discriminate against people with health conditions such as TB based on perceived susceptibility to the

condition and the severity of the consequences. It essentially explores how personal beliefs and perceptions influence decisions about health (Alyafei and Easton-Carr, 2024).

TPB suggests that behaviour is influenced by intentions, which are shaped by attitudes, subjective norms, and perceived behavioural control. In the context of stigma, the TPB can explain how negative attitudes towards a group (e.g., PWTB) can lead to intentions to discriminate and how perceived social norms (e.g., what others in the community believe) and perceived control (e.g., the ability to avoid contact with stigmatised individuals) can further influence behaviour (Oyedeji *et al*., 2024).

The SCT emphasises the reciprocal relationship between personal factors, environmental factors, and behaviour. It can be used to understand how exposure to negative media portrayals or social interactions can shape beliefs about stigmatised groups, and how interventions that increase self-efficacy and promote positive social interactions can reduce stigmatising behaviour. This theory is premised on the fact that learning as a cognitive process cannot be separated from the context in which it occurs, be it family, institutions or community (de la Fuente *et al*., 2023).

2.13.1 Theoretical frameworks to guide the study

2.13.2 The Health Stigma and Discrimination Framework

Globally, stigma hinders health-seeking behaviours, care retention and treatment adherence across many health conditions (Stangl *et al*., 2019). Stigma impacts population health outcomes by undermining social interactions and psychological and behavioural responses, resulting in poor health conditions (Hatzenbuehler *et al*., 2013). A multi-level theoretical framework is needed to guide the development of stigma reduction interventions, research and policy formulation if the harmful consequences of stigmatisation are to be mitigated. Unfortunately, the existing theoretical frameworks are disease or health condition-specific, stifling innovative public health responses (Stangl *et al*., 2019). Many of the health-related stigma frameworks explore psychological pathways at the individual level and focus on individuals experiencing stigma (Sikorski *et al*., 2015), those perpetuating it (Longdon and Read, 2017) or both (Fox *et al*., 2018). These

frameworks limit researchers' ability to develop a multi-level intervention to engage and meaningfully influence the stigmatisation process (Stangl *et al*., 2019).

The Health Stigma and Discrimination Framework (HSDF) articulates the unfolding of the stigmatisation process across the socio-ecological spectrum, which varies across low, middle and high-income countries. The process is divided into drivers and facilitators, stigma 'marking' and stigma manifestations (Stangl *et al*., 2019).

The first domain refers to factors that drive health-related stigma. These may vary by health condition and are conceptualised as inherently harmful. They include fear of infection, concerns about productivity due to poor health for chronic conditions, authoritarianism, social judgment, and blame (Stangl *et al*., 2019). Contrariwise, facilitators may be positive or negative influences [9]. The occurrence of stigma 'marking' is determined by drivers and facilitators.

Stigma 'marking' is the process by which stigma is applied to people or groups depending on the health conditions or other perceived differences, such as race, gender, class, sexual orientation or occupation (Stangl *et al*., 2019). Once applied, stigma manifests in various experiences and practices (i.e beliefs, attitudes and actions). Stigma experiences can include refusal of housing, verbal abuse or gossip (Stangl *et al*., 2013). Internalised or self-stigma is another stigma experience, defined as the adoption of negative societal beliefs, feelings and the social devaluation by the stigmatised group member. Other stigma experiences are perceived stigma (i.e perceptions about how stigmatized groups are treated in a given context), anticipated stigma (i.e expectations deviation being perpetrated by others of their health status is known) (Nofalia *et al*., 2020) and secondary or associative stigma (stigma experiences of family or friends of stigmatized individuals or among healthcare providers who provides care to stigmatized groups) (Holzemer *et al*., 2009). Stigmatising practices include stereotypes, prejudices, behaviours, and discriminatory attitudes (Stangl *et al*., 2019).

2.13.3 How the Health Stigma and Discrimination Framework is different

The HSDF differs from other frameworks in that it does not distinguish between the stigmatised and the stigmatiser (Yang *et al*., 2023). This absence challenges the distinction that enables people to label others as different. The danger of separating 'us' from 'them' is that it removes the ability of that vulnerable population to influence the social contexts driving their experiences, behaviours and actions. The HSDF shows the interconnections between power and vulnerability and the complexity that exists between them (Stangl *et al*., 2019). The framework is also more sensitive to change agents such as community leaders, advocates and policymakers (Stangl *et al*., 2019).

In addition, unlike the previous framework, HSDF separates manifestations into experiences and practices. This distinction explains the pathways to various outcomes following the stigma-marking phase of the process (Stangl *et al*., 2019). Those who experience, internalise, perceive and anticipate health-related stigma could experience poor health seeking, delayed treatment and poor treatment adherence that adversely affects their health outcomes (Trapence *et al.,* 2012). Stigma has been shown to foster resilience in stigmatised groups and promote the formation of advocacy groups, which could influence policy changes to improve access to healthcare for stigmatised people (Logie *et al*., 2011). The HSDF also demonstrates that stigma experiences and practices affect individuals, organisations, and institutions, influencing stigma's health and social impacts. By articulating these outcomes, the framework highlights the need for multilevel interventions to respond to health-related stigma. It also focuses on the far-reaching influence of health-related stigma on societies and individuals (Stangl *et al*., 2019). (See Figure 2)

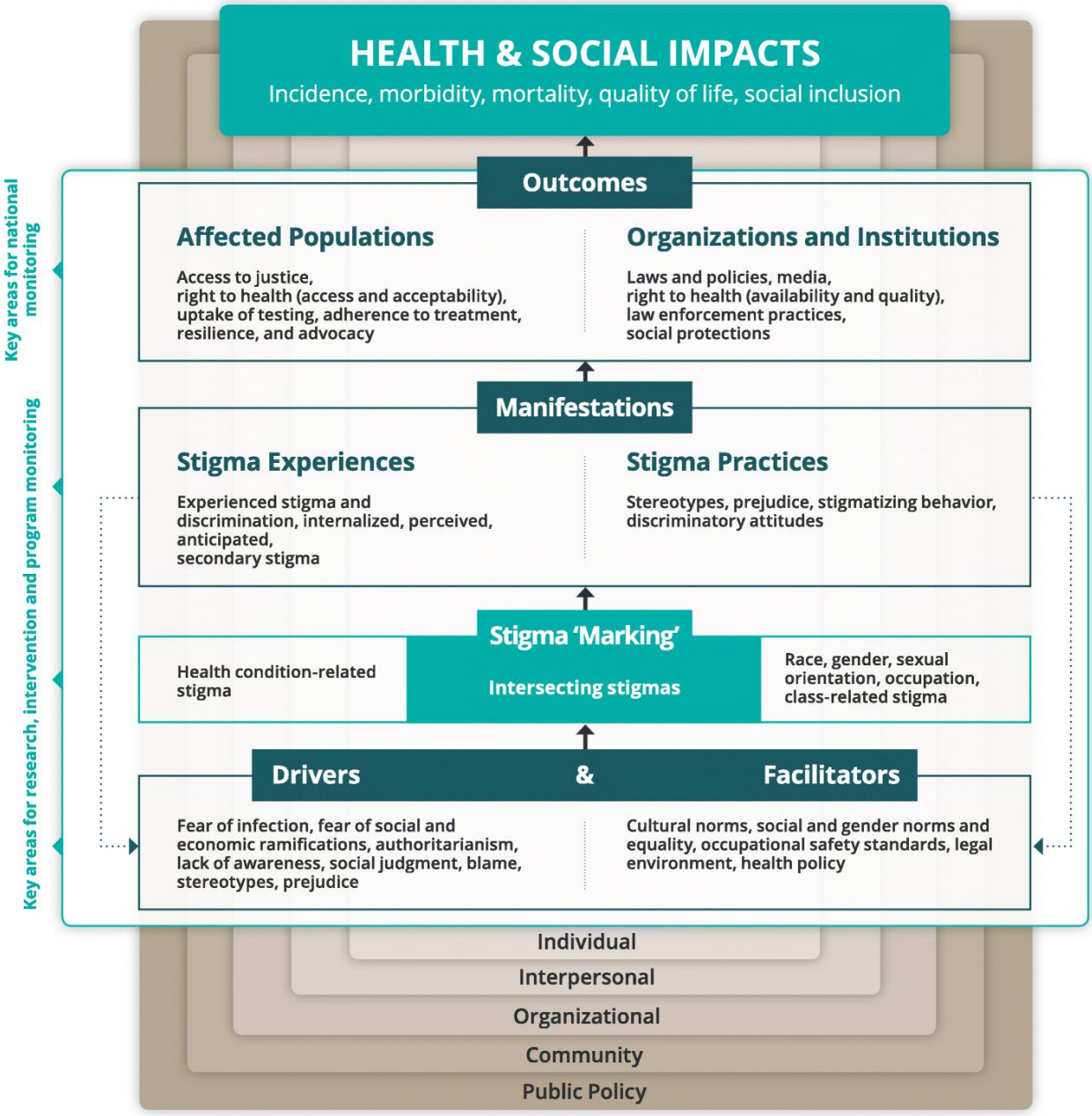

Figure 2: Theoretical Framework

2.14 Conceptual framework

This study is based on the framework in Figure 2. TB-related stigma has manifestations, consequences, and detrimental effects. However, experienced stigma and its effects can be modified by compassionate care, empowering care, resilience, temporal discounting, and economic, psychological, and social support. The presence of these modifiable factors varies from one person to another depending on the social, economic, psychological, and physical environment. This conceptual framework articulates the hypothesised relationships tested in this study. These relationships were drawn from the literature (Mukerji and Turan, 2018). (See Figure 3)

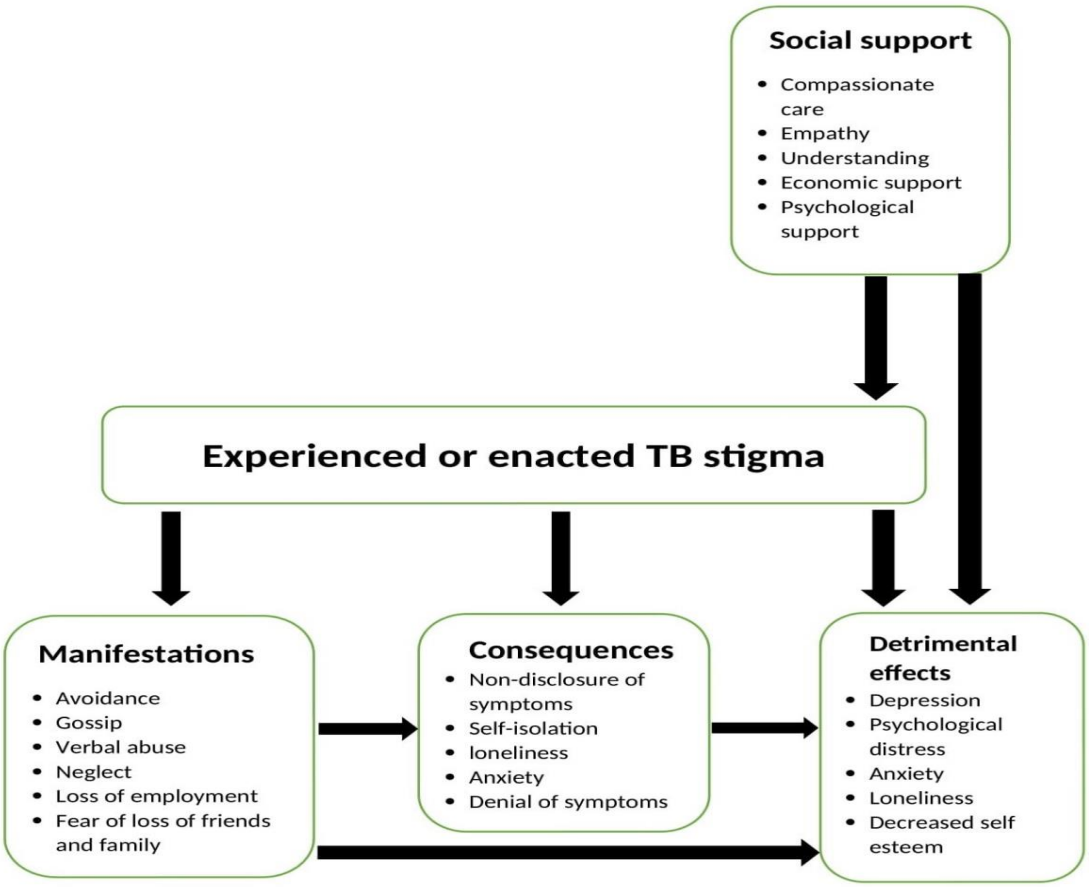

Figure 3: Conceptual Framework

In conclusion, TB-related stigma negatively impacts global TB control, and thus, its prohibition is one of the thrusts of the 'End TB strategy' if the goal of ending TB by 2050

is achieved (World Health Organization, 2021). Nigeria has one of the highest burdens of TB globally, and Lagos State accounted for about 22% of the country's rifampicin-resistant TB cases in 2019 (Adejumo *et al*., 2022). Despite the progress made to detect and treat PWTB, TB control in Nigeria is still characterised by poor access to testing and diagnosis, low case detection, high under-reporting, a long delay in treatment initiation, and high loss to follow-up (Oga-Omenka *et al*., 2019; Oga-Omenka *et al*., 2020; Gidado *et al*., 2022). TB control in Nigeria is, therefore, crucial if the global targets for TB control are to be achieved. Multiple studies on TB-related stigma have been conducted, and some of them have been reviewed in the text above; however, there are gaps that this present study aims to cover.

First, despite the high prevalence of TB-related stigma in Nigeria (Junaid *et al*., 2021; Oladele *et al*., 2020), there is a dearth of studies on the subject. The few available studies focused on the community perspective of TB-related stigma with an emphasis on drug-sensitive TB (Abioye *et al*., 2011; Oladele *et al*., 2020; Junaid *et al*., 2021). Though studies from other settings have shown that PwDR-TB suffers stigma more than PWTB because of the longer treatment duration, prolonged isolation and the shame and blame associated with treatment failure, studies that determined the prevalence of TB-related stigma among PwDR-TB in Nigeria are very scarce.

Secondly, stigma has been shown to cause anxiety, depression, and loneliness among PWTB. Additionally, social support has been shown to mitigate the effects of stigma. However, there are no studies in Nigeria that assessed whether social support moderated the effects of stigma on anxiety, depression, and loneliness. Temporal discounting is a concept that has been applied to various other chronic illnesses like obesity, diabetes, substance abuse and risky sexual behaviours, but little is known of its application to TB treatment. There are no studies in Nigeria that assessed the effect of temporal discounting on adherence to TB treatment and TB-related stigma.

Lastly, there have been calls for a patient-centred approach in DR-TB treatment, and resilience has been identified as one of the patient-centred approaches that have not been well explored in TB management. The relationship between resilience and adherence has not been assessed in Nigeria. This study aims to address these gaps.

CHAPTER THREE

PUBLISHED ARTICLE 1

Stigma Experienced by People with Drug-Resistant Tuberculosis in Lagos, Nigeria: A Cross-Sectional Study.

This Chapter is presented as a published article. It highlights the prevalence of stigma and its associated factors among PwDR-TB and addresses the first objective of this thesis. The format and references in this chapter are presented according to the journal's submission guidelines.

Article title: Stigma Experienced by People with Drug-Resistant Tuberculosis in Lagos, Nigeria: A Cross-Sectional Study.

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Journal: Transactions of the Royal Society of Tropical Medicine and Hygiene.

Status: Published (March 2025)

Trans R Soc Trop Med Hyg 2025; **0**: 1–8
https://doi.org/10.1093/trstmh/traf026 Advance Access publication 0 2025

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Stigma experienced by people with drug-resistant tuberculosis in Lagos, Nigeria: a cross-sectional study

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Received 9 July 2024; revised 16 January 2025; editorial decision 4 February 2025; accepted 19 February 2025

Background: Tuberculosis (TB) stigma is one of the factors responsible for low notification rates in Nigeria, especially among people with drug-resistant TB (DR-TB). This study assessed the factors associated with stigma among people with DR-TB in Lagos, Nigeria.

Methods: A descriptive cross-sectional study was conducted among 203 adults on DR-TB treatment. The Redwood DR-TB stigma scale was used to assess the stigma experienced by people with DR-TB. A logistic regression model was used to evaluate the factors associated with TB stigma.

Results: The prevalence of TB stigma was 65.5%. Being male (adjusted odds ratio [aOR] 2.59 [95% confidence interval {CI} 1.03 to 6.50], p=0.042), not earning an income (aOR 2.57 [95% CI 1.84 to 7.85], p=0.039), substance use (alcohol or cigarette smoking; aOR 1.61 [95% CI 1.06 to 3.88], p=0.028) and the duration of the DR-TB diagnosis (aOR 2.72 [95% CI 1.94 to 3.83], p<0.001) were associated with stigma among people with DR-TB. Human immunodeficiency virus (HIV)-negative participants experienced TB stigma 2.4 times more (crude OR 2.4 [95% CI 1.14 to 5.04], p=0.021) than HIV-positive participants, although the relationship was not sustained in the multivariate analysis.

Conclusions: Having identified the factors associated with stigma in this target population, it is imperative to address and control them among DR-TB patients in Lagos, Nigeria. The urgent need for stigma reduction strategies cannot be overemphasized.

Keywords: drug-resistant tuberculosis, experienced stigma, Nigeria, tuberculosis stigma

Introduction

Stigma is a social determinant of health defined as 'an undesirable attribute that degrades an individual's societal status'.[1] It is shaped by customs, interpersonal interactions and health institutions' culture.[2] The prohibition of stigma and discrimination against people with tuberculosis (PWTB) is a thrust of the End TB Strategy, because of its impact on global tuberculosis (TB) control.[3] Discrediting PWTB is counterproductive to TB care and elimination efforts because of the possible adverse effects on healthcare seeking, care delivery, adherence and recovery. Crucially, the behaviour of the community and healthcare workers towards PWTB can influence the timing, location and quality of care. It could also impact resilience and health outcomes, undermining community TB screening efforts.[4]

TB stigma can be experienced at interpersonal (public), social, structural and organizational levels, such as in the health sector. Experience of stigma varies according to cultural settings. In some settings, it may result in rejection or social seclusion from family members, friends, neighbours and healthcare providers.[5] This may result in divorce, loss of employment, eviction from accommodations, rejection of a marriage proposal and family isolation.[6] Mistreatment of people with TB can contribute to mental health sequelae, poor coping behaviours and comorbidities.[7] It hinders the disclosure of disease status to significant others—undermining efforts to break the chain of transmission—and is associated with decreased self-esteem, poor quality of life, psychological distress, feelings of guilt, isolation and depression.[8] Stigma may also negatively impact patients' social capital, disease resilience and household-level well-being.[9]

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Nigeria is a high TB burden country with an estimated incidence rate of 219 per 100 000 population.[10] In 2022, about 43% of the 408 500 drug-resistant tuberculosis (DR-TB) cases were enrolled for treatment, and Nigeria was among the 10 countries that accounted for 70% of the treatment initiation gap.[3] Studies from Nigeria and other TB-burdened countries have reported a high prevalence of TB stigma.[11–13] Age, education status, number of family members, place of residence, TB/human immunodeficiency virus (HIV) co-infection, poor social support, knowledge of TB, alcohol intake and cigarette smoking have been reported as factors associated with TB stigma in Nigeria, India, Ethiopia and China.[11,14,15] Unfortunately, very few studies have been conducted among people with DR-TB. People living with DR-TB are potentially more prone to stigma than PWTB because of the longer duration of treatment, prolonged period of isolation and the shame and blame associated with treatment failure, underscoring the need for more studies to determine the prevalence and factors associated with stigma among people with DR-TB. This present study assessed the factors associated with stigma among people with DR-TB in Lagos, Nigeria. To our knowledge, comparable studies that evaluate the prevalence of TB stigma experienced by people with DR-TB are scarce.

Methods

Study design

We conducted a descriptive cross-sectional study between 1 September and 20 December 2023 to assess the factors associated with stigma among people with DR-TB in Lagos, Nigeria.

Study setting

Lagos State is the commercial nerve centre and the smallest state in Nigeria in terms of land mass, with an estimated population of 21 million. The state is divided into 20 local government areas. TB control in Lagos State is under the purview of the Lagos State TB and Leprosy Control Programme headed by a control officer at the state level. Drug-resistant TB is diagnosed using the Xpert MTB/RIF assay. As part of the standard of care, people with positive results are contacted through the Short Message Service and other laboratory tests are conducted before the initiation of treatment. Sputum samples are also taken for sputum culture to determine whether there is resistance to other first- or second-line drugs.

Patients are treated with a shorter, longer or individualized regimen based on the assessment and laboratory results. The bedaquiline-based short oral regimen is given for 9–11 months and is given as a standardized regimen with little or no room for customization or substitutions during treatment. The longer oral regimen is used for people with DR-TB who are not eligible for treatment with the shorter regimen. The duration of treatment is 18 months. The individualized regimen was used for people with pre-extensively drug-resistant TB, according to the needs of the patient as determined by their doctor. Patients are referred for follow-up in the treatment centre closest to their residence. There are six treatment centres across the state: Mainland Hospital, General Hospital Ikorodu, Alimosho General Hospital, Ojo Health Center, Tolu Health Center and St. Kizito Hospital.

Study sites, sample size and participant selection

Five sites were purposively selected from the sampling frame of six DR-TB treatment sites in Lagos State based on the caseloads, to ensure geographical representation and diversity in patient demographics. One site was excluded from the main study as it was during the pilot study. The records of the Lagos State TB and Leprosy Control Programme show that 625 people were on DR-TB treatment in 2022. We anticipated a non-response rate of 15%; therefore, the formula for a cross-sectional study for a finite population was used to calculate the sample size of 200 using a prevalence of TB stigma of 18%.[12]

Convenience sampling was used to recruit participants who were ≥18 y of age, diagnosed using the Xpert MTB/RIF assay and had been on DR-TB treatment for at least 8 weeks. Eligible participants willing to participate in the study were consecutively recruited during visits to the outpatient clinic. Sick and hospitalized DR-TB patients and those who had cognitive, physical and psychological issues that prevented them from making an informed decision to participate in the study were excluded from the study.

Study instruments and measurements

Outcome measures

TB stigma experience is the outcome measure in this study using the 14-item Redwood DR-TB stigma scale.[16] The scale measures stigma across the four subscales: guilt, social exclusion, physical isolation and blame.[16] It is scored on a 3-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). Scores ranged from 0 to 42, with a higher score indicating a higher level of stigma. In this study, the stigma score refers to the sum of all the subscales. A mean score ≥1 indicated the presence of stigma.[16]

Independent measures

The independent measures included age (continuous), gender (categorical; male/female), marital status (categorical; single/married/divorced), HIV status (categorical; positive/negative/don't know), treatment facility type (categorical; primary health facility/secondary health facility), duration of diagnosis (in months/continuous), earn personal income currently from any source (categorical; yes/no), average family income (using an exchange rate of 800 naira to US$1, continuous), substance use (categorical; yes/no), had barrier to treatment (categorical; yes/no) where substance users were participants who consumed either alcohol or/and smoked cigarettes and perception of treatment (categorical; yes/no).

Pilot testing and data collection

Five trained research assistants with backgrounds in health sciences administered the questionnaire. The questionnaire was pilot tested in the DR-TB treatment facility, which was not selected for the study. Twenty participants were recruited for the pilot testing. Some items in the questionnaire were rephrased to improve validity and acceptability. We used Cronbach's α to assess the validity and internal consistency of the scale. In this

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Table 1. Sociodemographic details of participants (N=203).

Variable	Attribute	n (%)
Gender	Male	128(63.1)
	Female	75 (36.9)
Age group (years)	<30	54 (26.6)
	30–39	59 (29.1)
	40–49	50 (24.6)
	50–59	19 (9.4)
	>60	21 (10.3)
	Mean (SD)	39.2 (13.8)
Education status	No education/primary	43 (21.2)
	Secondary	101 (49.8)
	Tertiary	59 (29.1)
Marital status	Single	74 (36.5)
	Married	111 (54.7)
	Widowed/separated/divorced	18 (8.9)
HIV Status	Positive	35 (17.2)
	Negative	160 (78.8)
	Unknown	8 (3.9)
Duration of DR-TB diagnosis (months)	2–3	94 (46.3)
	4–5	55 (27.1)
	≥6	54 (26.6)
Employment status	Employed and working	105 (51.7)
	Employed not working	48 (23.6)
	A student attending school	22 (10.8)
	A student not attending school	5 (2.5)
	Unemployed	23 (11.3)
Breadwinner	Yes	99 (48.8)
	No	104 (51.2)
Use of substance (alcohol/cigarette)	Yes	94 (46.3)
	No	109 (53.7)
Currently earning income	Yes	153 (75.4)
	No	50 (24.6)
Average family monthly (US$) Income (US$)	<125	106 (52.2)
	≥125	97 (47.8)

study, the Cronbach's α coefficient for the Redwood DR-TB stigma scale was 0.725.

Ethical considerations

The Institutional Research Ethics Committee of Durban University of Technology South Africa (IREC 066/230) and the Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179) granted ethical approvals for this study. We also obtained permission from the Lagos State Ministry of Health and the Lagos State TB and Leprosy Control Officer to interview people with DR-TB in the five selected facilities. Written informed consent was obtained before data collection.

Data quality and analysis

The data were checked for errors and completeness after data entry. All inconsistencies were resolved by comparing the dataset with the completed questionnaires. All unresolved discrepancies were removed from the dataset before data analysis. The Statistics version 26 (IBM, Armonk, NY, USA) and Epi Info version 7.2 were used for data analysis. Continuous variables such as age, average family income, duration of DR-TB treatment and

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Table 2. Redwood DR-TB stigma scale.

Variable	n (%)
Experienced stigma	133 (65.5)
Subscales	
Guilt	129 (63.5)
Lost some of the joy since being diagnosed	111 (54.7)
Felt like a burden on your family	65 (32.0)
Felt like you have let your community down	27 (13.3)
Will be blamed if my acquaintance gets MDR-TB	59 (29.1)
Social exclusion	140 (69.0)
Felt unwanted when you attend social events since diagnosis	38 (18.7)
Expected to stay away from social activities	79 (38.9)
People gossip about you and your disease	50 (24.6)
People stand or turn their heads away when talking to them	52 (25.6)
Physical isolation	183 (90.1)
Ate separately, even when not in the infectious period anymore.	121 (59.6)
Could not sit close to your family members	142 (70.0)
Slept and ate separately from family for the duration of your treatment	88 (43.4)
Blame	101 (49.8)
Got MDR-TB because of working too hard	26 (12.9)
People said you got MDR-TB because of your job	23 (11.3)
Something that you did that caused you to get MDR-TB	49 (19.2)

experienced stigma were converted into categorical variables. Participants who answered affirmatively to the stigma tool were presented in percentages. Mean and standard deviation were used to represent continuous variables. Categorical variables were presented as percentages and compared using the χ^2 test. Epi Info was used to generate the crude odds ratio (COR). Logistic regression assessed the factors associated with experienced TB stigma after ensuring no normality, linearity or multicollinearity assumptions were violated. Variables significant at univariate analysis (gender, earning income, use of substance, HIV status, duration of DR-TB diagnosis, self-assessed severity of disease and perceived barrier to DR-TB treatment) were added into the regression model at once. For all statistical tests, $p<0.05$ was considered significant.

Results

A total of 224 people with DR-TB were eligible to participate in the study; of these, 203 participated in the study, giving a response rate of 90.6%. The median age was 37 y (interquartile range 28–47; range 18–80). The majority were male (63.1%) and HIV negative (78.8%), while about half had a secondary education (49.8%), were married (54.7%) and were diagnosed with DR-TB for at least 3 months (51.7%). About half (48.8%) were breadwinners; 75.4% earned an income and 52.2% earned <US$125/month (Table 1). A total of 133 (65.5%) reported experiencing TB stigma. Of the four TB stigma subscales, 90.1% of participants experienced physical isolation, 69.0% experienced social isolation, 63.5% experienced guilt and 49.8% had been blamed for their infection. Of the participants studied, 70.0% could not sit with family members, 59.6% ate separately even when not in the infectious period, 54.7% felt sad since the diagnosis, 38.9% stayed away from social activities, 32.0% felt like a burden to their families and 25.6% felt that other people turned their heads away from them during a conversation (Table 2). The associated factors of experienced stigma are shown in Tables 3 and 4. The odds of experiencing TB stigma was 2.33-fold higher in males (COR 2.33 [95% CI 1.28 to 4.23], p=0.006) than in females and 2.23-fold higher among those who were not earning any income (COR 2.23 [95% CI 1.06 to 4.68], p=0.035) compared with those earning an income. The length of diagnosis was associated with experienced stigma. The odds of TB stigma were 3.5-fold (COR 3.47 [95% CI 1.67 to 7.21], p<0.001) and 11.6-fold (COR 4.25 [95% CI 4.25 to 31.78], p<0.001) higher among those diagnosed between 4–5 months and >6 months, respectively, compared with those diagnosed with DR-TB for ≥3 months. The odds of TB stigma were 2.1-fold higher among participants who perceived DR-TB to be severe (COR 2.14 [95% CI 1.14 to 4.01], p=0.018) than those who perceived DR-TB to be mild/moderate in severity. The odds of experiencing TB stigma were 2.5-fold higher among participants who had a barrier to DR-TB treatment (COR 2.51 [95% CI 1.04 to 6.07], p=0.041) compared with their counterparts. HIV-negative participants experienced TB stigma 2.4 times more (COR 2.4 [95% CI 1.14 to 5.04], p=0.021) than HIV-positive participants, although the relationship was not sustained in the multivariate analysis (adjusted OR [AOR] 1.58 [95% CI 0.60 to 4.17], p=0.353). In the multivariate logistic regression model, being male (AOR 2.59 [95% CI 1.03 to 6.50], p=0.042), not earning an income (AOR 2.57 [95% CI 1.84 to 7.85], p=0.039), substance use (AOR 1.61 [95% CI 1.06 to 3.88], p=0.028) and the length of DR-TB treatment (AOR 2.72 [95% CI 1.94 to 3.83],

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Table 3. Sociodemographic factors associated with experienced stigma among DR-TB patients.

Variables	Experienced stigma, n (%)		COR (95% CI)	p-Value
	Yes (n=133)	No (n=70)		
Gender				
Male	93 (72.7)	35 (27.3)	2.33 (1.28 to 4.23)	0.006
Female	40 (53.3)	35 (46.7)	1	
Age group (years)				
<30	32 (59.3)	22 (40.7)	1	
30–59	85 (66.4)	43 (33.6)	1.36 (0.71 to 2.62)	0.359
>60	16 (76.2)	5 (23.8)	2.20 (0.70 to 6.89)	0.176
Marital status				
Single	47 (63.5)	27 (36.5)	1	
Married	73 (65.8)	38 (34.2)	1.10 (0.597 to 2.04)	0.753
Widowed/separated	13 (72.2)	5 (27.8)	1.49 (0.48 to 4.65)	0.488
Education status				
No education/primary	24 (55.8)	19 (44.2)	1	
Secondary	73 (72.3)	28 (27.7)	2.06 (0.98 to 4.34)	0.056
Tertiary	36 (61.0)	23 (39.0)	1.23 (0.56 to 2.75)	0.598
Currently earning income				
Yes	94 (61.4)	59 (38.6)	1	
No	39 (78.0)	11 (22.0)	2.23 (1.06 to 4.68)	0.035
Breadwinner				
Yes	70 (70.7)	29 (29.3)	1.57 (0.88 to 2.82)	0.130
No	63 (60.6)	41 (39.4)	1	
Average family income (US$)				
<125	66 (62.3)	40 (37.7)	1	
≥125	67 (69.1)	30 (30.9)	1.35 (0.76 to 2.42)	0.309
Household size				
1–2	44 (73.3)	16 (26.7)	1.40 (0.66 to 2.99)	0.378
3–4	42 (58.3)	30 (41.7)	0.72 (0.36 to 1.41)	0.333
≥5	47 (66.2)	24 (33.8)	1	

$p<0.001$) were associated with TB stigma among people with DR-TB (Table 5).

Discussion

TB stigma occurs because of the community's perception of unwanted characteristics. In this study, we assessed the factors associated with stigma experienced by people living with DR-TB in Lagos, Nigeria. Two-thirds (65.5%) of participants reported TB stigma. Being male, not earning an income, length of DR-TB treatment and substance abuse were associated with TB sigma in our study.

TB is a stigmatizing disease because it affects people of the lowest socio-economic status and is often intertwined with gender roles, relationships and cultural beliefs.[17,18] Our study shows that 65.5% of study participants experienced TB stigma. Available studies conducted among people with drug-sensitive TB from South Africa, India and Tanzania reported lower levels of TB stigma at 22.1%, 26% and 20.6%, respectively.[19,20,21] The prevalence of TB stigma is suggested to be higher among people with DR-TB than those with drug-sensitive TB because of the longer duration of treatment, the prolonged isolation and the shame associated with treatment failure.[22] TB stigma is experienced at home, in the workplace, in the community and in health facilities.[23] A Tanzanian study reported that 50% of the stigma experienced by people with TB was within the family, while the community and workplace contributed 36% and 10% to the stigma, respectively.[23] Our findings concur with this, as we noted that physical isolation was common among family members, as those with DR-TB were required to eat and sleep separately and also not sit close to other family members, despite the infectious period being over.

Furthermore, participants reported social exclusion, were expected to stay away from social functions and were gossiped about. A community-based study in Nigeria reported that about two-thirds of community members had no desire to help people with TB or to employ them.[24] A scoping review indicated that the fear of infection and poor infection control were significant drivers of the TB stigma among healthcare workers.[25] A qualitative study from Ghana opined that community members often mirrored the isolation and exclusionary practices of healthcare providers, and this may be responsible for diagnostic delays, low case findings and poor adherence.[26]

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Table 4. Treatment factors associated with stigma among people with DR-TB.

Variables	Experienced stigma, n (%)		COR (95% CI)	p-Value
	Yes (n=133)	No (n=70)		
Substance use (alcohol/cigarette)				
Yes	69 (73.4)	25 (26.6)	1.94 (1.07 to 3.52)	0.029
No	64 (58.7)	45 (41.3)	1	
HIV status (n=195)				
Positive	17 (48.6)	18 (51.4)	1	
Negative	111 (69.4)	49 (30.6)	2.40 (1.14 to 5.04)	0.021
Duration of DR-TB diagnosis (months)				
2–3	43 (45.7)	51 (54.3)	1	
4–5	41 (74.5)	14 (25.5)	3.47 (1.67 to 7.21)	<0.001
≥6	49 (90.7)	5 (9.3)	11.62 (4.25 to 31.78)	<0.001
Self-assessed severity				
Mild/moderate	74 (59.2)	51 (40.8)	1	
Severe	59 (75.6)	19 (24.4)	2.14 (1.14 to 4.01)	0.018
Had barrier to treatment				
Yes	29 (80.6)	7 (19.4)	2.51 (1.04 to 6.07)	0.041
No	104 (62.3)	63 (37.7)	1	
DR-TB treatment facility				
Primary HF	34 (65.4)	18 (34.6)	1	
Secondary HF	99 (65.6)	52 (34.4)	1.00 (0.52 to 1.96)	0.981
Perception of treatment				
Helpful	116 (65.2)	62 (34.8)	1	0.780
Not sure	17 (68.0)	8 (32.0)	1.14 (0.46 to 2.78)	

HF: health facility.

The effects of TB stigma vary among men and women, and cultural beliefs mediate the interaction between gender and TB stigma.[18] Some studies opined that women are more affected by TB stigma, which is contrary to our findings.[8,27,28] Our findings may be culture-related, as traditionally men are usually expected to be financially capable of providing for their families and may feel inadequate when they cannot perform their roles.[28] TB stigma threatens their survival, as many stopped working for social and physical reasons, contributing further to financial distress, especially among breadwinners.[27] It was also suggested that the prevalence of TB stigma may be higher among men because of the interaction between culture, masculinity and the biological predisposition of men to have TB.[29] Additionally, TB stigma caused marital problems and character insults from the community.[27]

Epidemiological studies have shown that smoking is an independent risk factor for TB infection, the progression of primary TB and poor treatment outcomes.[30,31] In this study, the odds of experiencing TB stigma were higher among participants involved in the use of substances such as alcohol and cigarettes, which is similar to the findings reported from Nigeria and Ethiopia.[11,15,32] This may be due to cultural norms and people's perceptions of the causes of TB. In a study from South Africa, people who consumed alcohol and smoked cigarettes were perceived to be most at risk of contracting TB and were blamed for the spread of TB.[33] Similarly, community studies from India and the Philippines suggested the habits of excessive smoking and drinking alcohol were perceived to be associated with TB.[34,35] In some settings, people with TB are labelled with socially unacceptable lifestyles and behaviours like drinking and smoking. Unfortunately, people with TB in some settings have accepted this profiling. In a study from South Africa, male patients attributed the TB infection to alcohol consumption and smoking.[36] It has been opined that the media has contributed to this stereotype because infectious diseases like TB are usually presented in a 'stigma' format, unlike non-infectious conditions like cancer and heart disease, which are presented sympathetically.[37]

The duration of DR-TB diagnosis was associated with TB stigma in this study, which is similar to a report from Ethiopia, where patients with TB for >1 month were 2.5 times more likely to have TB stigma than their counterparts.[32] This may be because the longer the DR-TB diagnosis, the greater the possibility of experiencing stigma. The fear of TB stigma and the associated sense of shame, guilt and social isolation often hinder symptom disclosure and healthcare seeking. It also causes avoidance of social interactions in response to social attitudes and behaviours, undermining the community's TB screening efforts.[2,38]

TB stigma has a more significant impact on people from lower socio-economic strata, and they are at a higher risk of health disparities.[2] In our study, a higher proportion of unemployed

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Table 5. Regression analysis of factors associated with experienced stigma.

Variables	AOR	95% CI	p-Value
Gender (ref: female)			
Male	2.59	1.03 to 6.50	0.042
Currently earning income (ref: yes)			
No	2.57	1.84 to 7.85	0.039
HIV status (ref: positive)			
Negative	1.58	0.60 to 4.17	0.353
Duration of DR-TB diagnosis	2.72	1.94 to 3.83	<0.001
Self assessed severity (ref: mild/moderate)			
Severe	1.41	0.62 to 3.22	0.415
Barrier to treatment (ref: no)			
Yes	1.86	0.64 to 5.39	0.251
Substance (alcohol/cigarette) use (ref: no)			
Yes	1.61	1.06 to 3.88	0.028

ref: reference.

participants who were not earning an income experienced TB stigma compared with their counterparts. This is in agreement with studies from Zambia and Ethiopia, which reported higher TB stigma among poor and socially disadvantaged people.[4,12] TB stigma is a complex phenomenon that involves an interplay between community perspectives of TB, the cultural norms and belief system, self-stigmatization by the victim and victim blaming by health workers and the community, which further reinforces the grip of stigma in communities and the health system.[12]

HIV co-infection was not associated with TB stigma in our study, contrary to reports from Ethiopia and Uganda,[15,17,32] where HIV co-infection with TB was associated with increased TB stigma. There is a complex relationship between TB and HIV.[26] HIV is a risk factor for the development of TB, and both diseases share common clinical presentations such as weight loss, which may drive the misconception that everyone with TB has HIV/acquired immunodeficiency syndrome (AIDS).[26] The negative stereotype of the association between promiscuity and HIV/AIDS also holds for TB.[4]

TB diagnosis can result in a reluctance to seek medical care because of the consequences of the stigma.[39] TB stigma affects health-seeking behaviours such as utilization of TB services and completion of TB treatment.[39] Similarly, stigma has been associated with lower testing levels in other infectious diseases, such as HIV, and has been perceived as an impediment to testing and treatment.[40] Thus, utilization of TB services may also be diminished due to stigma, which should be tackled to improve the utilization of services to improve treatment outcomes.

Limitations

Our study has some limitations. First, the study design was limited to exploring associations. A more robust study is needed in this area determine causality. There is also a potential risk of recall bias, which may affect estimates of the prevalence of TB stigma. There is the possibility of understating or overstating experiences. Lastly, caution must be exercised in generalizing our findings to the rest of the country, as our sample was from a single state and may not represent all people with DR-TB in Nigeria.

Conclusions

The prevalence of TB stigma experienced by people with DR-TB is high. Being male, substance use, duration of DR-TB and not earning an income were factors associated with stigma among DR-TB patients in Lagos, Nigeria. Community sensitization and enlightenment with social mobilization geared towards addressing the cultural norms and community misconceptions about TB are crucial stigma reduction strategies that will enhance TB control strategies of the Lagos State TB and Leprosy Control Programme.

Authors' contributions: OAA conceived the study, analysed the data and prepared the manuscript. OAA and FH were involved in the study design and literature search. CJ, OD and FH were involved in interpreting the data. FH, CJ and OD critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. OAA, FH and OD are guarantors of the paper.

Acknowledgements: The authors wish to acknowledge the Lagos State Ministry of Health, the medical directors of the DR-TB treatment sites, the Lagos State DR-TB focal person and the Lagos State TB and Leprosy Control Officer for their support. The research was self-funded and the findings and conclusions are those of the authors.

Funding: None.

Competing interests: None declared.

Data availability: The data underlying this article cannot be shared publicly to protect the privacy of individuals who participated in the study. The data will be shared upon reasonable request to the corresponding author.

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CHAPTER FOUR

PUBLISHED ARTICLE 2

“Association between experienced stigma, anxiety, depression and loneliness among people with drug-resistant tuberculosis in Lagos, Nigeria: The moderating role of social support”.

This Chapter is presented as a published article. It describes the prevalence of anxiety, depression, and loneliness among PwDR-TB in Lagos, Nigeria. The factors associated with anxiety, depression, and loneliness were also assessed. This chapter describes the effects of stigma on anxiety, depression, and loneliness and the moderating role of social support on stigma. This Chapter addresses objectives two and four. The format and references in this chapter are presented according to the journal's submission guidelines.

Article title: Association between experienced stigma, anxiety, depression and loneliness among people with drug-resistant tuberculosis in Lagos, Nigeria: The moderating role of social support.

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Journal: Tropical Medicine and International Health

Status: Published (October 2024)

DOI: 10.1111/tmi.14046

RESEARCH ARTICLE

Association between experienced stigma, anxiety, depression and loneliness among people with drug-resistant tuberculosis in Lagos Nigeria: The moderating role of social support

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Abstract

Background: This study assessed the moderating effect of social support on the association between experienced stigma versus anxiety, depression and loneliness among people with drug-resistant tuberculosis.

Methods: A descriptive cross-sectional study was conducted among 203 adults on treatment for drug-resistant tuberculosis for at least 8 weeks. Validated scales were used to assess experienced stigma, anxiety, depression, loneliness and social support. Partial correlations and hierarchical multiple regression were used to determine the moderating effect of social support on the association between experienced stigma versus anxiety, depression and loneliness. The interaction was visualised using slope analysis.

Results: Anxiety, loneliness and depression were reported by 148 (72.9%), 114 (56.2%) and 128 (63.1%) of the 203 participants, respectively. Experienced stigma was positively associated with depression ($B = 0.428$, $p < 0.001$), anxiety ($B = 0.374$, $p < 0.001$) and loneliness ($B = 0.285$, $p = 0.001$). Social support was negatively associated with depression ($B = -0.255$, $p < 0.001$), anxiety ($B = -0.406$, $p < 0.001$) and loneliness ($B = -0.270$, $p = 0.001$). The impact of experienced stigma on depression was different at low ($B = 0.567$, $SE = 0.115$, $p < 0.001$) and high ($B = 0.275$, $SE = 0.253$, $p = 0.024$) groups of social support. Similarly, at low social support, the effect of experienced stigma on loneliness ($B = 0.491$, $SE = 0.250$, $p < 0.001$) and anxiety ($B = 0.254$, $SE = 0.060$, $p = 0.044$) was different compared to the effect of experienced stigma on loneliness ($B = 0.275$, $SE = 0.253$, $p = 0.024$) and anxiety ($B = 0.127$, $SE = 0.094$, $p = 0.307$) at high group of social support.

Conclusion: In this study, social support reduced the effects of experienced stigma on anxiety, depression and loneliness suggesting that improving social support among people with drug-resistant tuberculosis is crucial in reducing the negative effects of stigma on anxiety, depression and loneliness.

KEYWORDS
anxiety, depression, drug resistant-tuberculosis, experienced stigma, loneliness, social support

INTRODUCTION

Tuberculosis (TB) stigma is a major social factor affecting global TB control [1]. It is a complex problem related to people's perceptions, attitudes and personal experiences influenced by social discrimination, either perceived, anticipated or experienced by people living with TB (PWTB) [2]. The Global Fund and United Nations recognise it as a global public health challenge [3, 4], and a formidable challenge to the World Health Organization's goal of ending TB by 2050 [5]. Stigma is described as a negative attribute often resulting in devaluing social status and position, rejection or exclusion [6]. It is a crucial factor in the development of power structures causing the degradation of some social groups or individuals, thus aiding social injustice and inequality [7].

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TB is considered a stigmatising disease because it disproportionately affects vulnerable groups such as the poor, prisoners, refugees and people living with HIV/AIDS [8]. TB stigma is more common and more severe among those with drug-resistant TB (DR-TB) because the duration of treatment is often accompanied by prolonged isolation, blame and shame, associated with poor treatment outcomes [9]. In some African settings, hereditary factors, promiscuity, witchcraft, smoking, HIV and poverty are some of the negative stereotypes connected with TB [8, 10]. These have oftentimes affected the social relationships of PWTB with community members and caregivers [11]. Crucially, the fear of infection and the poor knowledge about the mode of transmission and availability of effective chemotherapy are major drivers of TB stigma [10, 12]. The prevalence of TB stigma in low and middle-income countries with high TB burden is between 42% and 82% [13–16].

TB stigma is categorised into experienced, anticipated, internalised or self-stigma [13]. Experienced stigma involves discrimination, social isolation and rejection, either in the past or present, due to certain conditions, which may occur at home, work, health facilities and the community [8, 17]. These discriminatory behaviours include hindrance of educational opportunities, fear of divorce, inability to marry, inability to share meals and utensils with family members, being subjected to gossip, shame and ridicule within the family and community, loss of employment or the inability to get a job [8, 18], often resulting in loneliness, low self-esteem, poor quality of life, anxiety and depression [19]. In addition, the lifestyle changes imposed by the long course of DR-TB therapy and illness/sequelae often result in distress, isolation and lack of participation in normal routines which may result in low self-worth, low self-esteem and depression [20]. A systematic review showed the prevalence of depression to be 45.2% and 51.5% among people with drug-sensitive and DR-TB, respectively [21].

Social support refers to the care received from friends, relatives and the community [22]. People with good social support are likely to have a better quality of life and are less likely to be lonely, anxious, stigmatised or discriminated against [23]. Adequate social support increases people's life fulfilment and self-confidence. It enhances crisis adaptation and reduces the pressure on PWTB hence reducing the risk of psychological distress such as loneliness, anxiety and depression [24, 25]. Social support has been shown to moderate the effect of TB stigma on depression and anxiety in China and America [26, 27]. However, there are no reports from Nigeria or other parts of the African continent.

Nigeria has one of the highest burdens of TB globally and Lagos State accounted for about 22% of the country's rifampicin-resistant TB cases in 2019 [28]. The low TB notification rate and poor TB control in Nigeria are due to poor access to testing and diagnosis, low case detection, high under-reporting, a long delay in treatment initiation and high loss to follow-up [29–31]. A high prevalence of TB stigma was reported from community studies in Nigeria [32, 33]. To the best of our knowledge, no study has assessed whether social support has a moderating effect on TB stigma, anxiety, depression and loneliness in Nigeria. This study was conducted among people with DR-TB receiving treatment across Lagos state Nigeria. We hypothesised that:

1. Experienced stigma is positively related to anxiety, depression and loneliness.
2. Social support is negatively related to anxiety, depression and loneliness.
3. The association between experienced stigma, anxiety, depression and loneliness could be moderated by social support.

METHODS

Study design

An institutional-based descriptive cross-sectional study was conducted between September and December 2023 among people with DR-TB receiving treatment in five treatment centres across Lagos, Nigeria. The association between experienced stigma and measures of anxiety, depression and loneliness was explored. The influence of social support on anxiety, depression and loneliness was also investigated (Figure 1).

Study setting and context

Lagos State is the smallest state in Nigeria in terms of landmass and is the commercial nerve centre of the country, a mega city with a population of approximately 21 million. It is divided into 20 local government areas (districts) and 37 local council development areas. The initiation of DR-TB treatment in Lagos State is preceded by diagnosis using the Xpert MTB/RIF assay. Through the short message service (SMS), the state TB programme contacted newly diagnosed people with DR-TB [34]. Treatment initiation is usually at a designated hospital. During treatment initiation, people with DR-TB were educated about TB transmission, development and treatment of DR-TB, side effects of the second-line drug, and the care and support systems available for people with DR-TB. Pre-treatment laboratory tests are conducted after which they are linked to the treatment centre closest to their residence and a trained nurse conducts monitoring. Follow-up of people with DR-TB is done at six treatment centres in Lagos State (namely Mainland Hospital, General Hospital Ikorodu, Alimosho General Hospital, Ojo Health Center, Tolu Health Center and St. Kizito Hospital) [35]. The transport fare is reimbursed to enhance compliance with follow-up.

Selection of study sites

From the six DR-TB treatment sites in the state, the site with the least number of clients enrolled for care was purposively

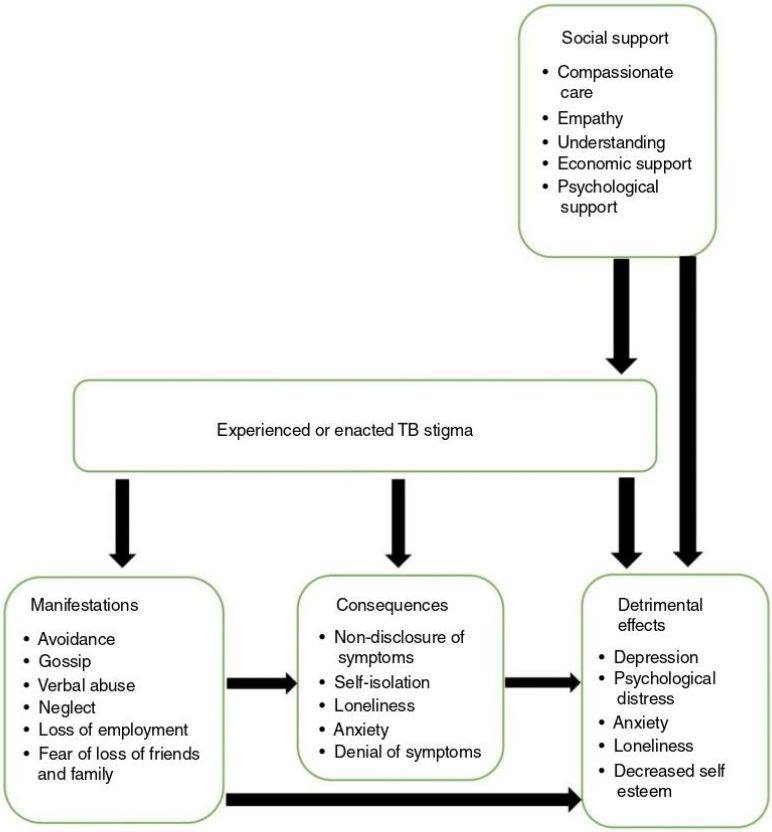

FIGURE 1 Conceptual framework.

selected for the pilot study. Study participants were recruited from the remaining five sites.

Sample size formula and participant selection

Using the sample size formula for a cross-sectional study for a finite population, an average TB stigma prevalence of 18% [14], 95% confidence interval, 15% non-response rate and the total population of 625 people with DR-TB on treatment in Lagos State as at September 2022, a minimum sample size of 200 was calculated. With the help of the healthcare providers, people with DR-TB who were 18 years and above, diagnosed using the Xpert MTB/RIF assay, and who had been on DR-TB treatment for at least 8 weeks were recruited for the study after written consent was obtained. Participants were recruited during routine out-patient clinic. The purpose of the research was explained to people with DR-TB during routing out-patient clinic and those who consented to participate were consecutively recruited into the study.

People with DR-TB who were very ill, hospitalised or unable to weigh the risks and benefits of the study and make an independent, informed decision about participation due to cognitive, physical or psychological factors were excluded from the study.

Study instruments and measurements

Five validated tools were used to collect data about experienced or enacted stigma, anxiety, depression, loneliness and social support. The assessment was based on participants' experiences 2 weeks before the study.

1. Experienced or enacted stigma: This was measured using the Redwood DR-TB stigma scale [36], which was developed and validated in Vietnam and demonstrated good

psychometric properties, including internal consistency, construct validity and reliability. The scale has 14 items, each scored on a 3-point Likert Scale ranging from 0 (strongly disagree) to 3 (strongly agree). The scale measures stigma across four factors: guilt, social exclusion, physical isolation and blame [36]. The score ranged from 0 to 42 with a higher score indicating a higher level of stigma. In this study, the experienced stigma scores refer to the sum of all the subscales. The Cronbach's alpha coefficient for the Redwood DR-TB stigma scale in this study was 0.725.

2. Loneliness was measured using the University of California Los Angeles (UCLA) loneliness scale version 3 [37]. The UCLA loneliness scale is a 20-item scale designed to measure one's subjective feelings of loneliness and social isolation. The scale is scored on a 4-point Likert scale from 1 (Never) to 4 (Often) with possible scores ranging from 20 to 80. The higher scores indicate a higher level of loneliness and a score ≥36 was considered lonely in this study [38]. The Cronbach's alpha coefficient for the UCLA scale in this study was 0.833.
3. Generalised anxiety measured using Generalised Anxiety Disorder-7 (GAD-7) [39]. The GAD-7 score is calculated by assigning scores of 0, 1, 2 and 3, to the response categories of 'not at all', 'several days', 'more than half the days' and 'nearly every day', respectively, and adding together the scores for the seven questions. A score of 5 and above was taken as the cut-off for anxiety in our study [39]. The tool had a high internal consistency (Cronbach's alpha coefficient = 0.823).
4. We measured depression using the Patient Health Questionnaire-9 items (PHQ 9) [40]. The PHQ-9 is the depression module, which scores each of the nine DSM-IV criteria as '0' (not at all) to '3' (nearly every day). The possible scores ranged from 0 to 27 with higher scores indicating a higher degree of depression. A score of 5 and above was categorised as depression [40]. The Cronbach's alpha coefficient for the PHQ-9 scale in this study was 0.836.
5. The Multidimensional Scale of Perceived Social Support (MSPSS) was designed to address the subjective assessment of social support adequacy. It is a 12-item scale scored on a 7-point Likert Scale ranging from 1 (Very strongly disagree) to 7 (very strongly agree) [41]. The MSPSS assesses the perceptions of social support adequacy from three sources: family, friends and significant other. The mean score was calculated and participants were categorised as follows: low support (mean score <3), moderate support (mean score 3–5) and high support (mean score >5) [41]. The score ranged from 1 to 84 and higher scores indicate high perceived social support. The Cronbach's alpha coefficient for MSPSS in this study was 0.780.

Assessment of knowledge of TB

The knowledge of TB was assessed using eight questions centred on TB transmission, prevention and control. Questions were derived from the literature review. Each correct answer was scored one mark while an incorrect or unsure response was scored zero. The median score (5) was used as a cut-off point. Participants with scores less than the median score were categorised as having poor knowledge and those with scores ≥5 were categorised as having good knowledge.

Self-assessment

Participants were asked to do a self-assessment of the severity of DR-TB symptoms and DR-TB treatment. The severity of DR-TB was categorised into mild, moderate and severe, while the perception of DR-TB treatment was categorised into helpful and not sure.

Measures

Outcome measure

In this study, the outcome measure was experienced stigma, a continuous variable.

Independent measures

These included anxiety, depression; loneliness and social support. Others include age, gender, marital status, HIV status, facility type, perceived severity of DR-TB, perception of DR-TB treatment, knowledge of TB, duration of treatment, income, cigarette smoking and alcohol intake.

Composite measure

An interaction term (a composite variable) was derived from the product of experienced stigma and social support variables.

Data collection

The study tools described above were combined into a tool that could be completed within 20 min. The questionnaire was divided into two parts. The first part collected sociodemographic details of participants, household characteristics, finances, self-assessment of disease severity, perception of DR-TB treatment and knowledge of TB while the second part measured experienced stigma, social support, loneliness, anxiety and depression. To ensure accurate data collection, we trained five research assistants with backgrounds in health sciences to administer the questionnaire. The training lasted for a day and it involved an explanation of study objectives, study background, participant selection and use of study tools. The pilot testing of the questionnaire

occurred in a DR-TB treatment facility not used for the main study. Cronbach alpha was used to assess the validity and internal consistency of the scales. Some items in the questionnaire were reworded after piloting to improve validity and acceptability.

Ethical considerations

Ethical approval was obtained from the Institutional Research Ethic Committee of Durban University of Technology South Africa (IREC 066/230) and the Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179). Permission to interview participants was obtained from the Lagos State Ministry of Health and the Directors of all the health facilities where data was collected. Participants signed a written informed consent form before enrolment in the study. They were assured of strict confidentiality.

Data analysis

The completed questionnaires were checked to ensure that all questions were answered before they were entered into IBM Statistics Version 26 (IBM Corporation, Armonk, State of New York) for statistical analysis by the research assistants. One of the authors assessed the accuracy of data entry by randomly selecting 30 questionnaires and cross-checking with the data entry. Test for normality was conducted for all the scales used in this study. Continuous variables were represented by means and standard deviation while percentages were used to describe categorical variables. The Student's *t*-test and one-way ANOVA were used to compare the mean scores of anxiety, loneliness and depression among people with DR-TB with different demographic and clinical parameters. The effect size was measured using Hedges' g and eta squared (η_p^2) for Student's *t*-test and one-way ANOVA, respectively. For eta squared 0.010–0.050 graded as small, 0.060–0.138 as medium and >0.138 as large while Hedges' g classified effect sizes as small (0.2), medium (0.5) and large (≥8) [42, 43]. Partial correlation analysis was conducted to evaluate the correlation of anxiety, loneliness and depression with experienced stigma while controlling for social support. Hierarchical multiple regression was applied to assess the moderating role of social support on the association between experienced stigma versus anxiety, loneliness and depression after controlling for the influence of gender, HIV status, knowledge of TB and income. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity (variance inflation factor was <10 and tolerance >0.1) and homoscedasticity. In step 1, all the controlling variables (gender, HIV status, knowledge of TB and income) related to anxiety, loneliness and depression were added. Experienced stigma and social support were added in step 2. The product of experienced stigma and social support was added in step 3. All the study variables were standardised before regression analyses were performed to reduce the effects of multicollinearity. A two-sided test was used in all the statistical analyses, the confidence interval was set at 95% and the *p*-value, <0.05 was considered statistically significant.

RESULTS

Demographic characteristics and factors associated with anxiety, loneliness and depression

Two hundred and fifteen people with DR-TB were screened, and 203 participants were recruited in this study, giving a 94.4% participation rate. Of the excluded persons, five were below 18 years and seven people with DR-TB had not been on DR-TB treatment for 8 weeks. The mean age was 39.2 ± 13.8 years. The majority were males (128, 63.1%), married (111, 54.7%), earned an income (104, 51.2%) and were negative for HIV (160, 78.8%). About a quarter (50, 24.6%) smoked cigarettes and three-quarters (151, 74.4%) received treatment at TB treatment centres located in a secondary health facility (Table 1). Factors associated with anxiety, loneliness and depression are indicated in Table 1. Of the participants sampled, 63.1% (95% CI 56.0%–69.7%) had depression, 72.9% (95% CI 66.2%–78.9%) had anxiety and 56.2% (95% CI 49.0%–63.1%) were lonely (Table 1). Being female, not earning any income, having HIV-negative status and having poor knowledge of TB were associated with anxiety, loneliness and depression ($p < 0.05$). In addition, cigarette smoking and being unsure of the effectiveness of the DR-TB treatment were associated with anxiety and depression ($p < 0.05$).

Relationship between experienced stigma versus anxiety, depression and loneliness

Partial correlation of the relationship between experienced stigma versus anxiety, loneliness and depression showed a strong positive correlation between experienced stigma versus anxiety ($r = 0.694$, $p < 0.001$), depression ($r = 0.689$, $p < 0.001$) and loneliness ($r = 0.529$, $p < 0.001$) before controlling for social support. However, after controlling for social support, there was a reduction in the correlation coefficient between experienced stigma versus anxiety ($r = 0.396$, $p < 0.001$), depression ($r = 0.454$, $p = <0.001$) and loneliness ($r = 0.273$, $p < 0.001$) (Table 2).

Hierarchical regression analysis

Table 3 contains the hierarchical regression analysis of anxiety, depression and loneliness. The linear combination of gender, earning an income, HIV status and knowledge of TB significantly explained depression ($F = 13.329$,

TABLE 1 Demographic and clinical details, showing association with anxiety, loneliness and depression among DR-TB patients.

Variable	$n = 203$	Anxiety, mean (SD)	*p*-value	Effect size	Depression, mean (SD)	p-value	Effect size	Loneliness, mean (SD)	p-value	Effect size
Gender										
Male	128 (63.1)	7.01 (3.94)	0.009[a]	0.383	6.56 (4.79)	0.036[a]	0.306	36.80 (9.15)	0.006[a]	0.401
Female	75 (36.9)	8.55 (4.11)			8.05 (4.79)			39.45 (6.87)		
Age group (years)										
<30	54 (26.6)	7.89 (4.28)	0.601	0.05	7.96 (5.23)	0.132	0.02	38.33 (8.71)	0.394	0.09
30–59	128 (63.1)	7.36 (3.91)			6.58 (4.52)			37.22 (8.29)		
>60	21 (10.3)	8.10 (4.50)			8.14 (5.84)			35.38 (9.39)		
Marital status										
Single	74 (36.5)	7.76 (4.18)	0.363	0.01	7.58 (4.06)	0.426	0.08	37.82 (8.93)	0.414	0.09
Married	111 (54.7)	7.28 (3.93)			7.61 (5.16)			36.68 (8.39)		
Widowed/ divorced	18 (8.9)	8.67 (4.39)			6.96 (4.53)			39.22 (7.51)		
Had income										
Yes	104 (51.2)	6.69 (4.15)	0.001[a]	0.45	5.88 (4.47)	<0.001[a]	0.53	35.67 (7.17)	0.004[a]	0.41
No	99 (48.8)	8.50 (3.77)			8.41 (4.99)			39.06 (9.46)		
HIV status										
Positive	35 (17.2)	6.31 (4.14)	0.040[a]	0.39	4.83 (4.27)	0.002[a]	0.59	34.23 (7.32)	0.024[a]	0.43
Negative	160 (78.8)	7.87 (4.00)			7.63 (4.84)			37.85 (8.73)		
Unknown[b]	8 (3.9)	7.25 (4.50)			6.75 (6.11)			40.37 (5.95)		
Smoking										
Yes	50 (24.6)	8.56 (3.72)	0.048[a]	0.32	8.22 (5.15)	0.065	0.30	37.42 (7.96)	0.928	0.02
No	153 (75.4)	7.25 (4.130			6.75 (4.76)			37.29 (8.71)		
Alcohol										
Yes	85 (41.9)	7.80 (3.59)	0.507	0.01	7.36 (4.88)	0.535	0.09	37.61 (8.84)	0.685	0.06
No	118 (58.1)	7.42 (4.38)			6.93 (4.91)			37.12 (8.30)		
Facility type										
Secondary	151 (74.4)	7.64 (4.05)	0.724	0.06	7.13 (5.01)	0.925	0.02	37.34 (8.59)	0.956	0.01
Primary	52 (25.6)	7.40 (4.12)			7.11 (4.89)			37.27 (8.39)		
Perceived severity of DR-TB										
Mild/moderate	125 (61.6)	7.24 (4.07)	0.145	0.21	6.86 (4.93)	0.344	0.14	37.26 (8.67)	0.897	0.02
Severe	78 (38.4)	8.10 (4.03)			7.53 (4.81)			37.42 (8.32)		
Perception of treatment										
Very helpful	178 (87.7)	7.58 (4.16)	0.983	0.01	6.86 (4.73)	0.048[a]	0.42	36.92 (8.29)	0.067	0.39
Not sure	25 (12.3)	7.56 (3.40)			8.92 (5.66)			40.24 (9.67)		
Knowledge of TB										
Poor	22 (10.8)	10.91 (2.86)	<0.001[a]	0.95	12.27 (4.37)	<0.001[a]	1.26	44.23 (5.57)	<0.001[a]	0.94
Good	181 (89.2)	7.17 (4.01)			6.49 (4.57)			36.49 (8.44)		
Treatment duration (months)										
<4	121 (59.6)	7.22 (4.05)	0.133	0.22	6.84 (4.91)	0.340	0.14	36.54 (7.80)	0.110	0.23
≥4	82 (40.4)	8.10 (4.05)			7.51 (4.86)			38.49 (9.41)		

[a]Significant values, mean age = 39.2 ± 13.8.
[b]Not part of the analysis. Depression was identified in 63.1% (95% CI 56.0%–69.7%), 72.9% (95% CI 66.2%–78.9%) had anxiety and 56.2% (95% CI 49.0%–63.1%) were lonely.

$R^2 = 0.219$, $p < 0.001$), anxiety ($F = 9.314$, $R^2 = 0.164$, $p < 0.001$) and loneliness ($F = 8.511$, $R^2 = 0.134$, $p < 0.001$). In the second step, the addition of experienced stigma and social support significantly improved the model fit of depression ($F = 41.228$, $R^2 = 0.568$, $\Delta R^2 = 0.349$, $p = <0.001$), anxiety ($F = 50.869$, $R^2 = 0.619$, $\Delta R^2 = 0.455$, $p = <0.001$) and loneliness ($F = 19.292$, $R^2 = 0.361$, $\Delta R^2 = 0.229$, $p < 0.001$). Experienced stigma demonstrated

TABLE 2 Partial correlation among experienced stigma, anxiety, loneliness and depression before and after controlling for social support.

Variables	Stigma, *r*, *p*	Anxiety, *r*, *p*	Depression, *r*, *p*	Loneliness, *r*, *p*	SS, *r*, *p*
Correlation before controlling for social support					
Stigma	1				
Anxiety	0.694, <0.001	1			
Depression	0.689, 0.001	0.539, <0.001	1		
Loneliness	0.529, 0.001	0.390, <0.001	0.541, <0.001	1	
Social support	−0.700, 0.001	−0.706, <0.001	−0.621, 0.001	−0.517, 0.001	1
Correlation after controlling for social support					
Stigma	1				
Anxiety	0.396, <0.001	1			
Depression	0.454, <0.001	0.181, 0.010	1		
Loneliness	0.273, <0.001	0.042, 0.552	0.328, <0.001	1	

TABLE 3 Hierarchical multiple regression analysis on depression, anxiety and loneliness.

	Depression			Anxiety			Loneliness		
	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3
Variable	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value	B, *p*-value
Gender	0.138, 0.037	0.147, 0.003	0.164, 0.001	0.193, 0.050	0.200, <0.001	0.186, <0.001	0.190. 0.006	0.195, 0.001	0.212, <0.001
Had income	0.218, 0.001	0.079, 0.117	0.070, 0.157	0.178, 0.090	0.030, 0.525	0.037, 0.426	0.146, 0.032	0.039, 0.519	0.030, 0.612
HIV status	0.202, 0.002	0.138, 0.006	0.137, 0.005	0.145, 0.035	0.070, 0.131	0.071, 0.123	0.162, 0.019	0.110, 0.065	0.109, 0.064
TB knowledge	−0.300, <0.001	−0.153, 0.002	−0.146, 0.003	−0.242, <0.001	−0.077, 0.131	−0.083, 0.073	−0.236, 0.001	−0.118, 0.049	−0.111, 0.063
Experienced stigma		0.428, <0.001	0.439, <0.001		0.374, <0.001	0.364, <0.001		0.285, 0.001	0.296, <0.001
Social support		−0.255, <0.001	−0.253, <0.001		−0.406, <0.001	−0.407, <0.001		−0.270, 0.001	−0.268, 0.001
Stigma × social support			−0.132 0.006			−0.107 0.019			−0.128 0.027
F	13.329, <0.001	41.228, <0.001	37.694, <0.001	9.314, <0.001	50.869, <0.001	45.477, 0.019	8.511, <0.001	19.292, <0.001	17.588, <0.001
R^2	0.219	0.568	0.585	0.164	0.619	0.630	0.134	0.361	0.374
Adjusted R^2	0.203	0.554	0.570	0.146	0.607	0.616	0.134	0.361	0.374
ΔR^2	0.219	0.349	0.017	0.164	0.455	0.011	0.152	0.229	0.016

a significant effect on depression (B = 0.428, $p < 0.001$), anxiety (B = 0.374, $p < 0.001$) and loneliness (B = 0.285, $p = 0.0$). Social support also exhibited a significant effect on depression (B = −0.255, $p < 0.001$), anxiety (B = −0.406, $p < 0.001$) and loneliness (B = −0.270, $p < 0.001$). The experienced stigma × social support interaction term in the depression model explained an additional 1.7% of the variance ($F = 37.694$, $R^2 = 0.585$, $\Delta R^2 = 0.017$, $p < 0.001$). Similarly, the experienced stigma × social support interaction term significantly explained an additional 1.1% ($F = 45.477$, $R^2 = 0.630$, $\Delta R^2 = 0.011$, $p = 0.019$) and 1.6% ($F = 17.588$. $R^2 = 0.374$, $\Delta R^2 = 0.016$, $p < 0.001$) of the variance in the anxiety and loneliness model respectively in the third step. The interaction term was negatively correlated with depression (B = −0.132, $p = 0.006$), anxiety (B = −0.107, $p = 0.019$) and loneliness (B = −0.128, $p = 0.027$) suggesting that social support plays a moderating role in the relationship between experienced stigma versus anxiety, depression and loneliness. Slope analysis demonstrated that the impact of experienced stigma on loneliness was different at low (B = 0.491, standard error [SE] = 0.250, $p < 0.001$) and high (B = 0.275, SE = 0.253, $p = 0.024$) groups of social support. Similar findings were obtained for depression (low social support: B = 0.567, SE = 0.115, $p < 0.001$ vs high social support: B = 0.275, SE = 0.253, $p = 0.024$) and anxiety (low social support: B = 0.254, SE = 0.060, $p = 0.044$ vs high social support B = 0.127, SE = 0.094, $p = 0.307$; Table 4; Figures 2–4).

Mean scores of social support subscales

The mean scores of the social support subscales are shown in Table 5. The significant others subscales had the highest mean scores (5.88 ± 1.07), compared to the mean family subscale score (5.56 ± 1.13) and the mean friends' subscale score (4.74 ± 1.29) ($p < 0.001$).

Having a special person who cares and who is a real source of comfort had the highest score of all 12 items.

DISCUSSION

This study assessed the moderating effects of social support between experienced stigma versus anxiety, loneliness and depression among people with DR-TB treatment in Lagos Nigeria. We found that experienced TB stigma correlated positively with anxiety, loneliness and depression. Social support correlated negatively with anxiety, loneliness and depression. The prevalence of anxiety, loneliness and depression 72.9%, 56.2% and 63.1%, respectively. Being female, HIV-negative, not earning an income and having poor knowledge of TB were associated with anxiety, loneliness and depression. The association between experienced stigma anxiety versus loneliness and depression was moderated by social support.

TB is a socio-medical condition accompanied by social and economic stressors. Although it is an infectious disease, it is also a biological manifestation of social inequality [44]. The social stressors for people with MDR-TB include stigma, lack of social support, family separation, loneliness and rejection often not addressed during TB care [45, 46]. Anxiety, depression and social isolation (loneliness) cause psychological distress common among PWTB [47]. In our study, the prevalence of depression was 63.1%, higher than the reported 53.2% among people with MDR-TB in a systematic and meta-analysis review [21]. Previous studies from Nigeria showed the prevalence of depression among people with drug-sensitive TB to be 28%–48.6% [48–50]. Similarly, studies have shown that the prevalence of depression is higher among people with DR-TB compared to those with drug-sensitive TB [21], type 1 and 2 diabetes [51] and HIV [52]. In our study, the prevalence of anxiety was 72.9%, similar to 86.3% obtained among people with MDR-TB in a study from Indonesia [53], but higher than the 54% and 66% obtained among people with MDR-TB and XDR-TB in India [54]. The cause of the high prevalence of depression

TABLE 4 Slope analysis showing the impact of experienced stigma on anxiety, loneliness and depression and low and high social support groups.

Variable	B	95% CI	SE	*p*
Anxiety				
Low social support	0.254	0.135–0.373	0.060	0.044
High social support	0.127	0.059–0.313	0.094	0.307
Loneliness				
Low social support	0.491	0.057–0.988	0.250	<0.001
High social support	0.275	0.228–0.778	0.253	0.024
Depression				
Low social support	0.567	0.339–0.796	0.115	<0.001
High social support	0.309	0.108–0.510	0.101	0.011

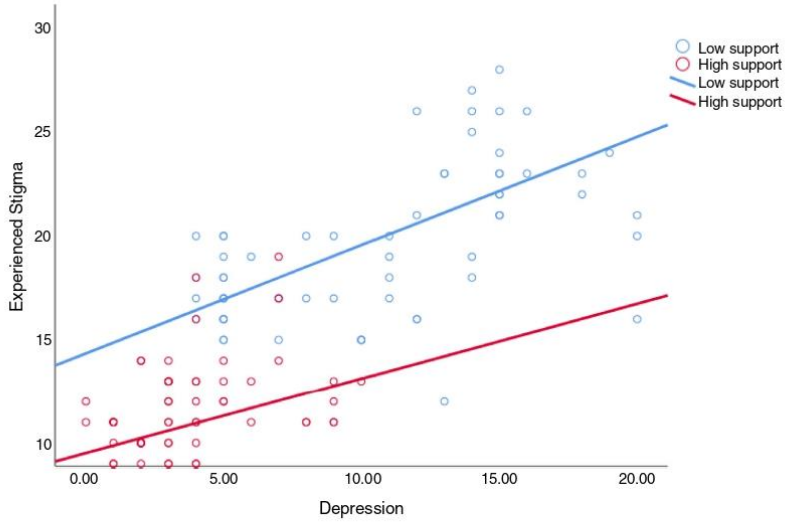

FIGURE 2 Simple slope plot of interaction between experienced stigma and social support on depression.

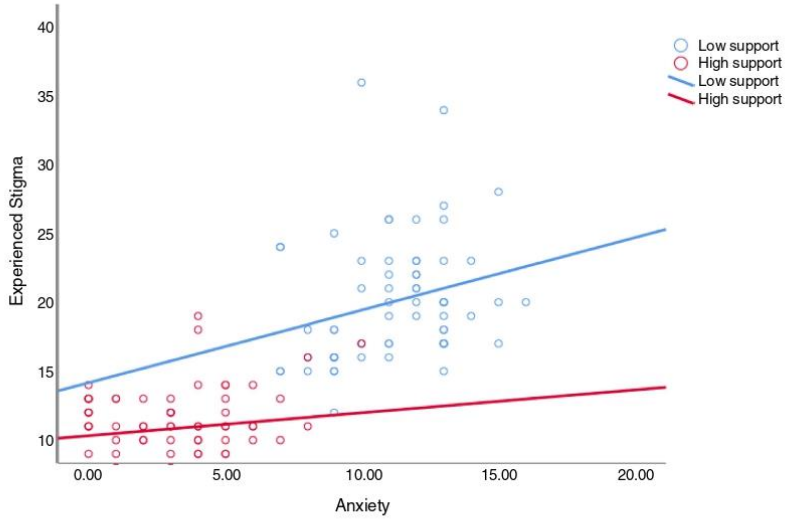

FIGURE 3 Simple slope plot of interaction between experienced stigma and social support on anxiety.

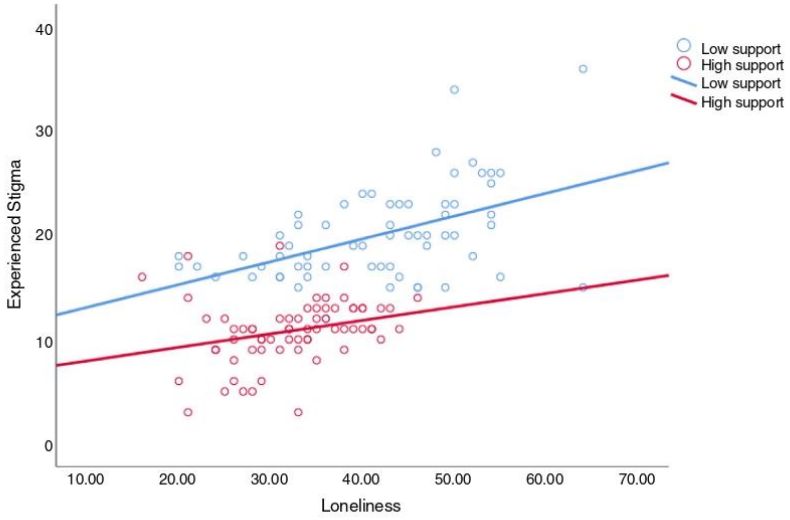

FIGURE 4 Simple slope plot of interaction between experienced stigma and social support on loneliness.

and anxiety among people with DR-TB is still controversial. While some believe it is due to the course of the illness and the side effects of cycloserine one of the second-line TB drugs [55], however, some recent studies have shown that there was no association between depression and cycloserine [56, 57]. Another study demonstrated that the prevalence of anxiety and depression was 86.3% and 68.6% respectively among people with MDR-TB who were yet to commence the second-line drugs [53].

Loneliness was present in 56.2% of our participants, higher than a reported 49% among PWTB in Turkey [58]. Humans are social beings and connection with others is needed for health and well-being. Social isolation (loneliness) can increase morbidity, reduce treatment adherence and reduce social support [59]. Physical isolation is often required during the initial treatment of TB for infection control purposes until they no longer continue to be public health threats [60]. However, family and friends extend this

TABLE 5 Mean scores of social support subscales.

Subscales	Mean (SD)
Significant others	5.88 (1.07)
There is a special person who is around when I am in need	5.77 (1.32)
There is a special person with whom I can share my joy and sorrows	5.87 (1.25)
I have a special person who is a real source of comfort to me	5.90 (1.24)
There is a special person in my life who cares about my feelings	5.99 (1.26)
Family	5.56 (1.13)
My family really tries to help me	5.84 (1.30)
I get the emotional help and support I need from my family	5.87 (1.18)
I can talk about my problems with my family	5.76 (1.42)
My family is willing to help me make decisions	4.75 (2.09)
Friends	4.74 (1.29)
My friends really try to help me	4.89 (1.53)
I can count on my friends when things go wrong	4.63 (1.52)
I have friends with whom I can share my joy and sorrows	4.94 (1.47)
I can talk about my problems with my friends	4.51 (1.68)
Total	5.39 (0.94)

Note: Mean difference between significant others, family and friends subscale social support score ($F = 51.531$, $p < 0.001$).

isolation for a considerable period, which may predispose PWTB to loneliness and depression [45]. The differences in the study tools, study designs, socioeconomic and culture and myths associated with TB may be responsible for these variations.

In our study, women were more likely to report anxiety, depression and loneliness. A systematic review demonstrated that among PWTB, the prevalence of depression was higher among females than males [21]. Studies from Pakistan and China showed that a significant proportion of females with DR-TB were depressed [61, 62]. Similarly, studies from Ethiopia showed that females had a higher chance of having anxiety compared to males [63, 64].

In our study, HIV co-infection was not a risk factor for anxiety, depression and loneliness. HIV infection often elicits psychological responses that can exacerbate a vicious cycle of anxiety and depression, which may threaten treatment adherence. The combination of two stigmatised diseases in addition to the more complex and challenging treatment of HIV and DR-TB may affect the mental health of the patients [65]. A study from Nigeria reported that psychological distress (anxiety and depression) increased 30-fold within 1 year of ART initiation [66]. The reason for our finding is unknown; a possible reason may be HIV diagnosis did not evoke significant psychological distress among people with DR-TB/HIV co-infection. HIV negatively affected interpersonal relations leading to loneliness in a study from Ghana [67]. Though the treatment of DR-TB is free, patients also bear some hidden costs such as the cost of transportation and opportunity costs. Our study suggested that participants who were not earning any income had higher levels of anxiety, depression and loneliness. A meta-regression analysis of low and middle-income countries demonstrated that about three-quarters of TB-affected households experienced catastrophic costs because the total cost incurred during an episode of the disease exceeded 20% of the patient's annual household income [68]. TB is a disease of the poor and most of the PWTB are further impoverished by the disease [69].

People with TB are often stigmatised because of its association with people in the lower socioeconomic class, poverty and HIV [32]. In a study among community members in an urban community of Lagos, Nigeria, 22.7% of participants had expressed TB stigma, 63.6% had no desire to help PTB and 64.3% mentioned that PWTB should not be employed [32]. People with TB are not well accepted by their family and community and these negative attitudes and social disconnections often result in psychological distress, social exclusion and isolation [45, 47, 64]. This may ultimately affect their mental health leading to anxiety and depression [47]. Other studies have demonstrated the association between TB stigma with anxiety [12, 19], depression [12, 70] and loneliness [71]. In some countries, people with DR-TB are often subjected to medically unnecessary isolation such as sleeping and eating separately from their families and separation from partners [23, 72].

Social support is essential in the management of chronic diseases like TB because it promotes adherence to treatment, buffers psychological distress, increases self-efficacy and promotes positive attitudes [73, 74]. Our study confirms that social support can play a protective role in the prevention of anxiety, depression and loneliness. This mirrors previous studies conducted on substance use disorders and people living with HIV [26, 52]. Crucially, our study demonstrated that social support moderated the association between experienced stigma with anxiety, depression and loneliness. In our study, there was a reduction in the strength of the correlation coefficient between experienced stigma versus anxiety, depression and loneliness after controlling for social support. Also at high social support, the effect of the association between experienced stigma was reduced, contrary to the exacerbated effect seen at low social support. This is similar to reports from China [26, 75]. Adequate social support reduces the impact of stigma and increases patient life fulfilment and self-confidence. It fosters patients' adaptation and reduces the risk of psychological distress.

In our study, participants rated social support from significant others (e.g., spouse) higher than support from family and friends. The support of a special person who was a real source of comfort, available and shared happy as well as sad moments was rated higher than any other social support from family and friends. TB is a stigmatising disease and people with TB often hide symptoms from friends and neighbours because of the negative attitudes of family and friends in some communities [47]. Social support is help

from loved ones, friends and family. It builds the psychological resilience necessary for maintaining a stable level of psychological and physical function after experiencing potentially stressful events. It is also needed for adaptation and recovery after experiencing adversity, threats, tragedy and trauma [76]. The stronger the social support network the better the ability to handle problems, and cope with psychological stress [77]. Studies have opined that people with a high social support score often have a low depression score [78]. Our study indicated that high social support was crucial to easing the unfavourable effects of stigma on anxiety, depression and loneliness. Presently, the Lagos State TB and Leprosy Control programme does not have a robust system to build or strengthen social support for people with DR-TB. Although a caregiver administers injections in their homes, there is no engagement with the family. No provision is made for psychological support for patients on treatment and there are no psychologists or social workers who could provide these services in their consortium of experts for DR-TB management.

STRENGTHS AND LIMITATIONS

Our study measures complex social and psychological constructs using previously validated scales. There are some limitations to our study. There is a risk of recall bias because patients were required to answer questions based on their experiences 2 weeks before the survey. There is a possibility of participants over or under-stating their experiences. In addition, participants tend to give socially satisfactory responses that may affect our findings. Thirdly, our cross-sectional study design made it impossible to explore the causality among the constructs. Our findings should be taken with caution and cannot be generalised to the entire country because of our sample size. Lastly, the study participants may not be representative of all people with DR-TB because those not accessing treatment were not included in the study.

CONCLUSION

In this study, there was a positive correlation between experienced stigma with anxiety, depression and loneliness. Also, social support moderated the association between experienced stigma versus anxiety, depression and loneliness. Support from significant others was higher than the support from family and friends. Our results point to the fact that improving social support among people with DR-TB is crucial in reducing the negative effects of stigma on anxiety, depression and loneliness. This will go a long way to reduce the psychological stress imposed by experienced stigma. We recommend that psycho-social interventions be part of the care received by people with DR-TB. This may include health workers' visits and counselling of family members of people with DR-TB. Community engagement in the care and support for people with DR-TB may go a long way to garner the social support necessary for the reduction of TB stigma and consequently TB control in Lagos, Nigeria.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the Lagos State Ministry of Health and the Lagos State TB and Leprosy Control Programme for granting permission to conduct this study. We also recognise the help and assistance of the management of the DR-TB treatment centres where the study was conducted. Special thanks to Ellen Mitchell for her advice and technical input during the conduct of this study.

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How to cite this article: Adejumo OA, Haffejee F, Jinabhai C, Daniel O. Association between experienced stigma, anxiety, depression and loneliness among people with drug-resistant tuberculosis in Lagos Nigeria: The moderating role of social support. Trop Med Int Health. 2024. https://doi.org/10.1111/tmi.14046

CHAPTER FIVE

PUBLISHED ARTICLE 3

“The effects of stigma and social support on the health-related quality of life of people with drug-resistant tuberculosis in Lagos, Nigeria”.

This Chapter is presented as a published article. It assesses the health-related quality of life of people with TB and its associated factors. The effects of stigma and social support on the health-related quality of life of people with TB were determined. This chapter answered the third and fourth objectives. The format and references in this chapter are presented according to the journal's submission guidelines.

Article title: The effects of stigma and social support on the health-related quality of life of people with drug-resistant tuberculosis in Lagos, Nigeria.

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Journal: Quality of Life Research

Status: Published (February 2025)

Quality of Life Research
https://doi.org/10.1007/s11136-025-03902-5

The effects of stigma and social support on the health-related quality of life of people with drug resistance tuberculosis in Lagos, Nigeria

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Accepted: 11 January 2025
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Abstract

Purpose This study assessed the effects of TB stigma and social support on the health-related quality of life (HRQoL) of people living with drug-resistant tuberculosis (DR-TB) in Lagos, Nigeria.

Methods A cross-sectional study was conducted in five DR-TB treatment centres in Lagos, Nigeria, between September and December 2023. A total of 203 adults on DR-TB treatment were recruited to complete a questionnaire including the Redwood DR-TB stigma scale, the Functional Assessment of Chronic Illness Therapy-TB (FACCIT) scale, and the Multidimensional Scale of Perceived Social Support (MSPSS). Student 't' test/one-way ANOVA, Pearson's correlation, and hierarchical linear regression analysis were conducted to explore the factors associated with HRQoL and the relationships between stigma, social support, and HRQoL.

Results The mean overall HRQoL was 41.1 ± 12.9 among people with DR-TB. The HRQoL score of the physical domain was the lowest (25.8 ± 13.8). Participants who were young, male, single, with higher education, and HIV-negative had higher HRQoL than their counterparts ($p < 0.05$). Stigma was negatively associated with HRQoL, while social support was positively related, collectively explaining 57.6% of the variance. In the final model, social support contributed more ($B = 0.576$) to predicting HRQoL than did stigma ($B = -0.414$).

Conclusion The overall HRQoL of people with DR-TB in Lagos, Nigeria, was poor. Strategies that improve social support systems and reduce stigma are needed to improve this. Further studies are also required to assess the changes in HRQoL over time and evaluate the impact of specific stigma-reduction interventions.

Keywords Health-related quality of life · TB-stigma · Social support · Nigeria

Plain English summary

There is a renewed interest in measuring the health-related quality of life of people with long-standing diseases because it measures the effect of diseases on regular activities and functions. This concept has been studied among people with tuberculosis. Several studies from Nigeria have assessed the factors associated with the health-related quality of life among people with tuberculosis, but little is known about the effect of stigma and social support on the health-related quality of life of people with tuberculosis in Lagos, Nigeria. We conducted a study among people receiving treatment for resistant tuberculosis in Lagos, Nigeria, and assessed the effect of stigma and social support on their health-related quality of life. Our study suggested that people with resistant tuberculosis's overall health-related quality of life was generally poor. However, the younger participants, males, those with higher education, and who were HIV-negative, had higher health-related quality of life than their counterparts. The greater the stigma experienced by our participants, the lower the health-related quality of life recorded. Conversely, the more social support received, the higher the health-related quality of life. In conclusion, our study suggested that strategies to reduce stigma and strengthen social

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Published online: 18 February 2025

support are needed to improve the health-related quality of life of people with resistant tuberculosis in Lagos, Nigeria.

Introduction

Health-related quality of life (HRQoL) assesses the impact of disease and its treatment on the person's daily perception of physical, mental and social well-being [1]. It is an essential concept because people with chronic diseases often prioritise their cognitive and social well-being the same way they do their physical health [2]. Patients are not concerned about bacteriological cures alone; their well-being, functional capacity, and illness experiences are equally important [3]. It is an important patient-reported outcome measure as clinicians could underestimate the impacts of disease and treatment on HRQoL [4].

HRQoL applies a broader concept of health status measurement beyond the usual mortality and morbidity indicators. It has become an area of interest to stakeholders because it measures the effect of diseases and outcomes on regular activities and functions [5]. Tuberculosis (TB) is one of the diseases that can adversely undermine the HRQoL [6] and can be influenced by several patient, disease and treatment-related factors in people with TB (PWTB) because of the multi-drug therapy, side effects of medications, social impacts, social support, social stigma and possible complications [7, 8]. Generally, HRQoL is lower in PWTB compared with healthy populations [9, 10] but higher among people with drug-sensitive TB compared with their counterparts with drug-resistant TB (DR-TB) due to a complex interaction between physical illness, psychological consequences of the disease and the financial burden [11].

Stigma is a global public health challenge and a significant factor affecting TB control globally [12]. Crucially, it is a barrier to achieving the World Health Organization (WHO) goal of ending TB by 2050 [12]. Deep-rooted myths, wrong perceptions and beliefs about TB and those affected are factors responsible for stigma at the family and community level [13, 14]. Goffman described stigma as an "attribute that is deeply discrediting that demeans people from a whole and usual person to a tainted, discounted one" [15]. Stigma weakens TB response and damages the lives and health of those who experience it [16]. The effects of TB stigma are far-reaching. Unfortunately, necessary attention has not been given to international TB prevention and control [17].

Social support is the perceived or actual care received from family, friends, and significant others [18]. It buffers adverse life events and improves TB treatment outcomes [19]. When adequate, social support improves self-confidence and life fulfilment, reducing psychological distress [20]. There is an intricate relationship between TB stigma, social support, and HRQoL. Studies have shown that people with TB who experienced a lower level of stigma had good HRQoL; however, in contrast, social support has the opposite effect [21, 22]. There is, however, a lack of studies that accessed which factor between stigma and social support made a significant contribution to predicting HRQoL in people with TB.

Nigeria is classified as a high-burden TB, TB/HIV and drug-resistant TB (DR-TB) country by the WHO, with an estimated incidence rate of 219 per 100,000 population [19]. In 2022, about 43% of the 408,500 DR-TB cases were enrolled globally. Nigeria and nine other countries (eight in Asia and one in Europe) accounted for 70% of the treatment initiation gap [23]. Lagos is a cosmopolitan state with an estimated population of about 21 million, accounts for 8.4% of the national TB burden and contributes 9.4% of the country's total TB notification [24]. As the country's commercial nerve centre, Lagos State has unique socio-cultural dynamics because of ethnic diversity. The health system challenges and the numerous slums (over 100) in the state reflect its mega-city status [25]. It was the first state to decentralise DR-TB treatment to the community because of its high population density and poor physical access to DR-TB treatment centres.

TB is a stigmatised disease and a formidable challenge to global TB control [12]. A high prevalence of TB stigma has been reported in Nigeria and other high-burdened TB countries [26–28]. HRQoL has been studied among people with drug-sensitive and drug-resistant TB in Nigeria. These studies focused on the effects of TB treatment on HRQoL and the socio-demographic and clinical factors associated with HRQoL [29–32]. There is a need to assess the impact of TB stigma and social support on the HRQoL of PWTB in Nigeria because of the burden of TB and the high prevalence of TB stigma in the country. Unfortunately, there is little evidence about the effect of stigma and social support on HRQoL among DR-TB patients receiving treatment. This present study assessed the effect of TB stigma and social support on the HRQoL and which factor contributed more to predicting HRQoL among people living with DR-TB in Lagos, Nigeria. We envisage that our findings will contribute to the call for integrated patient-centred care among people with DR-TB, which is one of the pillars of the End TB Strategy.

Methods

Study design and sampling: A descriptive cross-sectional study was conducted between September and December 2023 to assess the HRQoL of people with drug-resistant TB in Lagos, Nigeria, and determine the effect of TB stigma and social support. Of the six DR-TB centres in Lagos, five centres with high caseloads of people with DR-TB

enrolled for care were purposely selected for the study to ensure geographic representation and diversity in patient demographics.

Convenient sampling was used. Eligible participants willing to participate in the study were consecutively recruited. Enrollment in the study was done during the outpatient clinic. All study participants signed a written informed consent form before the research assistants administered the questionnaire.

Using the sample size formula for a finite population, the TB stigma prevalence rate of 18%, [20] a non-response rate of 15% and the average population of 625 people with DR-TB on treatment in Lagos (from the records of the Lagos State TB and Leprosy control program), a sample size of 200 was obtained. Two hundred and three participants were recruited for the study.

Eligibility criteria: Participants were recruited into the study if they were adults (18 years and above), diagnosed with Xpert MTB/RIF assay and had been on DR-TB treatment for at least eight weeks.

Exclusion criteria: People with DR-TB who were very ill, who didn't understand English, and those who were unable to make an informed decision on participation in the study due to physical, cognitive or psychological factors were excluded from the study.

Measurement of HRQoL

The HRQoL was measured in this study using the Functional Assessment of Chronic Illness Therapy-TB (FACIT) scale [33]. The FACIT scale has been used to measure HRQoL in the general population and chronic diseases such as HIV/AIDs, multiple sclerosis, Parkinson's disease, and rheumatoid arthritis. It is widely used and translated into over 45 languages [34] The FACIT Measurement System provides an array of generic and targeted measures. It has five subscales: physical, social, emotional, functional and spiritual. The health concepts described by the scale range in score from 0 to 188 (for the 47-item FACIT-TB), with higher scores indicating higher levels of function and better health. Scores obtained for each domain were transformed to 100 since each domain does not contain an equal number of questions. The participants' responses are presented as a profile of scores calculated for each sub-scale. The overall score was calculated by summing up all the sub-scale scores [33]. The Cronbach's alpha coefficient for the FACIT scale in this study was 0.825.

Measurement of stigma

The Redwood DR-TB stigma scale was used to measure experienced stigma termed TB stigma in this study. It is a 14-item scale scored on a 3-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). The score ranged from 0 to 42, and a higher score indicates a higher level of stigma. TB stigma is measured across four factors: guilt, social exclusion, physical isolation, and blame [35]. The sum of all the subscale scores refers to experiencing TB stigma in this study. The Redwood DR-TB stigma scale was specifically designed to assess the stigma experienced by people living with DR-TB and also aid in the evaluation of stigma reduction scales, unlike other scales [35]. The Redwood DR-TB stigma scale has a Cronbach's alpha coefficient of 0.725 in this study.

Measurement of social support

We measured social support using a 12-item Multidimensional Scale of Perceived Social Support (MSPSS). The scale is scored on a 7-point Likert Scale ranging from 1 (very strongly disagree) to 7 (very strongly agree) [36]. The MSPSS addresses the subjective assessment of the adequacy of social support from three perspectives: family, friends, and significant others. It is psychometrically sound and has good reliability and adequate construct validity. It is self-explanatory, simple to use and time-conserving, making it an ideal tool for participants with limited time [36]. The scores ranged from 1 to 84, and higher scores indicated a high perceived level of social support. In this study, Cronbach's alpha coefficient for MSPSS was 0.780.

Measures

Outcome measure: In this study, the outcome measure is HRQoL, measured as a continuous variable.

Independent measures: Age, gender, marital status, educational status, working status, HIV status, being a breadwinner, barrier to treatment, cigarette smoking and alcohol intake, TB stigma and social support.

Data collection: Data collection was done using a questionnaire divided into two sections. The first section collected sociodemographic details of participants, HIV status, intake of cigarettes and alcohol and barrier to treatment. The three (stigma, social support and HRQoL) tools described above were combined in the second part of the questionnaire. Five trained research assistants administered the questionnaire. The tools were piloted in the treatment facility not recruited for the study. Modifications were made to the tools to suit the local context and improve participants' acceptability and understanding after the pilot study. The validity and internal consistency of the scales were assessed using the Cronbach alpha.

Ethical considerations

The Institutional Research Ethic Committee of Durban University of Technology, South Africa (IREC 066/230, 20th September 2023) and the Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179, 20th June 2023) gave ethical approval for this study. The Lagos State Ministry of Health and the medical directors of the health facilities where participants were recruited permitted the participants' interview. Participants who were stigmatised and had poor quality of life were referred for counselling by a psychologist, which was at no cost to the participants.

Statistical analyses

The HRQoL scores of the different subscales were standardised before being summed up. In this study, a test for normality was conducted for the outcome variable (HRQoL). Continuous variables such as HRQoL and age were represented as mean and standard deviation. Categorical variables were expressed as percentages. The Student's t-test and one-way ANOVA were used to compare the HRQoL subscale scores with different demographic and clinical parameters. The effect size for the Student's t-test and one-way ANOVA was measured using Hedges'g and eta squared (η_p^2). For eta squared 0.010–0.050 graded as small, 0.060–0.138, medium and > 0.138, large while Hedges'g classified effect sizes as small (0.2), medium (0.5) and large (≥ 8) [37, 38]. Pearson's correlation analysis assessed the correlation between HRQoL, TB stigma and social support. Hierarchical multiple regression was applied to determine the effects of influencing factors on HRQoL. Preliminary analyses showed no violation of the assumptions of normality, linearity, multicollinearity (variance inflation factor was < 10 and > 0.1) and homoscedasticity. In step 1, age, gender, marital status, educational status and HIV status (which were associated with HRQoL in univariate analysis) were entered in step 1. Stigma was added in step 2, while social support was added in step 3. The IBM Statistics Version 26 (IBM Corporation, Armonk, State of New York) for statistical analysis was used for the statistical analyses. A two-tailed p-value of < 0.05 was considered statistically significant.

Results

Socio-demographic associations

Two hundred and three participants were recruited for the study with a mean age of 39.2 ± 13.8 years. There was no difference in the mean age of the males (40.1 ± 13.6) and females (37.8 ± 14.1) p = 0.256. A higher proportion of the males were breadwinners (63.3% vs 24.0%, p < 0.001), smoked cigarettes (35.9% vs 5.3%, p < 0.001), and took alcohol (54.7% vs 20.0%, p < 0.001) compared to the females. More females than males were HIV positive (19 ± 26.4 vs 16 ± 13.0, p < 0.019; Table 1).

HRQoL subscales and associations

The average overall HRQoL score was 41.1 ± 12.9. The average physical, social, emotional, functional and spiritual subscale scores were 25.8 ± 13.8, 61.2 ± 13.1, 36.7 ± 12.1, 50.8 ± 14.9 and 74.3 ± 15.9 respectively (Table 2).

Table 1 Socio-demographic and clinical details of participants

Variable	Total n = 203 (%)	Male n = 128 (%)	Female n = 75 (%)	p
Age group (years)				
< 30	54 (26.6)	30 (23.4)	24 (32.0)	0.256
30–59	128 (63.1)	83 (64.8)	45 (60.0)	
≥ 60	21 (10.3)	15 (11.7)	6 (8.0)	
Age—mean (SD)	39.2 (13.8)	40.1 (13.6)	37.8 (14.1)	
Marital status				
Single	74 (36.5)	44 (34.4)	30 (40.0)	**0.033**
Married	111 (54.7)	77 (60.2)	34 (45.3)	
Widowed/separated	18 (8.9)	7 (5.5)	11 (14.7)	
Educational status				
No education/primary	43 (21.2)	28 (21.9)	15 (20.0)	0.910
Secondary	101 (49.8)	64 (50.0)	37 (49.3)	
Tertiary	59 (29.1)	36 (28.1)	23 (30.7)	
Working status				
Working	105 (51.7)	71 (55.5)	34 (45.3)	0.163
Not working	98 (48.3)	57 (44.5)	41 (54.7)	
Bead winner				
Yes	99 (48.8)	81 (63.3)	18 (24.0)	**< 0.001**
No	104 (51.2)	47 (36.7)	57 (76.0)	
HIV status				
Positive	35 (17.2)	16 (13.0)	19 (26.4)	**0.019**
Negative	160 (78.8)	107 (87.0)	53 (73.6)	
Unknown[#]	8 (3.9)	5 (3.9)	3 (4.0)	
Barriers to TB treatment				
Yes	36 (17.7)	22 (17.2)	14 (18.7)	0.790
No	167 (82.3)	106 (82.8)	61 (81.3)	
Smoked cigarette				
Yes	50 (24.6)	46 (35.9)	4 (5.3)	**< 0.001**
No	153 (75.4)	82 (64.1)	71 (94.7)	
Alcohol intake				
Yes	85 (41.9)	70 (54.7)	15 (20.0)	**< 0.001**
No	118 (58.1)	58 (45.3)	60 (80.0)	

Bold values indicate p-value < 0.05 are considered significant

[#]Not part of the analysis

Table 2 Participants Health-related Quality of life domain scores

Variable	n	Mean (SD)	95%CI
Overall HRQoL score	203	41.1 (12.9)	39.3–42.8
Physical	203	25.8 (13.8)	23.9–27.7
Social	203	61.2 (13.1)	58.4–64.0
Emotional	203	36.7 (12.1)	34.3–39.1
Functional	203	50.8 (14.9)	47.8–53.8
Spiritual	203	74.3 (15.9)	71.3–77.3

The factors associated with the overall HRQoL and its subscales are shown in Table 3. The overall HRQoL scores were significantly higher among male participants, those below 30 years, who were single and with tertiary education than their counterparts ($p < 0.05$). Also, the overall HRQoL is associated with educational status, employment and HIV status ($p < 0.05$). Participants under 30 had a significantly higher HRQoL score in the physical, emotional and function subscales. Except for the social subscale, where the males had a higher HRQoL score than the females, there was no gender difference in the HRQoL scores in other subscales. Participants with tertiary education had higher HRQoL scores in the physical, social, emotional and functional subscales. Being HIV positive was associated with lower HRQoL scores in the physical and social subscale. Also, the physical, social, emotional and functional HRQoL scores were lower among widows/widowers and separated than the singles and married. (Table 3).

Relationship between HRQoL, social support and stigma

The correlation between the overall HRQoL scores and TB stigma and social support is shown in Table 4. The overall HRQoL was negatively correlated with the TB stigma ($r = -0.536$, $p < 0.001$) and positively correlated with social support ($r = 0.416$, $p < 0.001$). TB stigma was negatively correlated with social support ($r = -0.700$, $p < 0.001$). Figure 1 shows an increase in HRQoL as stigma decreases, implying a negative correlation. Also, HRQoL increases as social support increases (positive correlation), as shown in Fig. 2.

Hierarchical regression analysis

Table 5 contains the hierarchical regression analysis of the overall HRQoL. The independent variables associated with the overall HRQoL in univariate analysis ($p < 0.05$) were entered into the hierarchical multiple regression. In step 1, the combination of age, gender, marital status and HIV status accounted for 3.3% of the variance in HRQoL ($F = 1.274$, $R^2 = 0.033$, $p = 0.277$). In step 2, after controlling for the demographic variables, TB stigma was negatively associated with HRQoL ($B = -0.520$, $p < 0.001$) but accounted for 26.4% variance in HRQoL ($F = 13.215$, adjusted $R = 0.297$, $\Delta R^2 = 0.264$, $p < 0.001$). In step 3, social support was added to the model and was positively associated with HRQoL ($B = 0.578$, $p < 0.001$). Social support accounted for 31.2% of the variance in HRQoL ($F = 41.463$, $R^2 = 0.608$, $\Delta R^2 = 0.312$, $p < 0.001$). All the variables in the model explained 60.8% of the variance in HRQoL. Social support made a higher significant contribution ($B = 0.578$, $p < 0.001$) in predicting HRQoL than stigma ($B = -0.415$, $p < 0.001$). In the final model, social support contributed more ($B = 0.576$) to predicting HRQoL than stigma ($B = -0.414$).

Discussion

This study assessed the effects of TB stigma and social support on HRQoL among people with DR-TB on treatment in Lagos, Nigeria. In this study, the overall HRQoL score was poor. The physical and emotional subscales had the lowest HRQoL score, while the spiritual subscale had the highest score. Age, gender, marital status, educational status and HIV status were factors associated with the overall HRQoL. The duration of treatment was not associated with HRQoL. Stigma was negatively associated with HRQoL, while social support was positively associated with HRQoL. Social support contributed more to predicting HRQoL than stigma.

The overall low HRQoL score of participants in this study was similar to cross-sectional studies from China, Eritrea and India, where the HRQoL was significantly reduced among people with DR-TB [11, 39, 40]. Contrary to our findings, a study from Nigeria reported high HRQoL among people with DR-TB [31]. However, the above report did not state the duration of treatment of participants. Furthermore, different tools used to measure HRQoL and sampling variation may be responsible for this finding. People with DR-TB have difficulties related to their family life, social stigmatisation and financial hardship due to longer treatment duration, toxic medications, frequent adverse effects and associated poorer outcomes, consequently impairing their HRQoL [41]. The poor socio-economic conditions of people with DR-TB, the severity of the disease, the financial burden of the disease, and inadequate access to DR-TB healthcare services in Nigeria may also be responsible for our findings [11, 42].

Our study showed that the HRQoL score was highest in the spiritual subscale. A systemic review showed a positive association between spirituality/religiousness and the quality of life of adults [43]. Nigerians are very religious, and over 99% identify with one religion. The cultural settings of the ethnic groups in the country also shape people's belief systems [44]. Most individuals turn to their faith when faced with health challenges, which sometimes could be detrimental to their health. Understanding how religiousness

Table 3 Health-related quality of life scores

Variable	Physical Mean (SD), effect size	Social Mean (SD), effect size	Emotional Mean (SD), effect size	Functional Mean (SD), effect size	Spiritual Mean (SD), effect size	Total HRQOL Mean (SD), effect size
Age group (years)						
< 30	29.4 (15.9)*, 0.034	63.2 (20.7), 0.006	43.3 (18.2)*, 0.055	57.7 (22.5)*, 0.040	78.1 (19.7), 0.016	45.6 (14.5)*, 0.054
30–59	25.1 (12.5)	61.0 (20.2)	34.7 (16.4)	49.4 (21.6)	73.8 (22.7)	40.1 (12.4)
≥ 60	20.6 (6.5)	57.7 (18.5)	32.5 (14.1)	42.7 (18.5)	68.3 (21.8)	35.9 (7.4)
Gender						
Male	26.9 (14.5), 0.221	64.2 (20.2)*, 0.410	38.1 (18.0), 0.212	52.1 (22.6), 0.154	76.3 (21.9), 0.242	42.7 (13.7)*, 0.327
Female	23.9 (12.4)	56.1 (19.1)	34.4 (15.3)	48.7 (20.7)	71.0 (21.8)	38.5 (11.1)
Marital status						
Single	28.5 (14.4)*, 0.036	62.4 (20.8)*, 0.047	41.6 (19.6)*, 0.064	55.0 (24.2)*, 0.037	78.8 (18.4), 0.029	44.4 (14.1)**, 0.072
Married	25.0 (13.9)	62.7 (19.6)	35.1 (15.0)	49.8 (20.3)	72.5 (23.1)	40.4 (12.0)
Widowed/ separated	19.3 (7.2)	47.2 (15.7)	27.0 (12.1)	39.7 (17.2)	67.1 (25.3)	31.9 (7.3)
Educational status						
No educ/primary	22.4 (10.9)**, 0.081	54.7 (22.6)*, 0.042	29.4 (14.6)**, 0.090	44.1 (20.5)*, 0.039	69.8 (24.7), 0.015	35.7 (12.1)**, 0.097
Secondary	23.7 (11.9)	61.0 (19.2)	35.7 (15.9)	50.4 (21.0)	76.6 (20.9)	40.1 (10.4)
Tertiary	31.9 (16.9)	66.3 (18.5)	43.8 (18.4)	56.4 (23.4)	73.9 (21.4)	46.8 (15.2)
Working condition						
Presently working	28.3 (15.7)* 0.382	63.0 (20.6), 0.185	36.5 (17.8), 0.025	56.1 (22.9)**, 0.516	74.2 (23.3), 0.013	43.1 (14.5)*, 0.323
Not working	23.1 (10.9)	59.3 (19.5)	37.0 (16.4)	45.1 (19.4)	74.5 (20.4)	39.0 (10.5)
Bread winner						
Yes	23.9 (12.1), 0.262	59.2 (20.2), 0.197	34.1 (16.3)*, 0.299	49.5 (20.8), 0.113	72.6 (24.2), 0.151	39.1 (12.0)*, 0.298
No	27.6 (15.2)	63.1 (19.9)	39.2 (17.6)	52.0 (22.9)	76.0 (19.6)	42.9 (13.5)
HIV status						
Positive	19.6 (8.8)**, 0.576	54.5 (19.8)*, 0.441	34.4 (14.5), 0.163	45.2 (21.8), 0.303	70.5 (24.4), 0.206	36.0 (10.8)*, 0.493
Negative	27.4 (14.4)	63.3 (20.0)	37.1 (17.6)	51.7 (21.4)	75.1 (21.5)	42.3 (13.2)
Unknown[#]	20.0 (12.2)	49.1 (15.8)	39.2 (18.5)	56.7 (21.4)	77.1 (18.8)	38.7 (10.1)
Barrier to TB						
Yes	23.4 (12.5), 0.213	57.8 (19.7), 0.204	33.5 (13.9), 0.228	47.3 (21.2), 0.193	65.7 (24.0)*, 0.483	37.7 (11.3), 0.316
No	26.3 (14.1)	62.0 (20.2)	37.4 (17.7)	51.6 (22.0)	76.2 (21.1)	41.8 (13.1)
Ever smoked						
Yes	26.9 (15.0), 0.106	62.3 (21.4), 0.070	37.8 (18.0), 0.083	48.4 (22.6), 0.143	75.2 (24.4), 0.049	41.6 (13.5), 0.054
No	25.4 (13.5)	60.9 (19.8)	36.4 (16.8)	51.6 (21.7)	74.1 (21.2)	40.9 (12.7)
Alcohol intake						
Yes	26.5 (13.7), 0.087	63.2 (21.0), 0.168	38.2 (17.1), 0.149	51.6 (21.3), 0.058	75.2 (22.6), 0.066	42.2 (13.0), 0.148
No	25.3 (14.0)	59.8 (19.4)	35.7 (17.1)	50.3 (22.4)	73.7 (21.6)	40.3 (12.8)
Length of treatment						
1–2 months	25.8 (13.4), 0.000	63.6 (20.1), 0.008	36.8 (17.1), 0.000	46.2 (20.7), 0.025	73.3 (22.4), 0.008	40.7 (12.7), 0.001
3–4 months	25.7 (14.4)	61.3 (18.7)	36.4 (18.3)	51.1 (22.8)	74.1 (22.0)	41.1 (13.7)
≥ 5 months	25.9 (14.0)	59.3 (21.1)	36.9 (16.4)	54.3 (21.8)	75.3 (21.8)	41.5 (12.7)

NB: *p < 0.05, **p < 0.001, [#]Not part of the analysis, *SD* standard deviation

influences HRQoL could help develop patient-centred care in culturally diverse settings like Nigeria.

The effects of DR-TB treatment on HRQoL are variable. According to a study from Yemen, DR-TB treatment influenced the increase in HRQoL scores of people with DR-TB in the late phases of treatment [10]. Contrary to this, our study shows that the HRQoL did not increase with the duration of treatment. A follow-up study from Pakistan

Table 4 Scores and correlation of total HRQOL with stigma and social support

Variable	Mean (SD)	95%CI	Total HRQoL score	Stigma score	Social support score
Total HRQOL score	41.1 (12.9)	39.3–42.9	1	− 0.536**	0.416**
Stigma Score	15.9 (5.3)	15.1–16.6	− 0.536**	1	− 0.700**
Social support score	59.3 (12.6)	57.6–61.1	0.416**	− 0.700**	1

NB: Pearson's correlation analysis was used to analyze the correlation among HRQoL, TB stigma, social support

HRQoL Health related quality of life, *SD* Standard deviation

**p < 0.01

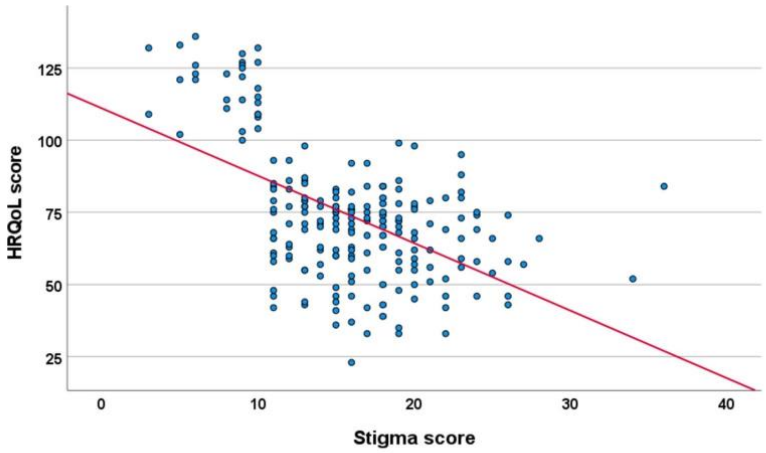

Fig. 1 The relationship between HRQoL and stigma

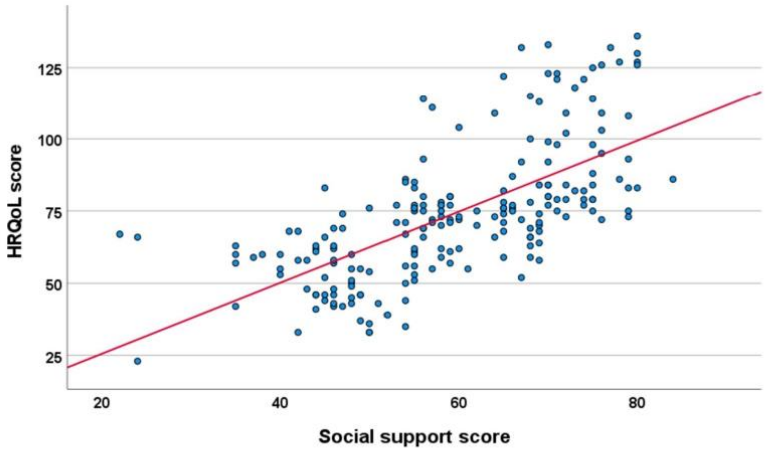

Fig. 2 The relationship between HRQoL and social support

showed a minimal clinically insignificant improvement in the HRQoL score after one year of DR-TB treatment [1]. The reason for this is unknown; the variations in the different study populations' cultural, socio-economic and social support systems may be contributory factors. The physical, emotional, and functional domain HRQoL scores in this study were poor, irrespective of the duration of treatment, similar to the findings from India [40].

Table 5 Hierarchical multiple regression analysis results of HRQoL

Variable	Step 1		Step 2		Step 3	
	B	p-value	B	p-value	B	p-value
Age	− 0.052	0.519	− 0.036	0.594	− 0.018	0.718
Gender	− 0.035	0.633	− 0.028	0.652	− 0.051	0.278
Marital status	− 0.160	0.047	− 0.121	0.080	− 0.027	0.601
Educational status	0.086	0.234	0.102	0.099	0.036	0.437
HIV status	− 0.087	0.239	− 0.011	0.174	− 0.014	0.767
Stigma			− 0.520	**< 0.001**	− 0.415	**< 0.001**
Social support					0.578	**< 0.001**
F	1.274	0.277	13.215	**< 0.001**	41.463	**< 0.001**
R^2	0.033		0.297		0.608	
Adjusted R^2	0.007		0.274		0.593	
ΔR^2	0.033		0.264		0.312	

Bold values indicate p-value < 0.05 are considered significant

In the assessment of the HRQoL scores among participants, we found that age had a significant effect on the overall HRQoL. The overall HRQoL was higher among the younger than the older age group. This conforms with previous studies from China, India and Nigeria [39, 45, 46]. The effects of advancing age, economic difficulties, poor mobility, and comorbidities, common among older people, could be responsible for this finding [47]. The younger participants were more likely to have better financial resources to access care, have good social relationships, have a better understanding of the disease process and have better self-esteem than the older participants [46]. Males had a higher score in the overall HRQoL than females in our study, consistent with findings from India [48, 49]. The patriarchal nature of Nigerians causes gender inequalities, which made the females the weaker sex, marginalised, discriminated against, and economically dependent on men and the cultural perceptions that relegate women to the background, without any opinion of their own, all of which potentially cause poor expression of views and feelings, may be responsible for the poorer HRQoL among women [46, 50]. Similar to our findings, studies have opined that a higher HRQoL was found among people with DR-TB who had a higher education compared to their counterparts [39, 51]. Education enables people to be well-informed, have better social connections, and understand the disease process, invariably improving their HRQoL [16]. Comorbidity has a powerful influence on HRQoL [39]. HIV-positive participants had poorer HRQoL than HIV-negative participants in this study, consistent with findings from other studies [52, 53]. TB and HIV co-infection are associated with unique therapeutic challenges and often pose a burden on the health system. Both diseases combine to impose physical and mental distress, leading to poor disease outcomes and poorer HRQoL [53].

One of the most critical factors affecting HRQoL among people with DR-TB is stigma. In our study, stigma alone explained more than a third of the variance in HRQoL. In agreement with other studies from China, India, Indonesia and Singapore [21, 22, 54, 55], our analysis shows that stigma was negatively associated with HRQoL. A systematic review from South Africa evaluating HRQoL among PWTB suggested that psycho-social burden such as stigma and social isolation impacts HRQoL more than clinical symptoms [56]. TB is a stigmatised disease because of fear of infection, its association with HIV disease and traditional myths [17]. TB stigma predisposes to depression, low self-efficacy, anxiety and ultimately poor HRQoL [57]. The prevention of TB stigma is crucial to global TB control because of its adverse effects on health-seeking behaviour and disease outcomes [58]. TB stigma can occur in the family, community, health facility and organisation. It may result in rejection, social exclusion, loss of employment, divorce and rejection of marriage proposals. This discrimination may result in mental distress and poor HRQoL [59]. Contrary to general belief, stigmatisation of people with TB is not limited to developing countries; it has also been reported in other low-burden TB countries [60].

There is a lack of studies evaluating interventions to reduce TB stigma despite its global importance. The public, healthcare workers managing TB patients, and other healthcare workers are possible sources of TB stigma. Interventions are optimised when simultaneously targeted towards more than one key population [61]. Nigeria can leverage TB stigma reduction interventions such as public awareness campaigns, stakeholder consultations, counselling, and peer support groups in high-burden settings [62]. Researching which intervention works best in a culturally diverse setting like Lagos could be the starting point.

For decades, social support has been recognised as an essential element in the control of TB [63]. In this study, social support was positively associated with the HRQoL of people with DR-TB, consistent with reports from India

and Zimbabwe [40, 64]. Patients with high social support are more likely to initiate diagnosis and treatment early [65], comply with treatment regimens [56], and experience less stigma [56, 57], ultimately leading to better HRQoL [66]. Social support includes support from family, friends, the community, and the health institution. When these are inconsistent, it is suggestive of societal stigma [64]. Institutional support from implementing partners and government agencies [31] and support in the workplace from healthcare providers and families positively influence the HRQoL of people with DR-TB [40]. Social support and TB stigma had opposite effects on HRQoL. However, social support impacted the HRQoL more than stigma in this study, similar to the findings from Pakistan [67]. Many studies have documented the effects of stigma and social support on HRQoL among people with TB; there is a need for further studies to ascertain which of the factors have a higher impact on HRQoL.

This study has some limitations. First, a causal relationship between TB stigma, social support, and HRQoL cannot be drawn from our research, as it is a cross-sectional study. Second, there is a possibility of having a response and ascertainment bias in the study because the measurements were self-reported.

Conclusion

This current study has established that the HRQoL of people with DR-TB in Lagos, Nigeria, is poor. Improvement in social support and reduction in stigma experienced by people with DR-TB will improve their HRQoL. The social support structure in the DR-TB programme needs to be evaluated and strengthened. There is also a need to encourage social support at the family and community levels. In contrast, policies that will reduce discrimination and stigma against people with DR-TB in the community, among healthcare providers and public health agencies, are urgently needed. Further studies are required to establish these associations, assess the changes in HRQoL over time and evaluate the impact of specific stigma-reduction interventions. Addressing the issue of stigma may facilitate the achievement of the prohibition of stigma and discrimination against people with TB, which is one of the thrusts of the End TB strategies.

Acknowledgements The authors wish to acknowledge the Ministry of Health and the Lagos State TB and Leprosy Control Programme for permission to conduct the study in the selected health facilities. We also acknowledge the management of the DR-TB treatment centres where the study was conducted.

Author contributions Olusola Adedeji Adejumo conceived and designed the study, prepared the material, performed statistical analysis, and wrote the first draft. Firoza Haffejee, Champaklal Jinabhai and Olusoji Daniel participated in the interpretation and presentation of findings. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding Open access funding provided by Durban University of Technology. The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Data availability The data underlying this article cannot be shared publicly due to the privacy of individuals who participated in the study. The data will be shared on reasonable request to the corresponding author.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethical approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179) and the Institutional Research Ethic Committee of Durban University of Technology, South Africa (IREC 066/230). Gatekeepers' permission to interview participants was obtained from the Lagos State Ministry of Health and the medical directors of the DR-TB treatment centres where participants were recruited.

Informed consent A written informed consent was obtained from all participants included in the study. The objectives of the study were explained to the participants. They were also informed that participation or non-participation in the study would not affect the provision of healthcare services. In addition, they were informed that they were free to withdraw their consent at any time during the study. The data was anonymized, and personal identifiers were not obtained.

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CHAPTER SIX

PUBLISHED ARTICLE 4

“Treatment Adherence among People with Drug-Resistant Tuberculosis in Lagos, Nigeria: The Effects of Stigma, Resilience, Social Support, and Temporal Discounting.”

This Chapter is presented as a published article. It assessed the prevalence of treatment adherence and the relationship between treatment adherence and resilience, temporal discounting, social support and stigma. The relationship between stigma, resilience, and temporal discounting was also determined. This chapter answered the second and fourth objectives of this thesis. The format and references in this chapter are presented according to the journal's submission guidelines.

Article title: Treatment Adherence among People with Drug-Resistant Tuberculosis in Lagos, Nigeria: The Effects of Stigma, Resilience, Social Support, and Temporal Discounting.

Authors: Olusola Adedeji Adejumo, Olusoji Daniel, Champaklal Jinabhai, Firoza Haffejee.

Journal: International Journal of Mycobacteriology

Status: Published (March 2025)

Original Article

Treatment Adherence among People with Drug-resistant Tuberculosis in Lagos Nigeria: The Effects of Stigma, Resilience, Social Support, and Temporal Discounting

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Abstract

Background: This study assessed the effects of social support, resilience, temporal discounting, and stigma on medication adherence among people with drug-resistant tuberculosis (PwDR-TB) in Lagos, Nigeria. **Methods:** A cross-sectional study was conducted between September and December 2023 among 203 adults on DR-TB treatment. The Morisky Medication Adherence Scale-8, Redwood DR-TB scale, multidimensional scale of perceived social support, brief resilience scale, and deferment of gratification scale were used to assess adherence, stigma, social support, resilience, and temporal discounting respectively. Pearson's correlation and hierarchical linear regression analysis were conducted to explore the relationships between adherence, stigma, social support, resilience, and temporal discounting. **Results:** The prevalence of low, medium, and high adherence was 20.7%, 73.4%, and 5.9%, respectively. Adherence was positively associated with social support ($B = 0.380$, $P < 0.001$), resilience ($B = 0.210$, $P < 0.001$), and temporal discounting ($B = 0.364$, $0 < 0.001$) and negatively associated with stigma ($B = -0.317$, $P < 0.001$). Temporal discounting made a higher significant contribution ($B = 0.343$, $P < 0.001$) in predicting adherence than social support ($B = 0.187$, $P = 0.005$), resilience ($B = 0.175$, $P = 0.002$) and stigma ($B = -0.317$, $P < 0.001$). **Conclusion:** Patient-centred interventions that promote social support, resilience, and temporal discounting are urgently needed to enhance adherence among PwDR-TB. Stigma reduction strategies are required at all levels.

Keywords: Adherence, drug-resistant tuberculosis, resilience, social support, stigma, temporal discounting

Submitted: 13-Nov-2024 **Revised:** 20-Dec-2024 **Accepted:** 24-Jan-2025 **Published:** 20-Mar-2025

Introduction

Adherence is crucial to tuberculosis (TB) control and is daunting due to the long treatment duration, the side effects, and personal behavioral and socioeconomic factors.[1] The focus of TB and drug-resistant TB (DR-TB) programs often centers on strategies that emphasize case detection and treatment adherence to achieve a cure. This rarely addresses patients' needs who had to deal with diagnostics bottlenecks, stigma, and maintenance of economic and family responsibilities throughout the extended treatment.[2] There is a rich body of research on the risk factors of nonadherence to TB treatment in high-burden countries. A meta-analysis of qualitative research from India identified three themes: personal influences on people with TB (PTB), healthcare providers' interactions with PTB, and other structural, social, economic, and cultural factors related to TB treatment.[3] Another review from Ethiopia outlined seven dimensions of adherence influencing factors: patient-centred, social, economic, health system, therapy, lifestyle, and geographic access factors.[4] TB is a stigmatized disease, and studies have shown that stigma hinders disclosure and is associated with poor quality of life, psychological distress, and poor treatment adherence.[5,6]

Many interventions have been implemented to enhance adherence among PTB, with varying successes. These include

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Website: https://journals.lww.com/IJMY

DOI: 10.4103/ijmy.ijmy_209_24

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How to cite this article: Adejumo OA, Daniel OJ, Jinabhai C, Haffejee F. Treatment adherence among people with drug-resistant tuberculosis in Lagos Nigeria: The effects of stigma, resilience, social support, and temporal discounting. Int J Mycobacteriol 2025;14:36-42.

directly observed treatment, reminders and tracers, incentives and enablers, patient education, short message services, video-observed therapy, and staff education.[1] Providing PTB with support systems improves treatment adherence, promotes treatment completion, and reduces the emergence of DR-TB.[1] Interventions must be patient-centred and build individual, household, and community resilience to achieve the desired results.[7]

Resilience and temporal discounting are two patient-centered factors in TB adherence that have not been given much attention. Resilience is the varied efforts to overcome difficulties through resource compromise, psycho-social coping skills, and enhancement of social structures and interactions.[8,9] On the other hand, temporal discounting is a concept that quantifies the degree to which future benefits are valued.[10] Managing chronic illnesses like TB requires individuals to make choices that may not yield immediate rewards. However, a vast body of evidence has demonstrated that temporal discounting is a strong predictor of obesity, pre-diabetes and type 2 diabetes prevalence, poor diets, low physical activity, and weight gain.[11] It is also hypothesized to underlie social behaviors, including addiction and risky sexual behaviors,[11] but little is known about its application to TB treatment adherence. This study assessed the association between social support, temporal discounting, resilience, stigma, and adherence. We also determined which factor contributes more to predicting adherence among people with drug-resistant TB (PwDR-TB) in Lagos, Nigeria.

Methods

Study design

A descriptive cross-sectional study was conducted between September and December 2023 among people receiving DR-TB treatment in five treatment centers in Lagos, Nigeria.

Study sites, sample size, and participant selection

Lagos is one of the southwestern states of Nigeria, with 20 local government areas used for administrative purposes. This study was part of a larger study that assessed the association between experienced stigma, anxiety, depression, and loneliness among PwDR-TB in Lagos, Nigeria. The sample size determination and selection of study sites and participants were previously published.[12] Five DR-TB treatment centers across Lagos state were selected based on their caseloads. A sample size of 200 was calculated using a sample size formula for a cross-sectional study of a finite population, a nonresponse rate of 15% and an 18% prevalence rate for TB stigma. Adults (18 years and above), diagnosed using Xpert MTB/RIF assay, who had been on DR-TB treatment for 8 weeks or more, were recruited for the study. PwDR-TB, who were ill and could not make informed participation decisions, was excluded.[12]

Study measurements

Adherence

Patient adherence was measured using the Morisky Medication Adherence Scale (MMAS-8).[13] It contains eight questions; the first seven items have a dichotomous answer (yes/no) indicating adherent and nonadherent behavior. The eight items expressed the frequency of nonadherence answered on a 5-point scale. The scale provides information on behaviors related to medication use that may be unintentional (e.g. forgetfulness) or intentional (e.g. not taking medications because of side effects). MMAS-8 scores ranged from 0 to 8. Scores <6 are considered as low adherence. A score of 7 is regarded as medium adherence, while a score of 8 is considered high.[13] The Cronbach's alpha coefficient for the MMAS-8 scale in this study was 0.809.

Stigma

Stigma was measured using the Redwood DR-TB scale.[14] It is a 14-item scale, scored on a 3-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). The score ranged from 0 to 42, and a higher score indicates a higher level of stigma. The Cronbach's alpha coefficient for the Redwood DR-TB scale in this study was 0.725.

Social support

The Multidimensional Scale of Perceived Social Support (MSPSS) was used to measure social support in this study.[15] It is a 12-item scale scored on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). It measures the adequacy of the subjective assessment of social support from three sources: family, friends, and significant others. The scores ranged from 1 to 84; a higher score indicates high perceived social support. The Cronbach's alpha coefficient for MSPSS in this study was 0.780.

Resilience

We measure resilience using the Brief Resilience Scale (BRS).[16] The BRS assessed the perceived ability to bounce back or recover from stress. It is a six-item scale, scored on a 5-point Likert scale ranging from strongly disagree to strongly agree. Items 1,3 and 5 are positively worded, while items 2, 4, and 6 are negatively worded. The BRS is scored by reversing the coding of items 2, 4, and 6 and finding the mean of the six items. The possible score ranges from 1 (low resilience) to 5 (high resilience). In this study, Cronbach's alpha coefficient was 0.825.

Temporal discounting

The Deferment of Gratification Scale (DGS) measures the ability of a patient to endure discomfort because of the hope of a better future.[17] The DGS is a 12-item scale asking about the preference or ability to defer gratification versus pursuing more immediate rewards. Six items are "positive," and six are reverse-coded. Response options range from 1, strongly disagree, to 7, strongly agree. Higher scores indicate a more significant postponement of gratification. In this study, the Cronbach's alpha coefficient was 0.780.

Data collection

The questionnaire was divided into two parts; the first part collected data on the socioeconomic details of the participants, household characteristics, self-assessment of disease

severity, and perception of treatment. The second part of the questionnaire contains validated tools measuring adherence, social support, stigma, resilience, and temporal discounting. Five research assistants with backgrounds in health sciences were trained for 1 day to collect data from participants. The DR-TB treatment center that was not recruited for the study was used for the pilot study, and some questionnaire items were rephrased after piloting to improve validity and acceptability. The validity and internal consistency of the scales were assessed using Cronbach alpha.

Measures

Outcome measure

In this study, the outcome measure was adherence measured as a continuous variable.

Independent measures include stigma, social support, resilience, and temporal discounting. Others are gender, age, marital status, HIV status, alcohol intake, cigarette smoking, educational status, perceived severity of DR-TB, length of treatment, and knowledge of TB.

Ethical considerations

The Institutional Research Ethic Committee of Durban University of Technology, South Africa (IREC 066/230) and the Health Research and Ethics Committee of the Lagos State University Teaching Hospital, Nigeria (LREC/06/10/2179) gave ethical approvals for this study. The Lagos State Ministry of Health and the administrators of each treatment facility where data was collected granted permission to interview participants. Written informed consent was obtained from participants before enrolment into the study. They were assured of the strict confidentiality of the data received.

Data analysis

Data were entered into IBM SPSS Statistics for Windows, version 26 (IBM Corp., Armonk, N.Y., USA) for statistical analysis by the research assistants and checked for accuracy and completeness by one of the authors by cross-checking 30 randomly selected questionnaires with data entry. We conducted a test of normality for all the scales. Means and standard deviation were used to represent continuous variables. The Student's-*t*-test and one-way ANOVA were used to compare the mean adherence with the sociodemographic and clinical details. Hedges'g and Partial eta squared (η_p^2) were used to measure the effect sizes for Student's-*t* test and one-way ANOVA. Partial eta squared 0.010–0.050 was graded as small, 0.060–0.138, medium, and >0.138, large, while Hedges'g classified effect sizes as small (0.2), medium (0.5), and large (≥8).[18,19] A partial correlation was conducted to evaluate the correlation of adherence, social support, resilience, and temporal discounting while controlling for stigma. Hierarchical multiple regression was applied to assess the effects of stigma, social support, resilience, and temporal discounting on adherence after controlling for variables with $P \leq 0.25$.[20] The assumptions of normality, linearity, multicollinearity (variance inflation factor was <10 and tolerance >0.1), and homoscedasticity were not violated. Variables such as employment status, cigarette smoking, knowledge of TB, HIV status, perception of treatment, length of treatment and perceived barriers to DR-TB services with a $P < 0.25$ in univariate analysis were entered in step 1. Social support, resilience, and temporal discounting were added in Step 2, while stigma was added in Step 3. The confidence interval was 95%; a two-sided test was used for all the statistical analyses, and a $P < 0.05$ was considered statistically significant.

Results

Sociodemographic characteristics and associated factors with adherence

A higher proportion (53.7%) of the 203 participants recruited for the study were between 30 and 49 years; 26.6% were <30 years, while only 19.7% were 50 years and older. The mean age of participants was 39.2 ± 13.8 years. Of the total, 151 (74.4%) participants were managed at the secondary health facilities. There were more males than females (63.1% vs. 36.9%), 35 (17.2%) were HIV positive, 36 (17.7%) had a barrier to DR-TB treatment, 181 (89.2%) had good knowledge about TB, 178 (87.7%) perceived the DR-TB treatment to be helpful and 78 (38.4%) perceived infection to be severe [Table 1]. The mean adherence score was 6.2 ± 1.5, while 42 (20.7%) participants had low adherence, 149 (73.4%) had medium adherence and only 12 (5.9%) had high adherence to DR-TB treatment [Table 1].

The adherence score was higher among participants who were employed (6.6 ± 1.2 vs. 5.9 ± 1.6, $P = 0.007$) and who had good knowledge of TB (6.3 ± 1.3 vs. 5.2 ± 2.1, $P < 0.001$) compared to their counterparts. The participants who perceived DR-TB treatment to be helpful (6.3 ± 1.3 vs. 5.7 ± 2.2, $P = 0.059$), who never smoked cigarettes (6.3 ± 1.3 vs. 5.9 ± 1.8, $P = 0.078$), who had no barrier to DR-TB treatment (6.3 ± 1.4 vs. 5.9 ± 1.6, $P = 0.165$) and who were HIV-positive (6.5 ± 0.8 vs. 6.1 ± 1.5, $P = 0.140$) had a higher adherence score than their counterparts, although not statistically significant. The length of DR-TB treatment was also associated with adherence score ($P = 0.031$) [Table 1].

Relationship between adherence versus social support, resilience, temporal discounting, and stigma

The partial correlation between adherence, social support, resilience, temporal discounting, and stigma is shown in Table 2. Before controlling for stigma, social support ($r = 0.600$, $P < 0.001$), resilience (0.530, $P < 0.001$), and temporal discounting ($r = 0.600$, $P < 0.001$) were positively correlated with adherence, while stigma ($r = -0.628$, $P < 0.001$) was negatively related with adherence. After controlling for stigma, the correlation coefficient of social support ($r = 0.313$, $P < 0.001$), resilience ($r = 0.400$, $P < 0.001$), and temporal discounting ($r = 0.512$, $P < 0.001$) were reduced.

Table 1: Sociodemographic and clinical details associated with adherence to drug-resistant tuberculosis treatment among participants

Variables size	*n*=203, *n* (%)	Adherence score, mean±SD	*P*	Effect
Age group (years)				
<30	54 (26.6)	6.0±1.7	0.475	0.007
30–49	109 (53.7)	6.2±1.4		
≥50	40 (19.7)	6.4±1.4		
Mean (SD)	39.2 (13.8)			
Gender				
Male	128 (63.1)	6.1±1.5	0.904	0.018
Female	75 (36.9)	6.2±1.3		
Educational status				
No education/primary	43 (21.2)	6.2±1.5	0.832	0.002
Secondary	101 (49.8)	6.2±1.3		
Tertiary	59 (29.1)	6.1±1.6		
Employment status				
Engaged in work	105 (51.7)	6.6±1.2	0.007	0.386
Not employed	98 (48.3)	5.9±1.6		
HIV status				
Positive	35 (17.2)	6.5±0.8	0.140	0.277
Negative	160 (78.8)	6.1±1.5		
Unknown[#]	8 (3.9)	5.6±2.3		
Breadwinner				
Yes	99 (48.8)	6.1±1.4	0.738	1.474
No	104 (51.2)	6.2±1.5		
Cigarette smoking				
Yes	50 (24.6)	5.9±1.8	0.078	0.287
No	153 (75.4)	6.3±1.3		
Alcohol intake				
Yes	85 (41.9)	6.2±1.5	0.828	0.031
No	118 (58.1)	6.1±1.4		
Perceived barrier to DR-TB				
Yes	36 (17.7)	5.9±1.6	0.165	0.255
No	167 (82.3)	6.3±1.4		
Knowledge of TB				
Poor	22 (10.8)	5.2±2.1	<0.001	0.758
Good	181 (89.2)	6.3±1.3		
Perception of treatment				
Helpful	178 (87.7)	6.3±1.3	0.059	0.403
Indifferent	25 (12.3)	5.7±2.2		
Type of facility				
Secondary	151 (74.4)	6.2±1.4	0.806	0.039
Primary	52 (25.6)	6.1±1.5		
Perceived severity				
Mild/moderate	125 (61.6)	6.2±1.5	0.532	0.090
Severe	78 (38.4)	6.1±1.3		
Length of treatment (months)				
≥3	94 (46.3)	6.4±1.3	0.031	0.034
4–6	68 (33.5)	5.8±1.6		
>6	41 (20.2)	6.3±1.3		

[#]Not included in the analysis. Mean adherence score±SD=6.2±1.5, Low adherence=42 (20.7%), medium adherence=149 (73.4%), high adherence=12 (5.9%). SD: Standard deviation, DR-TB: Drug-resistant tuberculosis

Hierarchical regression analysis

The hierarchical regression analysis of treatment adherence is shown in Table 3. The linear combination of employment status, cigarette smoking, HIV status, length of treatment, barrier to DR-TB treatment, and perceived usefulness of treatment significantly explained a 10.2% variance in treatment adherence (F = 3.023, R^2 = 0.102, P = 0.005). In step 2, the addition of social support (B = 0.380,

Table 2: Pearson's correlation between adherence, social support, resilience, temporal discounting, and stigma

Variables	Correlation before controlling for stigma				
	Adherence - *r, P*	Social support - *r, P*	Resilience - *r, P*	Temporal discounting - *r, P*	Stigma - *r, P*
Adherence	1				
Social support	0.606, <0.001	1			
Resilience	0.530, <0.001	0.343, <0.001	1		
Temporal discounting	0.600, <0.001	0.375, <0.001	0.400, <0.001	1	
Stigma	−0.628, <0.001	−0.680, <0.001	−0.386, <0.001	−0.364, <0.001	1
Variables	**Correlation after controlling for stigma**				
	Adherence - *r, P*	Social support - *r, P*	Resilience - *r, P*	Temporal discounting - *r, P*	Stigma - *r, P*
Adherence	1				
Social support	0.313, <0.001	1			
Resilience	0.400, <0.001	0.118, 0.094	1		
Temporal discounting	0.512, <0.001	0.186, 0.008	0.302, <0.001	1	

Table 3: Hierarchical multiple regression analysis of adherence

Variable	Step 1		Step 2		Step 3	
	B	P	B	P	B	P
Employment status	−0.154	0.029	−0.036	0.465	0.001	0.997
Smoked cigarette	0.047	0.502	−0.061	0.227	−0.071	0.137
Knowledge of TB	0.179	0.013	0.090	0.075	0.054	0.268
HIV status	−0.067	0.340	−0.004	0.930	0.015	0.742
Treatment helpful	−0.068	0.341	−0.051	0.316	−0.062	0.206
Length of treatment	−0.117	0.095	−0.002	0.968	−0.025	0.599
Had barrier to treatment	0.076	0.276	0.037	0.454	0.027	0.554
Social support			0.380	<0.001	0.187	0.005
Resilience			0.210	<0.001	0.175	0.002
Temporal discounting			0.364	<0.001	0.343	<0.001
Stigma					−0.317	<0.001
F	3.023	0.005	24.645	<0.001	26.940	<0.001
R^2	0.102		0.573		0.618	
Adjusted R^2	0.068		0.549		0.595	
ΔR^2	0.102		0.471		0.046	

TB: Tuberculosis

$P < 0.001$), resilience ($B = 0.210$, $P < 0.001$) and temporal discounting ($B = 0.364$, $P < 0.001$) was positively associated with treatment adherence. It improved the model of fit, explaining 47.1% of the variance in treatment adherence ($F = 24.645$, $R^2 = 0.573$, $\Delta R^2 = 0.471$, $P < 0.001$). In the third step, stigma was added to the model and was negatively associated with treatment adherence ($B = -0.317$, $P < 0.001$). It also accounted for 4.6% of the variance in treatment adherence. All the variables in the model explained 61.8% of the variance in treatment adherence. Temporal discounting made a higher significant contribution ($B = 0.343$, $P < 0.001$) in predicting adherence than social support ($B = 0.187$, $P = 0.005$), resilience ($B = 0.175$, $P = 0.002$), and stigma ($B = -0.317$, $P < 0.001$).

Discussion

This study assessed the relationship between stigma, social support, resilience, temporal discounting, and treatment adherence. We found that resilience, temporal discounting, and social support were positively associated with treatment adherence. In contrast, stigma was negatively associated with treatment adherence. The strength of the relationship of social support, temporal discounting, and resilience with treatment adherence was reduced after controlling for stigma. Temporal discounting significantly contributed more to predicting adherence than social support, resilience, and stigma.

In this study, 20.7% of participants had low adherence, lower than the 36% reported in Nigeria among PwDR-TB and the 20.6%–25% reported in a meta-analysis.[21,22] The method of assessment, assessment period (intensive/continuation phase), treatment regimen (first-line or second-line), selection criteria, and sampling variation may account for this variation.

The World Health Organization's framework for social support is divided into four subtypes. The first is informational, emotional, companionship, and material support.[23] Qualitative studies among PwDR-TB from Nigeria and Armenia showed that social support from family, friends, the healthcare system, and the community were crucial to treatment adherence and success, similar to what was obtained in this study.[21,24] Having someone observe drug intake, free treatment, provision of financial support for transportation, support from health workers and friends and the care and respect from family members were motivations for adherence.[21,24] Systemic reviews and meta-analyses showed that social support is necessary to improve treatment loss to follow-up and adherence among PwDR-TB.[25,26]

The challenges of PwDR-TB are multidimensional, and health provider services are limited in their ability to address them. Resilience is one of the person-centred approaches not fully explored but crucial in mitigating these challenges.[27] A qualitative study from India showed that the interaction of

participatory care, self-adaptation, and self-efficacy towards treatment aided by caregiver and health system support led to resilience among PwDR-TB.[27] The link between resilience and health benefits is complex and varies between communities. The many manifestations of resilience interact as resilience in one domain could influence vulnerability in another.[28]

Resilience has been linked with adherence to TB treatment.[27] Our study showed that adherence increases with increased resilience among PwDR-TB. In qualitative studies from Nigeria and India, a sense of responsibility to their families, willpower, and determination to get better-enhanced adherence.[21,24] Although resilience has long-term health benefits, an ethnographic health study from South Africa demonstrated that some manifestations of resilience, such as delaying intake of TB drugs when lacking food to avoid psychosis and alcohol consumption to better cope with therapy, may interact to undermine the health outcomes.[28] PwDR-TB often develops self-driven solutions and resilience to overcome the multi-dimensional challenges and consequences of DR-TB medications. There is a need for TB programs to promote a resilience-building approach that will leverage the strengths and vulnerabilities of PTB and their communities.[28]

Temporal discounting refers to an individual's ability to observe an anticipated outcome in the future as more valuable than the one at present. An individual with low temporal discounting believes that efforts made in the present are necessary to gain in the future.[29] This study found that PwDR-TB who hoped for a better future health outcome had better adherence than those who valued present gratification. Temporal discounting contributed more to predicting adherence than social support, resilience, and stigma. This agrees with studies from Nigeria and Ethiopia that showed the hope of a future cure was the motivation for adherence among PwDR-TB.[21,30] A meta-analysis opined that nonadherence to long-term therapies may result from failure to prioritize the future because patients are often more attracted to immediate rewards.[31] Resilience and temporal discounting are positively correlated in our study; more studies are needed to ascertain if they are mutually exclusive.

In this study, stigma was negatively associated with adherence and reduced the effects of social support, temporal discounting, and resilience on treatment adherence. Stigma is a social determinant of health that significantly impacts adherence among TB patients.[5,6] Stigma negatively impacts health-seeking behavior, care delivery, adherence, and patient recovery. Personal resilience and health outcomes are undermined by stigma.[32,33] Qualitative studies from China, Ethiopia, and India reported that perceived or experienced stigma were reasons for nonadherence to TB treatment.[34,35] Our findings imply that stigma may undermine all efforts to improve treatment adherence if no stigma reduction programs are implemented. A synergistic beneficial effect is produced when all the listed interventions are included in a DR-TB treatment program.

Conclusion

Temporal discounting made the most significant contribution to predicting adherence in our study. Stigma reduced the correlation between resilience, social support, and temporal discounting on adherence. Interventions that improve the resilience of PwDR-TB and also foster temporal discounting are needed to improve adherence to DR-TB treatment. PwDR-TB needs to be supported during treatment. Stigma reduction strategies at all levels are equally required to maximize these benefits.

Rational of study

Adherence to drug-resistant tuberculosis treatment is a major component of ensuring a cure for the disease. However, adherence could be very difficult for people with drug-resistant tuberculosis because of the side effects, long duration of treatment and other behavioural and socio-economic factors. Resilience and temporal discounting are two factors that could impact adherence significantly. Unfortunately, they have not been well-researched among people with tuberculosis. This study assessed the association between social support, temporal discounting, resilience, stigma and adherence. We also determined which factor contributes more to predicting adherence among people with drug-resistant TB in Lagos, Nigeria, after controlling for stigma.

Outcome of study

This study highlights that most participants (73.4%) with drug-resistant TB had medium adherence rates, whilst almost a quarter (20.7%) had low adherence rates. Key findings indicate that social support, resilience, and temporal discounting positively correlate with adherence, while stigma negatively impacts it. Notably, temporal discounting emerged as the strongest predictor of adherence, surpassing the contributions of social support, resilience, and stigma.

Limitation of study

Our study has some limitations. The assessment of adherence, social support, Resilience, temporal discounting, and stigma were self-reported, which raises the possibility of recall bias, information bias, and social desirability bias. A more direct method of assessing adherence, such as measuring drugs or metabolites, would be a more accurate measure of adherence.

Second, causality among the constructs cannot be explored because of the study design.

Acknowledgments

The authors wish to acknowledge the Ministry of Health and the Lagos State TB and Leprosy Control Programme for permission to conduct the study in the selected health facilities. We also acknowledge the management of the DR-TB treatment centers where the study was conducted.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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CHAPTER SEVEN

SUBMITTED MANUSCRIPT 1

‘The way they treat us is worse than the disease’: A qualitative study of the experiences of people with drug-resistant tuberculosis at healthcare facilities in Lagos, Nigeria.

This chapter comprises a manuscript currently under review by BMC Health Services Research. The manuscript is a qualitative study that explored the stigma experiences of PwDR-TB at healthcare facilities. It presented the struggles and challenges encountered at the health facilities and highlighted the perception of healthcare workers by PwDR-TB. This chapter addressed the fifth objective of this thesis. The format and references in this chapter are presented according to the journal's submission guidelines.

Manuscript title: ‘The way they treat us is worse than the disease’: A qualitative study of the experiences of people with drug-resistant tuberculosis at healthcare facilities in Lagos, Nigeria.

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Status: Under Review
Submission ID: 015b2764-da8d-438f-80da-33876fd12f66.

Date of submission: 7th April, 2024.

‘The way they treat us is worse than the disease’: A qualitative study of the experiences of people with drug-resistant tuberculosis at healthcare facilities in Lagos, Nigeria.

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Word count of text: 2473 Word count of abstract: 187 Number of Tables: 1 Number of references: 28

Running head: Tuberculosis stigma and healthcare workers

Abstract

Background: This study explored the stigma experiences of people with drug-resistant tuberculosis at health facilities in Lagos, Nigeria.

Methods: Focus group discussions were conducted with individuals receiving treatment for drug-resistant tuberculosis at five treatment centers in Lagos. Thematic analysis was conducted.

Results: The participants complained about the poor attitudes of healthcare workers, which they described as rude, hostile, and demeaning. These poor attitudes led some participants to consider abandoning treatment, whereas others wished that they knew where to lodge complaints against healthcare workers. The participants felt humiliated, and some described the feeling as worse than the disease symptoms. The counselling by healthcare workers about the use of separate cutlery and self-isolation at home evoked feelings of loneliness at home, which was disapproved of by many participants.

Conclusion: Reducing healthcare-associated stigma will require training healthcare workers on how to engage with people living with tuberculosis and their families, as well as providing necessary infrastructural support that will make healthcare workers feel safe working among people living with tuberculosis. There is a need for stigma reduction intervention research in Nigeria, as well as learning from other settings that have achieved relative success.

Keywords: Stigma, healthcare workers, drug-resistant tuberculosis, Nigeria.

Introduction

Tuberculosis (TB) is a stigmatised disease affecting mainly socially disadvantaged people, such as poor people, prisoners and refugees, and people living with HIV/AIDS [1]. In most high-TB-burden societies, TB-related stigma is a major sociocultural factor affecting the disease experience of people living with TB (PLWTB) because it influences the attitudes and behaviours of the community towards them [2]. It is shaped by deep-rooted myths and customs, incorrect perceptions and belief systems, and the culture of healthcare institutions [3-5].

TB-related stigma can affect the health-seeking behavior of symptomatic individuals. It hinders disease disclosure to family members and friends, encourages community spread, and undermines TB control efforts [6]. Because of the fear of contagion, many PLWTB are not treated well by family members, friends, neighbours, or healthcare workers (HCWs), which may lead to low self-esteem, feelings of shame and guilt, isolation, and psychological distress [6]. TB-related stigma is common among people with drug-resistant TB (PwDR-TB) because of the longer duration of treatment, the perceived severity of the disease, and the shame associated with poor treatment outcomes [7].

Stigma is a social construct comprising two significant components: identifying a differentiating trait or attribute and labelling or discrediting the individual due to that trait [8]. The attitudes of the community, especially HCWs, towards PLWTB may impact the timing, place, duration, and effectiveness of the care they receive [9,10]. HCWs occupy a position that can define a disease with negative attributes and influence the community's perception of it, consequently reinforcing the stigma attached to the disease by the community [11].

TB is still a disease of public health concern in Nigeria despite all TB control efforts. Nigeria is one of the 30 high-burden countries for TB, accounting for 87% of the global incidence of TB cases. Among the 408,500 people diagnosed with drug-resistant TB (DR-TB) in 2022 globally, 57% were not enrolled, and Nigeria is among the 10 countries that accounted for 70% of the gap in treatment initiation [12]. Studies from high-burden TB countries such as Nigeria, Ethiopia, and China have reported a high prevalence of TB-related stigma [13–15]. The poor treatment of PLWTB in healthcare settings has been

documented. Reports from Ghana and India have shown that HCWs are unfriendly towards, shunned, shouted at, avoided, disrespected, and discriminated against PLWTB [2, 16]. Another qualitative study from Ghana revealed that the isolation and precautionary practices and behaviours of HCWs towards PLWTB exposed them to stigmatisation in the community [11]. TB cannot be controlled without strategies in place to reduce stigma, and TB control in Nigeria is crucial to global control due to its high prevalence in the country. Based on the above narrative, TB patients' experiences in Nigeria's healthcare facilities require further exploration. Unfortunately, there is a dearth of such studies in Nigeria. This study examines the stigma experiences of PwDR-TB in healthcare facilities in Lagos, Nigeria.

Methods

This study was part of a larger study that assessed the moderating role of social support in the association between experienced stigma, anxiety, depression and loneliness among PwDR-TB in Lagos, Nigeria [17]. The study was conducted in Lagos State, Nigeria, between September and December 2023. Lagos State is a commercial hub in Nigeria, with an estimated population of 21 million. The state is divided into 20 local government areas (LGAs) and 37 local council development areas (LCDAs). The participants were drawn from five DR-TB outpatient clinics in Lagos State.

The study received ethical approval from the Institutional Research Ethics Committee of the Durban University of Technology, South Africa (IREC 066/230) and the Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179). The Lagos State Ministry of Health granted permission for the interviews with participants. The data were collected in five DR-TB treatment centers across Lagos State between February and April 2024. The five centers were purposively selected because of their geographical representation and diversity of patients, as well as their high volume of clinic attendance. Furthermore, patients reported unpleasant discriminatory experiences in some of these health facilities. Details about the study site selection were published previously [17].

Five focus group discussions (FGDs) were conducted, one at each of the selected health

facilities, and 53 participants (27 males and 26 females) aged 18-53 years participated in the discussions, which were held at the outpatient clinic. Participants who took part in the larger study were invited to participate in the FGDs. Eligible participants were people who commenced DR-TB treatment within three months of the interview or who had completed treatment and were not younger than 18 years [17]. Details of the focus group participants are shown in Table 1.

The focus group discussions were held at the health facility after the outpatient clinic and were moderated by the first author. Three research assistants were trained to assist with data collection, including recording discussions on audio tapes, note-taking, and transcribing the audio tapes. Each interview consisted of 9–12 participants and lasted 60–75 minutes. Focus group sessions were conducted in English and pidgin English using a focus group guide developed for this study (See supplementary file 1). Two bilingual research assistants translated and transcribed the recorded audio tapes verbatim within 48 hours after the data collection activity. Thereafter, the first author and another research assistant, who had not participated in the initial transcription, used the audio tapes and field notes to verify the transcriptions and ensure that the participants' words were accurately preserved and that correct transcriptions were produced. The whole team was involved in resolving conflicts in interpretation and achieving a consensus. All coauthors read the transcripts several times and scrutinised them. A codebook was developed, and the transcripts were tabulated into three themes to facilitate comparison by two coauthors. The coders discussed the data to ensure consistency in the meaning of the codes and assure interrater reliability. Verbatim quotations were selected to represent repeated discussions and ideas.

Results

Three themes emanated from the data. These encompass the attitudes of healthcare workers, the effects of these attitudes, and the isolation that results from the education of healthcare workers.

1. *Attitudes of health workers*

Many participants complained about the attitudes of the HCWs. They described their attitudes as demeaning because the HCWs were very rude, shouted at patients, and made uncomplimentary remarks about PwDR-TB.

… on my first visit here, I felt like the whole world was against me; the nurse made me think I was different, that there was something wrong with me, and she did not want me to come close to her. I don't want to come here if I can buy the medication elsewhere, I won't come here… (female participant, 38 years old, FGD 2)

….. when I arrived at the hospital, I gave the doctor the test results. Immediately, she saw what was there; she said, 'Madam, go outside.' She then went and put on two face masks. She asked anybody who sat beside me to move away from me. When more people arrived, she chased me away from the clinic and asked me to sit outside. I fell while trying to exit the clinic. The disgrace was too much (female participant, 43 years old, FGD 5)

Some of the participants wanted to abandon treatment because of the way they were attended to. Some even wished to die because of the attitudes of HCWs.

……. We sat down to see the doctor. When the nurse collected our test results, she shouted, "Go and sit down first." She shouted at us to stand up and chased us away like animals. As we tried to move out of the place quickly, my child hit his head on an iron. I was so embarrassed, I thought of abandoning the treatment and dying …. (female participant, 45 years old, FGD 4).

Some participants wished that they could report the HCWs to a higher authority for their bad attitudes, but felt that they could not take this step because they did not want people to know that they had DR-TB.

… the moment the woman saw my result, her attitude towards me changed; she shouted and embarrassed me. People asked me what went wrong. If I had the power, I would have reported her because I was treated as if I had leprosy….(male participant, 43 years old, FGD 1)

…I had to endure the way the health workers treated me; I felt terrible, but I kept it to myself. I am the sick one, and I don't want anybody to know I have TB…. (male participant, 48 years old, FGD 3)

2. *Effects of healthcare workers' attitudes*

Some participants reported experiencing adverse effects due to the poor attitudes of healthcare workers. Some felt humiliated, and some described the experience as being worse than the symptoms and the side effects of the drugs.

…..the way I am being treated matters more to me than the TB itself; my first experience at the health facility was terrible (female participant, 25 years old, FGD 3).

…… I told him it's not about the free medication; it's about the humiliation (female participant, 35 years old, FGD 2)

Owing to the attitudes of HCWs, some participants reported that it took courage to visit healthcare facilities to receive treatment. They would have chosen other options if possible.

….. It takes courage to come here; the way I am being treated could increase the problems I already have. If there were other options, I would not come here again… (male participant, 41 years old, FGD 5)

All the participants agreed that discriminatory behaviours were worse at the health facility than in the community. They reported that because they do not usually disclose their sickness to neighbours and friends, they do not become stigmatised. When asked if there is any other place they are discriminated against more than the health facility, they all chorused, "nowhere is worse than the health facility."

…Nowhere was I treated poorly except at the health facility. In the neighbourhood, nobody can know you have the disease… (male participant, 43 years old, FGD 2)

… this (referring to the hospital) is where we wear a face mask; at home, we are just like any other person; no one knows what's wrong with us. (male participant, 25 years old, FGD 1)

3. *Healthcare workers were responsible for isolation practices at home.*

Many participants recounted the health education provided by HCWs. This includes unfounded practices, which involve using separate cutlery, sleeping in separate rooms, and avoiding the items used by PLWTB. This advice caused severe emotional trauma to the PLWTB.

….. they (the healthcare workers) usually ask me if I am using my medications and who I live with. They advised that I should not share utensils with anyone, use my face mask properly, and they told me to ensure that I don't miss my drugs and always come for check-ups. (male participant, 20 years old, FGD 3).

…I became lonely. Even my wife now stays away from me. We were sleeping in the same room, but now she is far from me. They advised us not to share anything (male participant, 45 years old, FGD 1)

However, some family members showed a greater understanding of their loved ones. They were cognizant of the psychological effects of not sharing items within the household.

…at the hospital, they told us that my husband should not share my spoon or share a cup or anything with me. However, my husband refused; he said he did not want what they said would affect me (female participant, 42 years old, FGD 2).

Discussion

This study provides insight into the experiences of PwDR-TB at healthcare facilities. Health professionals hold a privileged position to shape society's perspective on any disease, owing to their specialised knowledge and social authority. Therefore, any human differences labelled by health professionals are accepted by society [18]. In some African countries, the practices and attitudes of HCWs are associated with stigmatisation. HCWs blame and impose restrictive practices that promote stigma. For example, in Ghana, HCWs impose that relatives are not allowed to see the PLWTB, shout at patients, run away when patients approach them and prohibit burial rites for people who die of TB [2,11]. In South Africa, poor attitudes toward providing grants, information, or treatment for TB have contributed to stigmatisation [18]. In Ethiopia, private providers are preferred over public TB healthcare providers because of the associated stigma [19].

This study highlights the struggles and challenges faced by PwDR-TB at healthcare facilities in Lagos, Nigeria. They were exposed to a system that labelled them as different and dangerous. They had to cope with the demeaning attitudes and behaviours of HCWs. These experiences were previously documented [20,21]. All the participants echoed that their greatest stigma challenge was at the healthcare facility. Many of the participants lamented the treatment they received from some HCWs. One participant described the treatment at the healthcare facility as worse than the symptoms of DR-TB. They craved acceptance, understanding, and empathy from the HCWs. We previously reported that social support reduced the effects of stigma on anxiety, loneliness, and depression among PwDR-TB in Lagos [17]. Getting the needed support from HCWs will significantly reduce the burden of DR-TB treatment. Studies have shown that HCWs working in DR-TB wards are hostile to patients because of the fear of infection [22-24], poor workplace infection prevention and control practices [24,25], lack of knowledge of infection control (IC) guidelines [22,25] and lack confidence in the facility's ability to provide DR-TB care [22].

There is a paucity of TB stigma reduction intervention programs. A study indicated that training HCWs in IC and enhancing administrative and operational IC standards could help reduce barriers to implementing IC but not the fear of infection [26]. The provision of infrastructure for sustainability must support the training of HCWs. This will reduce the stigma faced by HCWs working with PLWTB, experienced from colleagues not working with PLWTB.

There is a need for continual mentoring and supportive supervision. This is essential to HCWs' confidence in providing DR-TB care [22]. Faith-based interventions that have improved the quality of life among people living with HIV/AIDS and financial aid could strengthen PwDR- TB resilience to stigma [27].

There was a risk of self-selection bias common to focus groups because people with strong opinions or those who have been mistreated by HCWs are more likely to participate to express their displeasure at the HCWs' attitudes. We did not recruit participants on DR-TB treatment for less than three months; we therefore lacked information on their experiences. This is a qualitative study, and the information provided by participants may be affected by recall bias. The interviews took place at the health facilities where

participants were receiving treatment. This has the potential for social desirability bias because participants were aware that some answers are more socially acceptable than others based on the situations, which might have influenced the discussions.

In conclusion, this study helps elucidate the stigma experienced by PwDR-TB in healthcare facilities. This study also shows that TB-related stigma could be significantly reduced if healthcare-associated stigma is minimised. To address stigma, there is a need for patient education and a support structure to build resilience and empower patients as they navigate the disease. Nigeria can learn from Ethiopia and Nicaragua, where small groups of patients often meet to support one another throughout the treatment period [28]. This will help reduce the social isolation that patients typically experience. There is a need for community engagement, which provides an enabling environment for PLWTB to share their experiences and advocate for changes in social norms that reinforce stigma. Additionally, there is a need to train HCWs to engage PLWTB and their families, provide the necessary infrastructure to optimise IC in healthcare facilities and offer supportive supervision and mentoring to HCWs. There is a need for stigma reduction intervention research in Nigeria and learning from other settings that have achieved relative success.

Abbreviations:

DR-TB	Drug-resistant tuberculosis
FGDs	Focus Group Discussions
HCWs	Healthcare workers
Human immune deficiency syndrome/ Acquired Immune deficiency syndrome	
IC	Infection control
LCDAs	Local Council Development Areas
LGAs	Local Government Areas
PLWTB	People living with tuberculosis
TB	Tuberculosis
PwDR-TB	People with drug-resistant tuberculosis

Statements and declarations

Ethical approval: *This study was performed in accordance with the principles of the Declaration of Helsinki. Approval was granted by the* Health Research and Ethics Committee of the Lagos State University Teaching Hospital (LREC/06/10/2179) and the Institutional Research Ethics Committee of Durban University of Technology, South Africa (IREC 066/230). Gatekeepers' permission to interview participants was obtained from the Lagos State Ministry of Health and the medical directors of the DR-TB treatment centres where participants were recruited.

Informed consent: Written informed consent was obtained from all participants included in the study. The study's objectives were explained to the participants. They were also informed that participation or non-participation in the study would not affect the provision of healthcare services. In addition, they were told that they were free to withdraw their consent at any time during the study. The data were anonymised, and personal identifiers were not obtained.

Consent for publication: Not applicable.

Availability of data and materials: The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interest: The authors have no relevant financial or nonfinancial interests to disclose.

Funding: The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Authors' contributions: OAA conceived the study, analysed the data, and prepared the manuscript. OAA and FH were involved in the study design, literature search and coding of the transcripts. CJ, OD and FH were involved in interpreting the data and coding. FH, CJ and OD critically revised the manuscript for intellectual content. All the authors read and approved the final manuscript. OAA, FH and OD are guarantors of the manuscript.

Acknowledgements: The authors wish to acknowledge the Lagos State Ministry of Health and the Lagos State TB and Leprosy Control Programme for granting permission to conduct this study. We also acknowledge the assistance and support of the management of the DR-TB treatment centres where the study was conducted. Special thanks to Nnenna Karen Ihezie for working tirelessly while coding the transcripts.

Supplementary file

Focus Group Discussion Guide

Introduction: Good morning/afternoon. My name is Olusola, and I will interview you today. My colleagues and I are researching TB-related stigma, and we would like you to share your experience with us. I will start with some general questions, then I will go into more detail about your experiences as a MDR-TB patient. Before we begin, I would like to remind you how grateful we are for your time and that there are no wrong or right answers. This is a time for you to share your story and your knowledge. This interview

will be audio recorded. I want to reassure you that anything you say will be treated in confidence and that your name will not be on any documents related to the study. You can skip questions if you feel uncomfortable, or you can ask me to explain a question if it's unclear. Thank you for completing the consent form.

Key area of investigation	**Rationale**	**Themes**	**Example Questions**
WARM-UP **RAPPORT** **Basic background questions**	To learn the basic characteristics of the participants and start to make them feel comfortable	Income Education MDR-TB treatment months Age	Can you tell me a bit about yourself? ● What do you do for work? ● How are you feeling this day?
Daily life and social circle	To explore their household and social networks. This will be used to identify potential enacted stigma sources or treatment support networks later in the interview	Household Relationships Social activities	● Can you tell me about your home? Whom do you live with? ● How is your relationship with your partner? • How many children do you have? • What do you like to do for fun? With whom

Key area of investigation	Rationale	Themes	Example Questions
BACKSTORY	To identify if the DR-TB is primary or acquired	Diagnostic journey	• Can you tell me a bit about your TB story? How did you first get diagnosed? • What kinds of thoughts and feelings were foremost in your mind when you found out your TB was drug-resistant? • What have you learned about TB and TB treatment?
Health facility experiences and treatment	Problems with healthcare facilities can perpetuate stigma and deter patients from commencing or continuing with treatment. Some treatment side effects can cause anxiety and be depressing. This will help to differentiate internal stigma from treatment side effects	•How they started the treatment •Treatment adherence •Healthcare workers •Knowledge •Personable •Side-effects	• Why have you decided to get treated at this facility? • What do you think about the care being provided? • How is your relationship with the health care workers? • How do you think HCWs view MDR-TB patients? • How long have you been taking treatment? •How do the medications affect you? •How have these side effects affected your life? • Do you feel like the medications are working?

Key area of investigation	Rationale	Themes	Example Questions
Perceived Stigma (1)	This will give insight into the patient's interpretation of infection control policies/practices and identify the relationship between disclosure and stigma.	•Interpretation of infection control •Disclosure	• How does it feel to be at the facility? • How is the relationship between you and your caregivers at the facility? How did you expect the care to be, and how does it compare with the reality?
Experienced Stigma	This topic will explore how the people in their lives treat them regarding their diagnosis. This will be the first aspect of stigma to be discussed as it is more objective, and then the conversation can go into more depth into the	•Community members •Microaggressions •Friends •Family	• How has your social circle responded to your diagnosis and treatment? Are they aware? How have they engaged with you since they learned? How are the relationships? (Mmm, can you tell me more specifically what you've felt?) • Since you learned about TB, have you changed your social relationships? • Do people in your community know that you have MDR-TB? • Have you noticed anyone that you don't know very well treat you differently since your diagnosis? • Has your diagnosis impacted your relationship with your

Key area of investigation	Rationale	Themes	Example Questions
	participant's feelings.		family? Friends? Work colleagues? How?
Internalized Stigma	The area focuses on their feelings and the impact of the experienced stigma and MDR-TB has had on them. They may have experienced some forms of mental illness, such as anxiety or depression. It will also ask about possible things that helped them	From diagnosis (intrinsic) From experiences (extrinsic) Coping mechanisms Blame/shame Mental Illness	• How would you describe your general mood since you learned of your TB diagnosis? (probe: How so?…can you expand on that?) • How do you think this happened? • What about your partner/others? How do they think this happened? • How has the diagnosis affected you as a person? (probe: Can you give some examples?) • Has the experience of having TB changed the way that you think about yourself? (probe: Why do you think that?)
Perceived Stigma (2)	This is the second section of perceived stigma. It will focus on the potential self-imposed isolation due to perceived stigma.	Isolation Loss of Face	• How has MDR-TB affected you? • Do you still attend your normal social events? Why/why not? • Do you feel like you have lost confidence due to your illness? How do you think this happened?

Key area of investigation	Rationale	Themes	Example Questions
			• Have you ever tried to hide your symptoms? How did you do this?
Coping	This area will identify any coping mechanisms and also assess the participant's internal stigma by identifying 'hopelessness' which is a previously identifies feeling for MDR-TB patients	Coping Aspirations Hopes Plans	• When you think about your future, what do you see for the year ahead? • When you feel low, what kinds of messages or sources of strength do you draw on? (probe: Why do believe that these people, ideas, faith, etc. encourage you?) • Has there been anything in your life that has helped you to get through this difficult period in your life? • Do you have any plans for when you have completed treatment? Why/why not? • What would you like to happen next?/What do you think will happen?
Policy	This area is to identify priority areas of programmatic change	Expert advice	• What do you think would have made your MDR-TB treatment easier? • What advice or recommendations do you have for policymakers for improving the quality of TB treatment?

Key area of investigation	Rationale	Themes	Example Questions
Closing	Close on less emotive subjects- prepare them for follow-up.	Expressing gratitude for their time so far Final additions Express gratitude again	• We're nearly done, so thank you for your time in this interview. It has been really interesting and I have already learned a lot that will be very helpful for our study. • Is there anything else that you think I should know about or that you would like to share with me for this research?

Closing: Thank you for participating in this study. It's a privilege to hear your story. We appreciate you taking the time to discuss this sensitive and very important issue. This interview will be analyzed together with other interviews to gain an understanding of how stigma impacts MDR-TB patients, to be able to measure stigma and reduce stigma through improved MDR-TB services.

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Table 1: Background information of the participants in the focus groups

Groups	Number	Age range per group	Occupation (number)
FGD 1	6	19 – 45	Vulcaniser 1; Driver 2; Banker 1; Engineer 1; Barber 1
Male			
Female	4	20–38	Tailor 1; Hairstylist 2; Photographer 1;
FGD 2			
Male	4	20–52	Student 1; Artisan 1; Factory worker 1; Apprentice 1
Female	5	23 – 45	Trader 4, Business Owner 1.
FGD 3			
Male	5	18 – 53	Unemployed 2; Student 1; Footballer 1; Artisan 1.
Female	5	20–43	Civil servant 1, Trader 1, Tailor 1; Unemployed 2.
FGD 4			
Male	7	19 – 47	Student 2; Unemployed 2; Farmer 1; Plumber 1;
Female	5	18–48	Trader 2; Caterer 1; Unemployed 1; Hairstylist 1.
FGD 5			
Male	5	19 – 45	Factory worker 1; Bricklayer 1, Tailor 1, Business 2.
Female	7	21–43	Trader 2, Teacher 1; Photographer 1, Unemployed 3.

CHAPTER EIGHT

SUBMITTED MANUSCRIPT 2

The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study.

This chapter comprises a manuscript currently under review by BMC Research Notes. The manuscript is a qualitative study exploring the stigma experiences of PwDR-TB at home and in the community. It presented the reactions of participants to the diagnosis of DR-TB, the effects of having DR-TB, the stigma experiences of PwDR-TB at home and in the community, and how they coped with the challenges of DR-TB and the associated stigma. This chapter also addresses the fifth objective of this thesis. The format and references in this chapter are presented according to the journal's submission guidelines.

Manuscript title: The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study

Authors: Olusola Adedeji Adejumo, Olusoji Daniel, Firoza Haffejee, Champaklal Jinabhai,

Journal: Stigma and Health

Status: Under Review
Manuscript number: SH-2025-0105

Date of submission: 1st May, 2025.

The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study

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Abstract

Background: Tuberculosis-related stigma is a social determinant of health that can significantly undermine the tuberculosis response and negatively impact the lives and health of those who experience it. This study explores the stigma faced by individuals with drug-resistant tuberculosis in Lagos, Nigeria.

Methods: Five focus group discussions were conducted in five treatment centres involving 53 individuals (27 males and 26 females) receiving treatment for drug-resistant tuberculosis, and thematic analysis was conducted.

Results: The diagnosis of drug-resistant tuberculosis was received with shock, surprise and disappointment by participants, and many wondered how they contracted the disease. The physical changes resulting from the drug-resistant tuberculosis infection affected the self-esteem of many participants, which made them uncomfortable attending social functions. Some participants isolated themselves to avoid the discrimination that is associated with tuberculosis. Many participants complained about the isolatory practices at home, which almost cut them off from their families and disrupted the communal relationship that once existed in their families. Participants did not disclose their status to others to avoid stigma. Also, the social support from some friends and family and the faith for a better future, built some resilience against stigma.

Conclusion: To reduce stigma, interventions must be at the patient, family, community, and healthcare facility levels. Public health campaigns must emphasise tuberculosis treatment over transmission risk. Nigeria could learn from other settings that have achieved relative success in stigma reduction strategies.

Keywords: Stigma, drug-resistant tuberculosis, discrimination, Nigeria.

Clinical Impact Statement

This study unpacked the stigma experiences of people living with drug-resistant tuberculosis in Lagos, Nigeria. The diagnosis of resistant tuberculosis was received with shock and surprise by participants. The perception of stigma from the community was responsible for the non-disclosure of their status to family and friends. The isolatory practices at home and in the community caused some emotional distress to participants. How people with tuberculosis are treated in the community and elsewhere can affect the timing, location and quality of care. It could undermine TB screening efforts within the community, hence threatening global tuberculosis control.

Introduction

Stigma is a human rights-related barrier to undermining global tuberculosis (TB) control. The World Health Organization (WHO) defines stigma as a mark of dishonour, discrediting or humiliation resulting in rejection and exclusion of an individual from community participation (WHO, 2022). TB-related stigma is characterised by unfavourable social discrimination, which may be perceived, anticipated, or experienced by people with TB (PWTB) (Daftary *et al*., 2018; Teo *et al*., 2020). It could be experienced at home, the workplace, the community, and health facilities (Kapyolo *et al*., 2023). Stigma seriously undermines the TB response and could hurt the lives and health of those who experience it. Fear of losing one's work, relationships, house, school or other forms of discrimination due to TB makes people less likely to get tested and treated, which exacerbates an already challenging prognosis (Ashaba *et al*., 2021; Kamble *et al*., 2020). The fear of being discriminated against may make PWTB avoid taking precautions such as wearing masks in public, leading to the community spread of TB (Kamble *et al*., 2020).

TB-related stigma contributed to relationship difficulties, prolonged self-medication, health-seeking delays, non-disclosure of status and self-imposed isolation with the family and community, resulting in community transmission and poor health outcomes among PWTB in Ghana and Tanzania (Dodor, 2012; Miller *et al*., 2017). Another study reported that TB-related stigma played a vital role in the large number of pre-treatment losses to follow-up recorded in India (Thomas *et al*., 2020). The longer duration of treatment and prolonged isolation make TB-related stigma higher among people with drug-resistant TB (PwDR-TB) than those with drug-sensitive TB [10]. Studies among PwDR-TB showed that stigma was responsible for the extended isolation period beyond the period during which they were no longer infectious, discouraged treatment uptake and adherence (Redwood *et al*., 2022; Shringarpure *et al*., 2016).

TB is still a disease of public health concern in Nigeria because of the high burden of the disease in the country. The WHO estimated the TB incidence in Nigeria to be 219,219 (95% UI 143 – 311) per 100,000 population in 2023 (WHO, 2023). Of the estimated 492,743 people who fell ill with TB, 371,019 (75.3%) were notified (FMOH 2023). Also, of the 15,000 people estimated to develop drug-resistant TB (DR-TB) in

Nigeria in 2023, 2,975 (19.8%) were diagnosed (WHO, 2023). Nigeria is among the high-burden countries for TB, TB/HIV and DR-TB, and the country is among the eight countries accounting for more than two-thirds of the global TB burden (WHO, 2023).

Studies have shown that the high prevalence of TB-related stigma is a significant factor affecting TB control in Nigeria (Junaid *et al*., 2021; Oladele *et al*., 2020). A recent study reported TB-related stigma to be high at 65.5% among PwDR-TB (Adejumo *et al*., 2024). Therefore, TB control in Nigeria is crucial for achieving the global targets for TB control, which may be possible without addressing TB-related stigma in the country. Unfortunately, there is a scarcity of studies on TB-related stigma, especially among PwDR-TB in the country. The return on investment in the End TB strategy is to reduce TB incidence by 90% by 2035 (WHO, 2023). may not be realised until the structural, cultural and ideological basis for TB-related stigma is removed (Daftary *et al*., 2018). This present study, which was part of a larger study that assessed the moderating role of social support in the associations among experienced stigma, anxiety, depression and loneliness among PwDR-TB in Lagos, Nigeria (Adejumo *et al*., 2024), explored the stigma experiences of PwDR-TB in Lagos, Nigeria.

Methods

This study draws on qualitative data about stigma and related experiences from five focus group discussions (FGDs) conducted among PwDR-TB across five DR-TB treatment sites in Lagos, Nigeria, between February and December 2023. Lagos State is a country's metropolitan area with an estimated population of 21 million. Lagos State accounted for 22% of the country’s DR-TB notifications in 2019 (Adejumo *et al*., 2022). The study was approved by the Ethics Committees of Durban University of Technology, South Africa (IREC 066/230) and Lagos State University Teaching Hospital (LREC/06/10/2179). Administrative approval to interview PwDR-TB attending the health facilities was obtained from the Lagos State Ministry of Health and the Medical Directors of the selected facilities.

The participants who took part in the survey were purposively invited to participate in the FGDs (Adejumo *et al*., 2024). Five DR-TB treatment facilities were purposively selected due to their high outpatient attendance, diversity of patients, and geographical representation. The rationale for the study was explained to the selected

participants during the outpatient clinic. One FGD was conducted in each selected health facility, involving 53 participants (27 males and 26 females) between 18 and 53 years. Eligible participants were PwDR-TB diagnosed using the Xpert MTB/RIF assay who commenced DR-TB treatment at least three months prior to interview. FGD participants' details are shown in Table 1.

The focus group sessions were held at each selected health facility after the outpatient clinic and moderated by the first author. Each focus group was conducted in English and pidgin English and lasted 60-75 minutes. Between 9 and 12 participants took part in each focus group. Three trained research assistants recorded discussions on audio tapes, took notes, and transcribed audio tapes.

The topics covered during the FGD were based on the authors' working experience with the TB control program and their knowledge and literature. The topics explored the participants' reactions to DR-TB diagnosis, the consequences of having DR-TB, stigma experiences in the community and how they coped with the disease and stigma. Within 48 hours after data collection, two bilingual research assistants translated and transcribed the interviews in English using the recorded audio tapes and field notes. The transcripts were verified by the first author and another research assistant who did not participate in the initial transcription to ensure accurate transcription and preservation of participants' words. The whole team resolved conflicts in the interpretation of the interviews.

The content analysis method described by Creswell was used to analyse the data (Creswell, 2009). All co-authors read and reviewed the transcripts several times to get a general sense of the information obtained and reflected on the overall meaning. The transcripts were coded into topics, and similar topics were organised into themes. Five themes and nine subthemes were identified and organised in a codebook. The five themes identified are: experiences after diagnosis, effects of having DR-TB, stigma experiences in the community, coping measures and recommendations on stigma reduction. The coders discussed ensuring consistency in the meaning of codes and inter-rater reliability. Verbatim quotations were selected to represent repeated discussions and ideas.

Availability of data and materials: *T*he datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Results

The data are presented based on the themes identified, and the subthemes are highlighted under the themes

1. Reactions to DR-TB diagnosis

Being diagnosed with DR-TB was accompanied by negative emotions. All participants expressed various forms of emotions when they were diagnosed with DR-TB. Some were shocked, scared, devastated, ashamed, and terrified. A few cried for days, while some thought it was a death sentence.

…I was very sad and depressed; I lost hope when I discovered what was wrong with me; when I discovered that it was resistant TB, I had already lost hope; I thought it was finished… (Male participant, 33 years old, FGD 1).

…the first time I was diagnosed with TB, I was shocked and terrified because it was something that had happened to somebody in my family; we could not prevent it on time and due to that, he died, so I was so scared, I cried... (Female participant, 32 years old, FGD 5).

Some participants were surprised by how they contracted DR-TB. They felt they could never contract the disease. Some questioned how they contracted the disease and thought of the likely source of the infection.

…I felt unhappy because I did not know how I contracted the disease. I felt so sad… (Male participant, 25 years old, FGD 1).

… I felt very sad because I used to hear about it, but I never knew I would come in contact with it, maybe it was in the office or the house, I do not know how I came about having TB…(Female participant, 32 years old, FGD 3).

Some participants who were previously treated for TB were disappointed and ashamed of having to go through the treatment again. For some, it was the previous stigma experience that worried them. One of the participants was concerned about how it would impact her children and how her colleagues would perceive her.

…so when I was informed that I had resistant TB, I was destabilised and devastated. I wept, but the people around me did not know why I was weeping. I asked myself, will I go through this same stigmatisation again? Now that I am an adult working, how

would my children be treated? How would my colleagues in the office react to me? That was what played back to me; it was terrifying… (Female participant, 40 years old, FGD 3).

The news had such a profound impact that it nearly led one of the participants to be involved in an accident.

…when I went there after 3 months, they said I had TB again; I was so disappointed, I was ashamed of myself, and how would I retake this drug? That day, I was almost hit by a vehicle. I cried for 2 weeks, I could not eat, I was ashamed, and I hid it from people; only my husband knows… (Female participant, 46 years old, FGD 4).

2. Effects of having DR-TB.

The consequences of DR-TB infection identified in this study are: loss of self-esteem, change in physical appearance and delay of academic and career pursuits.

Loss of self-esteem

Participants' physical appearance and symptoms resulted in a loss of self-esteem. Many participants lost confidence and felt uncomfortable when friends and neighbours inquired about their health status.

…I don't have confidence or self-esteem. I have seen the mirror in the way I look. I love taking pictures and going out frequently, so I saw how I was. Some people ask me what kind of sickness is wrong with me. I knew something was wrong, so I have not attended parties since then… (Female participant, 29 years old, FGD 1).

…my self-confidence is gone. I am not proud of my appearance, which affects my self-esteem. I have low self-esteem… (Female participant, 39 years old, FGD 4).

Change in physical appearance.

Having DR-TB comes with many consequences. TB-associated weight loss changed the physical appearance of many participants. The changes in their physical appearance and the negative attitudes of others affected their interactions with them. This caused many participants to self-impose isolation, keeping them away from friends, family, and social functions.

…my circle of friends have reduced. I do not want to see them because I have seen how I look. I looked in the mirror and discovered that I had changed a lot. I already know something is wrong; I do not look good at all… (Male participant, 42 years old, FGD 2).

They also avoided gatherings, including events that they were invited to, due to their poor physical appearance.

…I don't go out to parties or any gatherings because people will ask why I have lost so much weight… (Male participant, 42 years old, FGD 5).

Another participant reiterated,

…I was very lean. I also noticed that my skin is darker. I am not okay. When we have a family function, and I am called, I try to avoid it. I do not want to go because I will not be happy with myself if I see others, especially my younger ones, and how they look… (Female participant, 38 years old, FGD 1).

The change in physical appearance and persistent cough forced some participants to quit their jobs. They described the situation as embarrassing each time they went out to work. They do not feel comfortable whenever they are at any gathering because their cough will attract the attention of others.

…I am a photographer. My job requires me to stand among a large number of people. When I talk, the air gets into my mouth, which makes me cough. I cannot be coughing among people, so I am not always interested in going out and working. I do not feel okay among people…(Female participant, 27 years old, FGD5).

…I am a musical artist and can't sing because of the cough, but they told us we can't spit out. I can't do all those things I used to do before because of that…(Male Participant, 33 years old, FGD 4).

Delay of academic and career pursuits

DR-TB temporarily halted some participants' academic and career pursuits. Some could not continue their career because of weakness, lack of stamina and inability to be up-to-date with events.

…the only thing I lost was a university admission. During the time of the sickness, because I wasn't able to know what was wrong with me and start treatment on time, I

wasn't able to follow up with my admission. I missed the screening date by one week because I was so weak, and by the time I was able to put on my phone to check, I found that I had lost it…(Male Participant, 22 years old, FGD 4).

…I told you that I used to play football, and I disqualified myself from screening. Yes, because I told you I breathe fast. Furthermore, I can't play for 30 minutes. I disqualified myself because I don't have stamina… (Male participant, 19 years old, FGD 3).

3. Stigma experiences.

Participants encountered stigma in the family and within the community

Isolation within the family

Many participants endured some emotional problems because of the stigma attached to the disease. Participants recounted the negative attitudes and segregation within family and household contacts because of the fear of infection. Participants could no longer share a room and other items they previously shared with family members. These isolatory practices at home hindered the intimacy between couples.

…at home, there is segregation, and I always feel bad, and it makes me sad. My husband doesn't know it. He says we can't share the same room, plate, or even sleep on the same bed because of the health worker's advice, which breaks my heart… (Female participants, 42 years old, FGD 3).

…before my illness, I ate together with my mother. However, since I was diagnosed with TB, she does not want to get close to me again; I can't share anything with my brothers, and my mother will say they should not eat it. I sleep in a separate room, and no one shares a plate, spoon or cup with me… (Female participant, 19 years old, FGD 4).

…I became lonely. Even my wife now stays away from me. We were sleeping in the same room, but now she is far from me…(Male participant, 45 years old, FGD 1).

The fear of infection led to the separation between mother and child. One participant said her child was forcefully taken away from her by her father to prevent infection.

…after completing 6 months, I was told that the treatment failed, and I now have resistant TB, and I was referred here for treatment. When I got home, my father's family took my 7-year-old son away. I am a widow. I have a separate cup, plate and

spoon for food. All my younger ones ran away from me…(Female participant, 38 years old, FGD 1).

Participants sometimes initiated isolation because they didn't want to infect others. They put restrictions on how other family members relate to them.

…the reason I said I excluded myself from everybody because I don't want to associate myself. I don't want the people living in my house to come to my room or touch my things. I don't want to have any issues, and I don't want to infect them…(Female participant, 35 years old, FGD 2).

Isolation from the community

Friends in the neighbourhood also exhibited negative attitudes towards the participants. The participants reported that some friends stopped visiting them after they became aware of their health status. Participants complained that some friends do not want them to visit or stay long in their company because of the fear of infection.

…when my neighbour found out that I have TB, she refused for me to come to her house. If I go to her house, she will run out and say we should stay outside, even when I wear my face mask. She will not want me to stay in her house. I felt bad. This affected our relationship. I don't go to her house again. Moreover, she made me feel like not visiting somebody. I used to visit my neighbours' or friends' houses, but now I don't do that anymore… (Female participants, 26 years old, FGD 1).

…after this incident happened to me, my friends reduced. They ran because whenever they saw me wearing a face mask, they would ask what had happened to me. I said I was treating a cough, but they believed something was wrong with me whenever they saw me with a face mask… (Male participant, 27 years old, FGD 3).

4. Coping strategies

Participants deployed non-disclosure of status to people who may discriminate against them, faith in the effectiveness of the medication and a better future, and the social support received from family and friends as coping strategies against stigma.

Non-disclosure of status

Many participants did not disclose their symptoms to people they believed might discriminate against them in the community. They also reported hiding their health

status from people as much as possible. Some thought it was best to keep their health status away from their friends to avoid discrimination.

…I didn't tell anybody about my condition; I changed my routine, I don't stay around people, I don't invite people to my house… (Female participant, 28 years old, FGD 2).

Participants expressed a fear of others gossiping about their illness. This also prevented disclosure.

…if we tell people, they will run away from us, and gossip about our condition…(Male participant, 41 years old, FGD 3).

…I did not disclose it to anybody; my family and friends don't know I have TB. This is because TB has the same stigma as leprosy; my story will spread everywhere…(Female participant, 35 years old, FGD 4)

Faith in medication effectiveness

PwDR-TB faced many challenges ranging from the shock of the diagnosis, the associated social stigma, the side effects of the drugs and the cost of treatment. Despite all these challenges, they found a way to cope and persevere with these perplexing situations. The hope for a cure due to the medication built resilience in some participants, which empowered them to endure any situation they encountered.

…I noticed some improvement in my body when I started taking the medications. Since I got here, my health has improved…(Male participants, 34 years old, FGD 1).

…the medications helped me a lot. I noticed changes in my body, which gave me hope… (Female participant, 25 years old, FGD 1).

Faith in a better future

Some participants hoped for a better future. They were convinced that their health would improve and that they would recover completely. Such faith kept them going despite all the challenges they encountered.

…I can cope because of the faith that all will be well. I believe that after 6 months, everything will work…(Female participant, 39 years old, FGD 5).

…I believe that what does not kill me makes me stronger. When it didn't kill me, life continued, and since I am not dead right now, I believe I am going to overcome this…(Male participant, 42 years old, FGD 4).

Social support from family and friends

The participants appreciated the social support from friends, family and health workers. This was leveraged to provide the resilience needed to cope with the challenges of the DR-TB treatment and its associated stigma. Participants appreciated the emotional, financial, and other social support from family members and friends.

… some people where I was trading felt I was feeling fine; they didn't know what was wrong with me; they brought some food items to my house and also gave me some money…(Female participant, 33 years old, FGD 3)

5. Stigma reduction recommendations from participants

Participants suggested public enlightenment and awareness about TB that will highlight the signs and symptoms of TB and information about where to access treatment as a strategy to reduce TB-related stigma

…There are some people that they did not know they have it, and some people have it but don't know what to do they need more enlightenment on this so that when you have TB or you are coughing too much, you can go to the hospital and check because some people only know that coughing is only coughing out blood…(Male participant, 22 years old, FGD 4)

They felt that education by the government would assist in providing the required information, which could lead to people seeking medical assistance if they experienced any symptoms. Such governmental education would also reduce stigma.

…I think for the government to reduce the stigma, they will need to enlighten people that there is a cure for TB. I believe many people will come forward and enlighten others: if I have been taking cough syrup for six months and my cough persists, let me run a test…(Female participant, 28 years old, FGD 2).

Discussion

This study provided perspectives on the effects of DR-TB diagnosis, the burden of DR-TB disease, the stigma experiences and how PwDR-TB cope with the disease and its stigma. Qualitative findings are not easily generalisable. However, this study is helpful

given the paucity of contextualised data on the stigma experiences of PwDR-TB in Lagos, Nigeria and the global need to deal with stigma to achieve global TB control.

This study shows that PwDR-TB are aware of the sociocultural dimensions, community perceptions and the shame associated with TB. Their reactions exemplified this after being diagnosed with DR-TB. Our findings revealed that participants showed feelings of regret, shock, anxiety and disappointment after DR-TB diagnosis because of a wrong perception of curability, the trauma of treatment and the stigma attached to the disease. Research results from Indonesia and Ethiopia reported that community TB-related stigma caused painful feelings of shame, anxiety and helplessness for PWTB (Nasir *et al*., 2024; Assefa *et al*., 2023).

We have previously reported on the high prevalence of TB-related stigma and that stigma imparts anxiety, depression and loneliness among PwDr-TB in Lagos, Nigeria (Adejumo *et al*., 2024; Adejumo *et al*., 2025). This qualitative study helps to contextualise the experiences of stigma and the coping strategies adopted by PwDR-TB in Lagos, Nigeria. Some participants in our study lost hope of survival because of past experiences of loved ones who died from the disease, and some kept the diagnosis secret to avoid the stigma and protect their family from possible stigma. This confirmed their awareness of the community's perception of TB and was a significant source of anguish for them. Our findings are similar to those reported in other settings. A study from Uganda showed that 30% of PWTB did not disclose their status to family members, while 65% of PWTB in a South African study did not disclose their status to non-family members (Nyangoma *et al*., 2020; Bond *et al*., 2017). In South Africa, India and Croatia, PWTB avoid disclosing status due to fear of stigma and the adverse effects on their reputation or marriage prospects (Cramm and Nieboer, 2011., Shringarpure *et al*., 2016; Jurcev-Savicevic´, 2011).

Isolation among participants was either self-imposed or imposed by the family or community. The drivers of self-isolation are multidimensional and interconnected. Our study demonstrated that participants self-isolate because they feared reputation loss due to their poor physical appearance, fear of being stigmatised, and fear of infecting others. TB is usually associated with profound weight loss, similar to HIV/AIDS. Community members often associate TB with HIV/AIDS due to the weight loss

common to both. This link between the two diseases altered the community's perception of TB, thus exacerbating the TB-related stigma (Bond & Nyablade, 2006).

In our study, many participants were advised not to share cutlery or sleep in the same room as other family members, a recommendation similar to those from Vietnam and Ghana (Redwood *et al*., 2022; Dodor *et al*., 2009). Our study participants expressed dissatisfaction with the self-isolation practices. Many expressed emotional and psychological pain because of self-isolation at home and in the community. Many felt depressed, lonely, and ostracised. Couples could no longer share the same room, and sometimes, mothers could not play with their children. A qualitative study reported the psychological burden imposed by societal stigma on PWTB, which affects their emotional state and prevents them from social interactions (Nasir *et al*., 2024).

Our study participants drew strength and resilience from the social support of family and friends (when this was given), their faith, and the hope for a better future. We previously showed that social support exerted a protective effect against stigma and improved the health-related quality of life of PwDR-TB (Adejumo *et al*., 2024; Adejumo *et al*., 2025). There is a paucity of TB stigma reduction intervention programs to leverage, but the government needs to do more than the awareness creation suggested by participants in this study; there is a need for more research that is patient-centred and culturally sensitive. Faith-based interventions that have improved the quality of life among people living with HIV/AIDS and financial aid could strengthen PwDR-TB resilience to stigma (Daftary *et al*., 2021).

Since our identities as authors may influence their approach to science and interpretation of findings, they wish to provide our audience with information about our background. Regarding gender, one of the authors identified as a woman and three others as men. Regarding race, all the authors are Africans: two South Africans and two Nigerians. Two authors are from the country where the research was done and have worked with the state TB program for about 20 years. One of the authors works in a health facility where people with drug-resistant TB are managed.

In conclusion, this study has helped to elucidate the burden of DR-TB and the stigma experienced by PwDR-TB in the family and community. Stigma reduction strategies are needed at the patient, family, community, and health system levels. Active involvement of PWTB in treatment decisions, treatment initiation, and monitoring will

buffer against self-stigma (Nafradi *et al*., 2017). The TB program can learn from the differentiated service delivery model used in human immunodeficiency virus (HIV) programs, which, when applied, will show that PWTB are logical and normal (Demissie *et al*., 2003). There is also a need to counsel patients on problem-solving and emotional skills, and offer financial support, which renders them less vulnerable to stigma (Wingfield *et al*., 2015). At the community level, raising community awareness through culturally sensitive and scientifically sound media messages to prevent gossip, neglect, and social exclusion. Public health campaigns must emphasise TB treatment's efficacy over transmission risk (Daftary *et al*., 2018). At the facility level, healthcare professionals' training should include empathy, concern, respect for the patient, and cultural sensitivity. They should empower patients, uphold their rights and prevent deductive disclosure of patient status (Wingfield *et al*., 2015). Lastly, there is a need for stigma reduction intervention research, and Nigeria could learn from other settings that have achieved relative success in TB-related stigma reduction strategies.

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Table 1: Socio-demographic details of participants in the focus group discussions

FGD	Gender	Number	Age range per group	Occupation (number)
FGD 1	Male	6	19 – 45	Vulcanizer 1; Driver 2; Banker 1; Engineer 1; Barber 1
	Female	4	20 – 38	Tailor 1; Hairstylist 2; Photographer 1
FGD 2	Male	4	20 – 52	Student 1; Artisan 1; Factory worker 1; Apprentice 1
	Female	5	23 – 45	Trader 4, Business Owner 1.
FGD 3	Male	5	18 – 53	Unemployed 2; Student 1; Footballer 1; Artisan 1.
	Female	5	20 – 43	Civil servant 1, Trader 1, Tailor 1; Unemployed 2
FGD 4	Male	7	19 – 47	Student 2; Unemployed 2; Farmer 1; Plumber 1
	Female	5	18 – 48	Trader 2; Caterer 1; Unemployed 1; Hairstylist 1
FGD 5	Male	5	19 – 45	Factory worker 1; Bricklayer 1, Tailor 1; Business 2
	Female	7	21 – 43	Trader 2, Teacher 1; Photographer 1; Unemployed 3

CHAPTER NINE

DISCUSSION, RECOMMENDATIONS, AND CONCLUSIONS

This study assessed the effects and modifiers of experienced stigma among PwDR-TB tuberculosis in Lagos, Nigeria. Being male, unemployment, substance abuse and the duration of DR-TB diagnosis were associated with elevated stigma. The prevalence of anxiety, loneliness, and depression was high among PwDR-TB. TB-related stigma was positively associated with anxiety, depression, and loneliness; however, social support had the opposite effect on anxiety, depression, and loneliness. Social support reduced the effects of stigma on anxiety, depression, and loneliness. The overall HRQoL of PwDR-TB was poor. Participants who were male, single, with higher education, and HIV-negative had higher HRQoL than their counterparts. Stigma was negatively associated with HRQoL, while social support positively affected HRQoL. Social support contributed more to predicting HRQoL than did stigma.

The prevalence of adherence was low among PwDR-TB. Adherence was positively associated with social support, resilience, and temporal discounting, while negatively associated with stigma. Temporal discounting and resilience were negatively correlated with stigma. Results from qualitative studies showed that participants received the diagnosis of DR-TB with disappointment and shock because of the associated stigma. They reported experiencing stigma at home, in the community, and healthcare facilities. Participants did not disclose their status to many people, ended some relationships and avoided social functions to avoid stigma. Resilience against stigma was built through their faith for a better future, and social support was received from some friends and family.

The prevalence of TB-related stigma varies across diverse cultural settings. Chapter three of this thesis reports that 65.5% of study participants experienced TB-related stigma, which is higher than the 18% reported among people with drug-sensitive TB in Lagos by Abioye *et al.* (2011). However, this finding is similar to the 69.3% and 50.6% prevalence obtained among drug-sensitive TB patients in India (Baskaran *et al.,* 2023; Shah *et al.,* 2020). Studies from other high-burden TB countries like Ethiopia, Thailand and Afghanistan reported a high prevalence of TB-related stigma of 57.1%, 63.3% and 88.3%, respectively (Mohammedhussein *et al.,* 2020; McArthur *et al.,* 2016; Van Rie *et al.,* 2008). Some studies reported low prevalence (between 20.6%

and 26%) of TB-related stigma among people with drug-sensitive TB (Stanikzai *et al.,* 2024; Kapyolo *et al.,* 2023; Machavariani *et al.,* 2023). The tools used to assess TB-related stigma, cultural setting, the type of TB, and sampling variation may be responsible for the observed differences. A systematic review reported a higher prevalence of stigma among PWDR-TB compared to those with drug-sensitive TB (Baskaran *et al.,* 2022). As shown in chapters seven and eight of this thesis, stigma is experienced in the community and health care settings, where participants complained about discrimination within the family, community, and healthcare facilities. The study participants expressed dissatisfaction with the self-isolation practices. Most expressed emotional and psychological pain because of self-isolation at home and in the community. Many felt depressed, lonely, and ostracised. Couples could no longer share the same room, and sometimes, mothers could not play with their children.

… before my illness, I ate together with my mother. But since I was diagnosed with TB, she does not want to get close to me again; I can't share anything with my brothers, and my mother will say they should not eat it. I sleep in a separate room, and no one shares a plate, spoon, or cup with me (Female participant, 19 years old, FGD 4).

At the healthcare facilities, participants were exposed to a system that labelled them as different and dangerous. They had to cope with the poor attitudes of the healthcare workers, which they described as rude and demeaning.

… on my first visit here, I felt like the whole world was against me; the nurse made me think I was different, that there was something wrong with me, and she did not want me to come close to her. I don't want to come here if I can buy the medication elsewhere, I won't come here… (Female, participant, 38 years old, FGD 2)

Similar TB-related stigma has been reported among family members, neighbours and healthcare workers in Zambia, South Africa, India, Kenya, and Ghana (Thomas *et al.,* 2016; Mason *et al.,* 2015; Nyblade *et al.,* 2019; Somma *et al.,* 2008; Thomas *et al.,* 2021). In Tanzania, 50% of TB-related stigma was from the family, while the community and workplace contributed to 36% and 10%, respectively (Stanikzai *et al.,* 2024). Two-thirds of community members in a Nigerian study showed no desire to help or employ PWTB (Dodor *et al.,* 2009).

Being male, having a longer duration of DR-TB diagnosis, unemployment and substance use were associated with TB-related stigma as indicated in chapter

t hree of the experienced stigma paper. Previous studies have also reported that customs and norms mediate the gender differences in the effects of TB-related stigma (Junaid *et al.,* 2021).

In chapter three, we report that men have a 2.5-fold higher chance of experiencing TB-related stigma than women. The finding may be due to the gender role of men as breadwinners. Traditionally, as breadwinners, men are expected to provide for their families; hence, they may feel inadequate when this role is compromised (Chikovore *et al.,* 2015; Akanle *et al.,* 2020). The threats to their survival may be exacerbated as many have stopped working due to physical reasons, further worsening their financial distress (Chen *et al.,* 2021a). On the other hand, Somma *et al.* (2008) suggested that the cultural beliefs about TB could reinforce stigma among women because they have better health-seeking and treatment-adherence behaviours than men. In contrast, other studies reported a higher prevalence of TB-related stigma among women. The effects of TB-related stigma vary between men and women (Miller *et al.,* 2017; Chen *et al.,* 2021a). Among women, it often results in complex marital relationships and doubts about their integrity from the community; in contrast, male TB-related stigma threatens their survival (Krishnan *et al.,* 2014). The link between stigma, cultural norms about gender roles, and the biological predisposition of men to develop TB may put men at a greater risk of suffering from TB-related stigma than women (Horton *et al.,* 2016).

In chapter three, an association is shown between the duration of DR-TB diagnosis and TB-related stigma, which is similar to a report from Ethiopia, where PwDR-TB diagnosed for longer than one month had a greater chance of experiencing TB-related stigma than those with a shorter duration of diagnosis (Mohammedhussein *et al.,* 2020). This may enhance the community spread of TB because the shame, guilt, social exclusion, and isolation that accompany TB-related stigma may hinder symptom disclosure and access to healthcare, hence, undermining community screening efforts (Courtwright and Turner, 2010; McArthur *et al.,* 2016).

There was no association between HIV-coinfection with DR-TB and TB-related stigma in chapter three, due to possible sample variation. This finding is contrary to studies from Ethiopia and Uganda, which reported higher stigma among people with HIV/AIDs and DR-TB co-infection (Ashaba *et al.,* 2021; Mohammedhussein *et al.,* 2020). HIV and TB are stigmatised diseases, and the combination of the two diseases may amplify the

effects of the stigma experienced (Kane *et al.,* 2019). There is an intricate relationship between TB and HIV. Both share similar symptoms, such as weight loss. Hence, PWTB are often perceived as having HIV/AIDS because of the clinical presentation. HIV is also a risk factor for the reactivation of dormant TB. (Junaid *et al.,* 2021). In some communities, promiscuity is associated with both TB and HIV/AIDS (Cremers *et al.,* 2015), hence contributing to the stigma associated with these diseases.

Environmental risk factors associated with poverty, such as indoor pollution, smoking, poor nutrition, overcrowding, and excessive alcohol consumption, have been linked with TB. There is epidemiological evidence showing that smoking is a risk factor for TB infection (Burusie *et al.,* 2020), TB progression and poor treatment outcomes. In chapter three, the use of cigarettes and alcohol was associated with TB-related stigma, similar to findings from Ethiopia and Nigeria (Mohammedhussein *et al.,* 2020; Abioye *et al.,* 2011). The use of substances such as alcohol and cigarettes was associated with TB in some South African and Indian societies; people who smoke cigarettes or consume excessive alcohol are assumed to be at risk of TB and are often blamed for spreading TB (Møller *et al.,* 2010; Atre *et al.,* 2004). In another study, Naidoo *et al.* (2009) reported that men with TB attributed the disease to habits such as alcohol consumption, smoking, and prostitution. Abstinence from alcohol and cigarettes was shown as the most crucial determinant of compliance with TB treatment in a South African study (Cramm and Nieboer, 2011).

Chapter four illustrated the association between stigma, anxiety, depression, and loneliness among PwDR-TB and the moderating role of social support. The prevalence of loneliness, depression, and anxiety was high. TB-related stigma was positively associated with anxiety, loneliness, and depression, while social support was negatively related to anxiety, loneliness, and depression. In chapter four, 63.1% of PwDR-TB reported depression, which is in keeping with the prevalence of 65.7% reported among PwDR-TB from China (Dan-ni *et al.,* 2024). A study from India reported a higher prevalence of 78.3% (Solanki *et al.*, 2024), and a systematic and meta-analysis review reported a lower prevalence of 53.2% PwDR-TB (Duko *et al.,* 2020). The differences in study tools, study designs, socioeconomic status of study populations, culture, and myths associated with TB may contribute to these variations in the prevalence of depression. Most study participants in chapter four are from the lower socio-economic class.

Depression is a common psychological distress among PWTB because of the disease's chronicity and its psycho-socioeconomic stressors (Dong *et al.,* 2020). The impact of depression is more significant among PwDR-TB than those with drug-sensitive TB. Studies have demonstrated a higher prevalence of depression among PwDR-TB compared to those with drug-sensitive TB, probably due to the longer duration of treatment, more pill burden, and more significant side effects of DR-TB medication (Solanki *et al.*, 2024; Duko *et al.,* 2020). Relatedly, the prevalence of depression reported in chapter four is higher than the reported 28%-48.6% among people with drug-sensitive TB from Nigeria (Amole *et al.,* 2020; Umar-Shittu *et al.,* 2019); 43.4% from Ethiopia (Duko *et al.,* 2015), 39.5% from India (Balaji *et al.,* 2013) and 61.1% from Cameroon (Kehbila *et al.,* 2016).

Similarly, in chapter four, the prevalence of anxiety was 72.9%, comparable to the rates of 80% and 86.3% reported in studies from India and Indonesia (Solanki *et al.,* 2024; Susanto *et al.,* 2023). Other studies among PwDR-TB and people with XDR-TB in India reported a lower prevalence of anxiety at 54% and 66% (Srinivasan *et al.,* 2021). Dan-ni *et al.* (2024) reported a prevalence of anxiety at 57.5% among PWDR-TB in China. Sampling variation may be responsible for these differences. The qualitative study reported in chapter eight corroborates the findings in chapter four. Many participants expressed feelings of shock, devastation, anxiety, and depression when they were diagnosed with DR-TB due to their awareness of the sociocultural dimensions, community perceptions, and the shame associated with TB. Agarwal and Sarthi (2020) corroborate this; they reiterated that TB diagnosis is accompanied by shock, anxiety, shame, disappointment, and elevated psychological stress.

……. I was very sad and depressed; I lost hope when I discovered what was wrong with me; when I discovered that it was resistant TB, I had already lost hope; I thought it was finished (Male participant, 33 years old, FGD 1).

Humans are social beings, and social interactions are needed for wellness. Loneliness could increase morbidity and reduce social support and treatment adherence (Leigh-Hunt *et al.,* 2017). In chapter four, loneliness was reported in 56.2% of participants, comparable with a report from Türkiye among people with drug-sensitive TB (Yilmaz and Dedeli, 2016). Infectious control measure requires physical isolation, usually for two weeks for drug-susceptible and one to three months for DR-TB treatment (Dharmadhikari *et al*., 2014). TB could cause depression and loneliness when the

isolation period is extended for a longer period by family and health workers (Alene *et al.,* 2018). In the absence of clinical advice, PWTB could be trapped in continual physical and social isolation (Petersen *et al.,* 2017). Redwood *et al.* (2022) reported that PwDR-TB in Vietnam practised isolation long after being non-infectious because of the fear of infecting others, which led to loneliness (Redwood *et al.,* 2022). Prolonged isolation, even after PWTB were not infectious, was perpetrated by health workers in a Ghanaian study, a practice copied by community members to stigmatise PWTB (Dodor *et al.,* 2009). The findings in chapters seven and eight also corroborated the loneliness experienced by PwDR-TB.

…I became lonely. Even my wife now stays away from me. We were sleeping in the same room, but now she is far from me. They (the health workers) advised us not to share anything (male participant, 45 years old, FGD 1).

TB-related stigma manifests in discriminatory behaviours such as denial of educational opportunities, fear of divorce, refusal of a marriage proposal, inability to get a job, loss of employment, inability to share eating utensils with family members, isolation within the family and ridicule within the community often resulting in loneliness, anxiety, and depression (Ashaba *et al.,* 2021; Chen *et al.,* 2021b; Petersen *et al.,* 2017). In chapter four, we report that a higher proportion of participants who experienced stigma had depression, anxiety, and loneliness. The qualitative studies in chapters seven and eight substantiated the possible reasons for these findings. The shame associated with TB and the stigma attached to the disease caused anxiety and depression in some participants. The poor physical appearance of some participants resulted in self-imposed isolation from family and friends, leading to loneliness. During the long course of DR-TB treatment, the physical and socioeconomic changes impose lifestyle modifications, which may result in low self-worth, low self-esteem, and depression (Morris *et al.,* 2013).

...my circle of friends have reduced. I do not want to see them because I have seen how I look. I looked in the mirror and discovered that I had changed a lot. I already know something is wrong; I do not look good (Male participant FGD 2).

Chapter Five illustrated the effects of stigma and social support on the HRQoL. Findings from the chapter revealed that the HRQoL of PwDR-TB was diminished, which is in keeping with the findings from other studies from China, Eritrea, and India, which

demonstrated poor HRQoL among PwDR- TB (Araia *et al.,* 2021; Wang *et al.,* 2024; Laxmeshwar *et al.,* 2019). Contrary to the finding in chapter five, another Nigerian study reported a higher HRQoL among PwDR-TB (Bamidele *et al.,* 2024). The tools used to assess HRQoL, sampling variation, differences in the social support received, especially from Implementing Partners, and the treatment duration of participants at recruitment could be responsible for the variations.

TB is one of the diseases that could significantly impact the HRQoL as it is influenced by patient, disease, and treatment factors due to the multi-drug therapy, medication side effects, social support, stigma, and complications (Dujaili *et al.,* 2015; Brown *et al.,* 2015). PWTB have lower HRQoL compared to the general population. However, HRQoL is higher among people with drug-sensitive TB than PwDR-TB because of the impact of the disease and its treatment on an individual's daily perception of physical, mental, and social well-being (Araia *et al.,* 2021; Ahmad *et al.,* 2016).

Stigma is one of the most critical factors affecting the HRQoL among PwDR-TB, explaining more than one-third of the variance in HRQoL in chapter five. The finding of a negative relationship between stigma and HRQoL is consistent with studies from China, India, Indonesia, and Singapore (Fuady *et al.,* 2024; Zhang *et al.,* 2020; Ow *et al.,* 2015; Kaur *et al.,* 2015). Kastien-Hilka *et al.* (2016), in their systematic review with a focus on South Africa, illustrated that psycho-social burdens such as stigma impact HRQoL more than clinical symptoms.

In chapter six, results indicated that 20.7% of participants had low treatment adherence, in alignment with the 20.6–25% low adherence rate reported in a systematic and meta-analysis review (Zegeye *et al.,* 2019). However, earlier studies from Nigeria showed adherence to DR-TB treatment to be 36% and 64.7% for community-based and hospital-based treatment, respectively (Adagba *et al.,* 2023). The different adherence assessment methods, treatment phase in which treatment adherence was evaluated (intensive or continuation), treatment regimen, sampling variation, and selection criteria could explain the differences in treatment adherence.

Treatment adherence is crucial to TB control. Non-adherence / sub-optimal adherence and inappropriate treatment are known causes of the development of DR-TB (Cadosch *et al.,* 2016). Treatment of DR-TB could be complex and daunting for PwDR-TB and their healthcare providers because of associated socio-economic and

behavioural factors in addition to managing the side effects of the medication (Dodor *et al.,* 2009; Deshmukh *et al.,* 2017). The average success rate of DR-TB treatment is poor at 63% when compared to 88% of drug-sensitive TB, which makes adherence very crucial in DR-TB management (Cox and Loveday, 2021).

An increase in stigma was associated with low adherence in chapter six. Qualitative studies from China and Ethiopia showed that stigma was responsible for non-adherence among PWTB (Du *et al*., 2020; Gebremariam *et al.,* 2010). Multiple attempts have been made, and various interventions implemented to improve treatment adherence among PWTB with varying success. These interventions include: directly observed treatment, video-observed therapy, reminders with short message service, tracers, incentives and enablers, and patient and health worker education (Alipanah *et al.,* 2018). The factors associated with non-adherence are complex, and identifying modifiable factors is crucial for effective intervention (Yan *et al.,* 2018). In addition to studies that reported the clinical characteristics and social support systems associated with treatment adherence in PWTB (DiMatteo, 2004; Tang *et al.,* 2015), social stigma has also been shown to negatively impact adherence among patients with infectious diseases, such as TB (Yan *et al.,* 2018). Though the provision of support systems to PWTB will improve medication adherence, the findings in chapter six imply that these measures could fail if there are no stigma-reduction interventions in place.

Chapters four, five, six, and eight illustrate the various effects of social support. In chapter four, the findings showed a negative relationship between social support and stigma. In addition, social support reduced the impact of stigma on anxiety, depression, and loneliness, which suggests that improving social support among PwDR-TB is essential in reducing the effects of stigma on anxiety, depression, and loneliness. The findings emphasise that the burden of psychological stress among PwDR-TB could be reduced with improved social support. These findings are in keeping with findings from Chinese studies, which demonstrate that the impact of the association between stigma versus anxiety and depression was reduced by social support (Qiu *et al.,* 2018; Wang *et al.,* 2022; Zhang *et al.,* 2023). Social support cushions the impact of adverse life events, enhancing self-confidence and life fulfilment (Deshmukh *et al.,* 2018). It enhances the ability to adapt to crises and reduces pressure on patients, thereby decreasing psychological distress (Qiu *et al.,* 2018). Social support refers to the care received from family, relatives, friends, and the

community (Li *et al.,* 2014). It can also indicate stigma when social support is inconsistent (Zarova *et al.,* 2018). Participants in chapter eight leveraged social support received from family and friends to withstand the socio-economic stress imposed by DR-TB disease.

… some people where I was trading felt I was feeling fine; they didn't know what was wrong with me; they brought some food items to my house and also gave me some money… (Female participant, 33 years old, FGD 3).

Chapter five highlighted the importance of social support in enhancing the HRQoL of PwDR- TB. Increased social support was associated with improved HRQoL of PwDR-TB. Zhang *et al.* (2020) and Faudy *et al.* (2024) demonstrated that HRQoL was high among PWTB, particularly those with higher levels of social support. With high social support, patients are more likely to access diagnostic and treatment services early in the disease course (Deshmukh *et al.,* 2018), experience less stigma and discrimination and have a better HRQoL (Kastien-Hilka *et al.,* 2016; Deshmukh *et al.,* 2018). Studies have demonstrated the positive effects of financial and emotional support from implementing partners, government agencies, healthcare providers and families on the HRQoL of PWDR-TB (Bamidele *et al.,* 2024; Laxmeshwar *et al.,* 2019).

Social support improved treatment adherence among PwDR-TB in chapter six, consistent with qualitative studies from Nigeria and Armenia. These studies showed that social support from friends, family, the healthcare system, and the community was crucial to medication adherence and a favourable treatment outcome (Adagba *et al.,* 2023; Grigoryan *et al.,* 2022). Systematic reviews and meta-analyses also demonstrate that social support is crucial for improving treatment loss-to-follow-up and adherence among PwDR-TB (Law *et al.,* 2019; Wen *et al.,* 2020).

The qualitative study in chapter eight substantiated the finding in chapter six. Participants in the FGD reported that the social support they received facilitated their treatment adherence.

… at the location where I collect my medication, a lady usually assists me in collecting my drugs; sometimes, if I do not have the money, she helps me with the transportation fare to the hospital… (Male participant, 35 years old, FGD 4).

PwDR-TB face multidimensional challenges which require a patient-centred approach. Resilience building is one of the patient-centred approaches not fully explored but

important in meeting these challenges (Nagarajan *et al.,* 2024). Chapter six revealed that resilience is associated with treatment adherence among PwDR-TB. The DR-TB medications are toxic and associated with many side effects. Adhering to the treatment regime will require significant effort and resilience from patients. Results from chapter eight elaborated that DR-TB medications make some participants feel weak and tired, despite the increased appetite.

…… I eat a lot whenever I take the medication; it also makes me feel very weak. It does not allow me to take care of my kids…. (Female participant, FGD 3).

Qualitative studies from Nigeria and Armenia demonstrated that having a sense of family responsibility, willpower, and determination to improve were key drivers of medication adherence among PwDR-TB (Adagba *et al.,* 2023; Grigoryan *et al.,* 2022). Nagarajan *et al.* (2024) linked medication adherence with resilience, illustrating that participatory care, self-adaptation, and self-efficacy, aided by support from caregivers and the health system, produced resilience among PwDR-TB in India (Nagarajan *et al.,* 2024). PwDR-TB often develop self-driven solutions and resilience to overcome the multi-dimensional challenges and consequences of DR-TB medications. There is a need for TB programs to adopt a resilience-building approach that leverages the strengths and vulnerabilities of PWTB and their communities (Cremers *et al.,* 2018).

Furthermore, chapter six demonstrated a positive correlation between resilience and stigma. Crowe *et al.* (2016) demonstrated the complex relationship between stigma and resilience. They opined that resilience caused less stigmatisation if it occurred first, but stigma could hinder resilience building in patients. The knowledge of this complex relationship can be leveraged by counsellors to assess whether the client is resilient or is overshadowed by stigmatisation (Crowe *et al.,* 2016). Resilience is protective against stigma and impacts the long-term outcomes of chronic diseases (Post *et al.,* 2021).

Temporal discounting refers to an individual's ability to value an expected future outcome more than the present reality (Bahrami and Borhani, 2023). In chapter six, PwDR-TB who hoped for a better health outcome in the future had better treatment adherence than those who valued present gratification. Temporal discounting contributed more to predicting adherence than stigma, resilience, and social support. This was further supported by the results in chapter eight, which showed that

participants demonstrated faith, resilience, and hope in a better future. This belief system was an anchor they held on to during DR-TB treatment.

... I believe that what does not kill me makes me stronger. When I am still alive, life continues, and since I am not dead right now, I believe I am going to overcome this. (Male participant, FGD 4).

The findings from chapter six align with those from a mixed-methods study in Nigeria and a qualitative study in Ethiopia, which emphasised that a future cure was the primary motivation for adherence among PwDR-TB (Adagba *et al.,* 2023; Sahile *et al.,* 2018). A systematic review reported that non-adherence to long-term treatment may arise from the inability to prioritise the future due to a preference for immediate gratification (Sapkota *et al.,* 2015). Resilience and temporal discounting are positively correlated in chapter six; however, further research is needed to determine if they are mutually exclusive.

This study employed a mixed-methods approach (explanatory sequential design). In this design, the quantitative data were collected and analysed first, before the qualitative data were collected. This approach was helpful in understanding and explaining the quantitative findings in this study. The quantitative studies highlighted in Chapters three to six emphasised the high prevalence of TB-related stigma among PwDR-TB. The psychological effects of TB-related stigma, such as anxiety, depression, and loneliness and the resultant adverse effects on the HRQoL and treatment adherence were highlighted. The FGDs (Chapters seven and eight) conducted showed that these psychological effects started at the diagnosis of DR-TB and were not primarily due to TB-related stigma, an indication of the internal response to the awareness of the magnitude of TB-related stigma in the community. The feeling of loneliness may be an interplay of TB-related stigma and the loss of self-esteem, most likely due to the poor physical appearance from the profound weight loss experienced by PwDR-TB. The study also highlighted that the HCWs perpetrated most of the TB-related stigma experienced by PwDR-TB, and this threatened treatment adherence. The role of a strong social support, resilience and temporal discounting in reducing the adverse effects of TB-related stigma and improving the HRQoL and treatment adherence among PwDR-TB was also supported by the FGDs conducted. In addition, the FGDs showed that PwDR-TB were able to minimise experiencing stigma by non-disclosure of their status to people whom they perceive may stigmatise

them. Figure 3 below shows the framework that captures the thesis's combined findings.

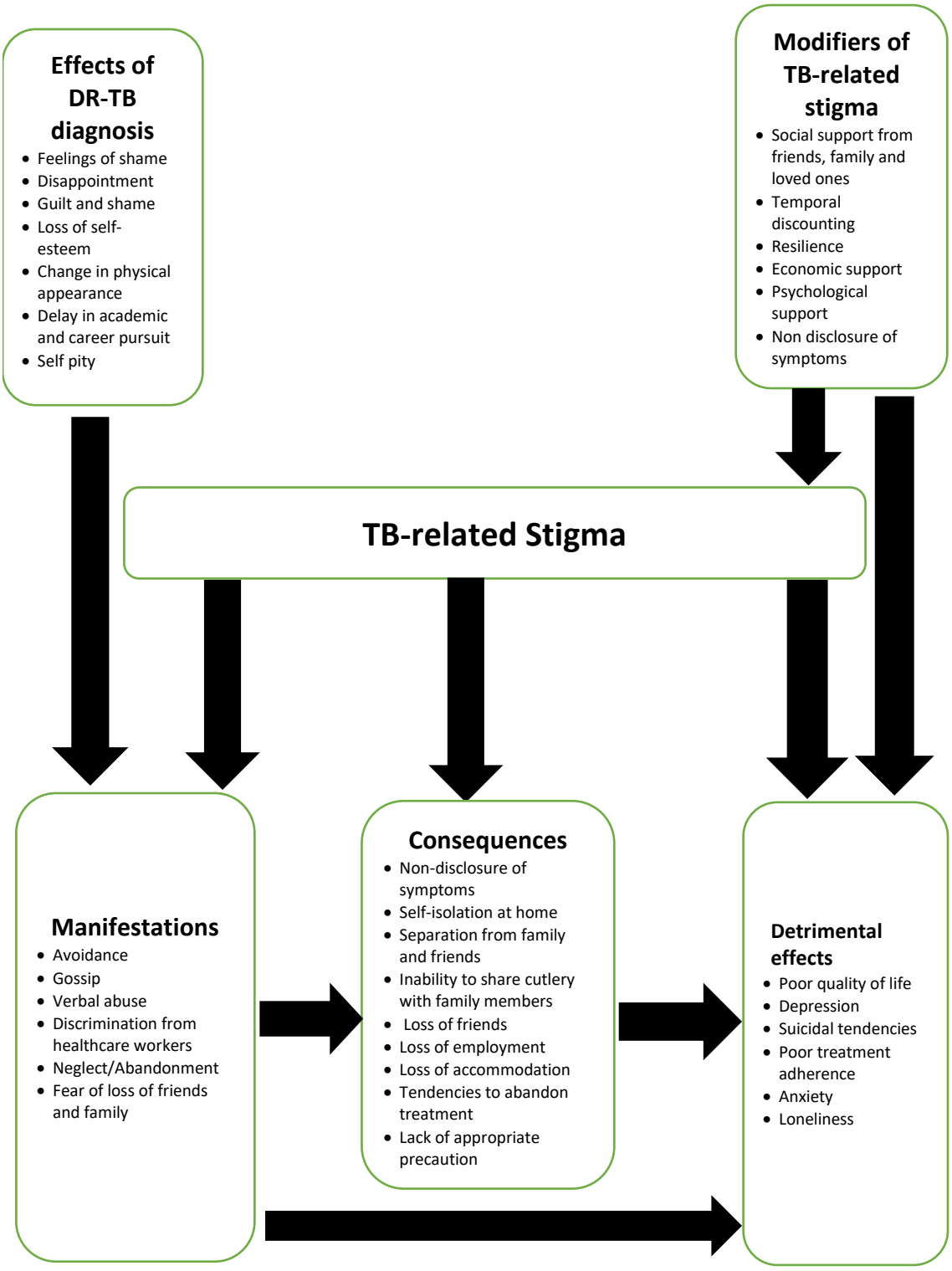

Figure 4: Framework showing the combined study findings

9.1 Strengths and limitations

9.2 Strengths

The study has contributed to knowledge. Firstly, PwDR-TB represent a unique study population among whom stigma is not well-researched in Nigeria. Secondly, this study has contributed to providing knowledge about the prevalence of TB-related stigma among PwDR-TB in Nigeria. This was previously a knowledge gap. Furthermore, some of the constructs measured in this study, such as resilience and temporal discounting, have not been previously assessed in Nigeria among PwDR-TB. The mixed-methods design of this study, specifically an explanatory sequential design, enabled quantitative data collection before the qualitative phase. It allowed for explaining the quantitative results and sometimes outliers entirely consistent with the quantitative data. Also, this study measured complex social and psychological constructs using previously validated scales pretested and adapted to the study population. The multi-centre data collection approach ensures geographical representation and diversity of patient demographics. Lastly, the multiplicity of constructs used in this study enabled the assessment of relationships between these constructs.

9.3 Limitations

The assessments of the constructs, stigma, anxiety, depression, loneliness, social support, resilience, health-related quality of life, and temporal discounting were self-reported. Hence, the possibility of recall bias, information bias, ascertainment bias and social desirability bias was high. To reduce recall bias, PwDR-TB who were still on treatment were recruited for the study, and gravely ill participants whose cognitive functions may have declined were not recruited. Secondly, the tools used to assess treatment adherence were dependent on the participant's ability to recall drug intake two weeks prior, which may have increased the tendency for recall bias. A more direct method of assessing adherence, such as measuring drugs and metabolites, would be a more accurate measure of adherence, but it was not within the scope of the study. Thirdly, the study findings may not be generalisable to the entire country because the number of PwDR-TB receiving treatment during data collection was not robust enough

to permit a probability sampling method. Therefore, a convenient sampling method was employed. A relatively large sample size and the multi-centre approach ensure geographical representation and diversity of patient demographics, which were used to reduce the effect of non-generalisability as much as possible. Also, the study participants may not represent all PwDR- TB because the very sick and those not undergoing treatment were excluded from the study. Lastly, the temporal association among the constructs could not be explored because of the study design. Cross-sectional studies are not used to determine temporal relationships.

9.4 Recommendations

TB-related stigma is high among PwDR-TB in Lagos, Nigeria. TB-related stigma needs to be addressed for effective TB control in Nigeria. PwDR-TB face extensive socio-economic and psychological challenges before and after diagnosis.

1. There is a need to address the cultural norms and misconceptions driving stigma. Minimising stigma at the family, institutional, and community levels will significantly contribute to reducing the psychological distress and other effects of stigma on PWTB. To achieve this, strong political will and the involvement of stakeholders at all levels will be required in a high-burden country like Nigeria. Public enlightenment and social mobilisation by the government will go a long way in correcting some erroneous TB beliefs.
2. The Lagos State TB, Leprosy, and Buruli Ulcer control program needs to evaluate and reengineer its social support structures to reduce psychological distress among PwDR-TB. Psychosocial support should be included as part of the care received by PwDR-TB and their families. This should consist of home visits and counselling of families of PwDR-TB.
3. The patients bear the hidden cost of TB treatment; providing free drugs may not be enough to alleviate the economic burden of TB treatment. The government should provide financial support for transportation costs and food to enhance medication adherence.
4. TB is a stigmatised disease of the poor. Strong social support will go a long way toward reducing social stigma and alleviating the economic burden of the disease.

5. The government must initiate policies that guarantee social protection for PwDR-TB. Policies protecting against workplace stigma are vital in safeguarding patients' jobs and promoting their reintegration into society after treatment.
6. Patient education and a support structure are needed to address stigma, build resilience, and empower patients as they navigate the disease. Support groups could be formed where PwDR-TB meet to share experiences and advocate for changes in social norms that reinforce stigma.
7. Healthcare workers should be trained to engage PwDR-TB and their families, provide the necessary infrastructure for infection control, and provide supportive supervision. They also need to feel safe when providing services to PwDR-TB.
8. Further research is needed. Patient-centred and culture-specific stigma interventions are needed because of the diversity in the cultural perspective underlying stigma in a multi-cultural and multi-ethnic setting like Nigeria. Findings from research to understand the myths and norms related to TB and stigma reduction strategies should be leveraged for effective intervention.

9.5 Conclusion

This study assessed the effects of experienced stigma of PwDR-TB in Lagos, Nigeria. The first objective of determining the prevalence of stigma experienced by PwDR-TB in Lagos, Nigeria, was achieved in chapter three. The prevalence of TB-related stigma among PwDR-TB was high at 65.5%. Being male, using substances such as alcohol and cigarettes, duration of DR-TB diagnosis, and not earning an income were associated with experiencing stigma among PwDR-TB.

The second objective was to determine the prevalence of loneliness, anxiety, depression, and adequate treatment adherence and their association with experienced stigma. This objective was addressed in chapters four and six. Anxiety, depression, and loneliness were reported by 72.9%, 63.1%, and 56.2%, respectively, while 20.7% had low adherence to DR-TB treatment. Experienced stigma was positively associated with depression, anxiety, and loneliness; in contrast, it was negatively correlated with adherence. The prevalence of anxiety, loneliness, and

depression was high among PwDR-TB, and the higher the stigma experienced by PwDR-TB, the more the effects on anxiety, depression, and loneliness, and the less the treatment adherence.

Chapter five addressed the third objective, which was to determine the association between experienced stigma and quality of life among PwDR-TB in Lagos, Nigeria. The overall HRQoL of PwDR-TB was poor. Being young, male, single, highly educated, and HIV-negative was associated with higher HRQoL. Stigma was negatively associated with HRQoL. Stigma reduction strategies are needed at all levels to improve the HRQoL of PwDR-TB.

Chapters four, five, six, and eight addressed the fourth objective: determining the association (if any) between the protective effect of social support, resilience, and temporal discounting on stigma among PwDR-TB in Lagos, Nigeria. In chapter three, social support reduces the effects of stigma associated with depression, anxiety, and loneliness. Chapter four indicated that higher social support improved the HRQoL of PwDR-TB, and in chapter six, the positive association between social support and treatment adherence was revealed. The qualitative study in chapter eight provided context for other studies included in this thesis. During the FGD, participants shared experiences of how social support from family, friends, and health workers served as a motivation to continue treatment despite the stigma experienced at home, in the community, and the healthcare facilities.

Chapter six addressed the protective effects of temporal discounting and resilience. Treatment adherence improved with increased resilience and temporal discounting, while the opposite effect of resilience and temporal discounting was present on stigma.

The qualitative studies in chapters seven and eight answered the fifth objective. Most participants in the FGD experienced stigma at home, in the community, and at health facilities. Participants expressed concern about the stigma experienced at the health facilities. Self-isolation and non-disclosure of status were used to cope with stigma from family and community. However, the participants needed social support, resilience, and temporal discounting to cope with the stigma at the healthcare facilities.

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APPENDICES

Appendix 1: General Questionnaire

Clients to be interviewed: DR-TB patients currently on treatment not less than eight weeks or completed treatment at most three months before data collection

1.	Name of Facility	
2.	Gender	Male=1, female= 2,
3.	Age (in years)	
4.	Marital Status	1=Married 2= Single 3= Separated 4= Divorced 5= Widow/widower
5.	Highest education level	0=No school 1=Primary, 2=secondary 3=tertiary 4= Post graduate
6.	How would you describe your work situation?	Employed and working Employed, but not working because of my illness A student attending school A student not attending school because of my illness Unemployed or only temporarily employed

		Hospitalized 99. other
7.	Occupation (specify)	
8.	Average family monthly income	1. = < 30k 30k - 60k 61 - 99k 100 - 200k >200k
9.	Are you the bread-winner of your family	Yes No
10.	Are you the bread winner of your family?	Yes No
11.	**If yes to no 10 above:** Do you have trouble meeting the needs of your family because of your present condition?	1=yes, 2=no, 3= NA
12.	How many people live in your household, including yourself?	
13.	In your household, how many rooms are used for sleeping?	
14.	How long have you been on DR-TB treatment (Months)	
15.	HIV status	1= Positive 2 = negative 3 unknown
16.	Ever smoked	1 = Yes 2 = No
17.	Ever taken alcohol	1 = Yes 2 = No
18.	How do you perceived the severity of your illness	1 = Mild 2 = moderate 3 = Severe

19.	Is the DR-TB treatment you are receiving helpful	1 = Not helpful 2 = Somewhat helpful 3 = very helpful 4= Don't know
20.	Do you have any barrier to DR-TB treatment	1 = Yes 2 = No
21.	TB **cannot** be transmitted through the air when a person with TB coughs or sneezes	1 = Yes 2 = No
22.	TB transmission **cannot** be prevented by covering mouth and nose when coughing/wear a mask	1 = True 2 = False
23.	Who can be infected with TB	1 = Anybody 2= Few people 3 = Nobody
24.	Is TB curable?	1 = Yes 2 = No
25.	Is TB a serious disease	1 = Yes 2 = No 3 = Don 't know
26.	Have you ever heard of the word stigma?	1 = Yes 2 = No
27.	Do think TB stigma is a problem?	1 = Yes 2 = No
28.	Where do you feel TB stigma is a problem **(Tick all that applies)**	My family My community My workplace The health facility School Others___
29.	Have you experienced stigma during the course of your illness	1 = Yes 2 = No

30.	If YES to Question 31. Where did you encounter stigma **(Tick all that applies)**	My family My community My workplace The health facility At School 7. Others_____

Appendix 2: Redwood DR-TB Stigma Scale

Now, I would like to read to you a list of ideas and experiences about having TB, and I want you to tell me whether you agree or disagree. I will read a statement, think about your opinion, and then please answer 'strongly agree', 'agree', 'disagree', or 'strongly disagree'. Considering the past two weeks, please read each question carefully and indicate how much you agree or disagree with the following statements using the following scale.

Nos	Questions	Strongly disagree	Disagree	Agree	trongly Agree
RW1	Have you lost some of the joy (happiness) in your life since being diagnosed				
RW2	Do you feel like a burden (problem) on your family				
Rw3	Do you feel like you have let your community down (Disappointed my community)				
RW4	Will you be blamed (accused) if my acquaintance (friends or family) gets MDR-TB				
RW5	Since being diagnosed, do you feel unwanted (unwelcomed) when you attend social events.				
RW6	Are you expected to stay away from social activities (outings)				
RW7	Do people gossip about you and your disease (talk at your back)				
RW8	Do people stand or turn their head away from you when you are talking to them				
RW9	Do you still eat separately, even though you are not in the infectious period anymore.				
RW10	Do you sit close to your family members				
RW11	Did your family ask you to sleep and eat separately for the duration of your treatment				
RW12	Do you think you got MDR-TB because you worked too hard				
RW13	Are people saying you got MDR-TB because of your job				
RW14	Do you think it was something that you did that caused you to get MDR-TB				

Appendix 3: Brief Resilience Scale

I want to know how you have responded to difficult situations in the past. Please choose the response that best describes your situation. Please respond to each item by marking one box per row.

Nos	Questions	Strongly Disagree	Disagree	Neutral	Agree	trongly Agree
RES1	I tend to bounce back quickly after hard times					
RES2	I have hard times making it through stressful situations					
RES3	It does not take me long to recover from a stressful event					
RES4	It is hard for me to snap back when something bad happens					
RES5	I usually come through difficult times with little trouble					
RES6	I tend to take a long time to get over set-backs in my life					

Appendix 4: Deferment of Gratification Scale

Now I want to ask you a little about your thoughts on the present and future. I will read a statement, and I would be grateful if you could think about how much this statement matches the way you are thinking about your situation. I will read a statement, think about your opinion, and then please answer 'strongly agree', 'agree', 'disagree', or 'strongly disagree'. You can also say you 'do not know' or 'choose not to answer.

Nos	Questions	STRON GLY AGREE	AGREE	NOT SURE	DISAGR EE	STRON GLY DISAGR EE
DGS 1	You are good in saving your money so you can buy bigger things at a later time					
DGS 2	Relief from stress in the present is more important to you than having good health in the future					
DGS 3	As a child I saved any pocket money that I had					
DGS 4	When I am at the supermarket, I buy more things than I planned for.					
DGS 5	I am constantly without money.					
DGS 6	I agree with the philosophy eat drinK and enjoy yourself for tomorrow we may all be dead.					
DGS 7	I describe myself as acting without thinking for my own good.					
DGS 8	I often think it is important to wait and think things over before deciding.					
DGS 9	I like spending my money immediately I get it.					
DGS 10	It is hard for me to avoid losing my temper when someone makes me angry.					
DGS 11	It is easy for me to be patient when waiting for things most times.					
DGS 12	You think you are good at planning for things ahead.					

Appendix 5: Functional Assessment of Chronic Illness Therapy-Tuberculosis (FACIT-TB) FACIT-TB Scale

The following questions relate to what you think about the quality of your life. Choose the most appropriate response.

Nos	Questions	Not at all	Occasio nally	Often	Most times	Always
Domain: Physical Well-being						
FACCIT 1	Do you feel ill					
FACCIT 2	Do you get tired easily					
FACCIT 3	Do you lack energy					
FACCIT 4	Do you have pain					
FACCIT 5	Do you feel weak all over					
FACCIT 6	Are you feeling fatigued					
FACCIT 7	Do you have shortness of breath					
FACCIT 8	Do you have nausea “a sense of vomiting outbreak”					
FACCIT 9	Do you have trouble meeting the needs of my family because of your physical condition.					
FACCIT 10	Are you bothered by fever (episode of high body temperature)					
FACCIT 11	Are you forced to spend time in bed					
FACCIT 12	Do you have discomfort or pain in your stomach area					
FACCIT 13	Did you have itching					
FACCIT 14	Did you have a loss of appetite					
FACCIT 15	Have you been coughing					
FACCIT 16	Are you bothered by side effects of treatment					
FACCIT 17	Do dust worsens your symptoms					
Domain: Social and economic well-being						
FACCIT 18	Do you feel close to your friends					

FACCIT 19	Do you get emotional support from your family					

FACCIT 20	Are you satisfied with family communication about your illness					
FACCIT 21	Have your family accepted your illness					
FACCIT 22	Do you feel close to my partner (or the person who is your main support)					
FACCIT 23	Do you get support from my friends					
FACCIT 24	Have your physical condition and/or medical treatment cause you financial difficulties					
Domain: Emotional well-being/Stigma of having TB						
FACCIT 25	Do you worry that your condition will get worse					
FACCIT 26	Do you worry about dying					
FACCIT 27	Are you concerned about what the future holds for you					
FACCIT 28	Are you embarrassed by your illness					
FACCIT 29	Is it hard to tell other people about your disease					
FACCIT 30	Are you losing hope in the fight against your illness					
FACCIT 31	Are you bothered by the change in your weight					
FACCIT 32	Are you worried about spreading your infection					

FACCIT 33	Do you feel nervous (uneasy)					
FACCIT 34	Do you feel sad					
FACCIT 35	Are you satisfied with how you are coping with your illness					
Domain: Functional well-being						
FACCIT 36	Are you content with the quality of your life right now					
FACCIT 37	Is your work (include work at home) fulfilling					
FACCIT 38	Are you able to work (include work at home)					
FACCIT 39	Are you able to enjoy life					
FACCIT 40	Do you enjoy the things you usually do for fun					
FACCIT 41	Have you accepted your illness					
FACCIT 42	Are you sleeping well					
Domain: Spiritual well-being						
FACCIT 43	Do you find strength in your faith or spiritual belief					
FACCIT 44	Has your illness strengthened your faith or spiritual belief					
FACCIT 45	Is your life still productive					

Appendix 6: Morisky 8-item Medication Adherence scale

Now I am coming back to ask some specific questions about how you find taking TB medicines.

Nos	Questions	Yes	No
MOR 1	Do you sometimes forget to take your TB pills?		
MOR 2	Over the past two weeks, were there any days when you did not take your TB medicine?		
MOR 3	Have you ever cut back or stopped taking your medication without telling your doctor because you felt worse when you took it?		
MOR 4	When you travel or leave home, do you sometimes forget to bring along your medications?		
MOR 5	Did you take your TB medicine yesterday?		
MOR 6	When you feel like your TB symptoms are under control, do you sometimes stop taking your medicine?		
MOR 7	Taking medication every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your TB treatment plan?		
MOR 8	Are there any additional challenges that you face in trying to complete your TB treatment?		

Appendix 7: Generalised Anxiety Disorder 7-item scale.

Over the last two weeks, how often have you been bothered by the following problems?

Nos	Questions	Not at all	Several Days	More than half the days	Nearly every day
GAD 1	Feeling nervous, anxious, or on edge				
GAD 2	Not being able to stop or control worrying				
GAD 3	Worrying too much about different things				
GAD 4	Trouble relaxing				
GAD 5	Being so restless that it is hard to sit still				
GAD 6	Becoming easily annoyed or irritable				
GAD 7	Feeling afraid, as if something awful might happen				

If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all _____ Somewhat difficult _____ Very difficult _____ Extremely difficult_____

Appendix 8: Patient Health Questionnaire (PHQ 9)

Now, I want you to tell me how often you have felt these feelings in the last two weeks. You can say “not at all,” several of the days,” “more than half the days,” or “almost all the days.” Over the last 2 weeks, how often have you been bothered by any of the following problems?

Nos	Questions	Not at all	Several days	More than half the days	Nearly every day
PHQ1	Little interest or pleasure in doing things				
PHQ2	Feeling down, depressed, or hopeless				
PHQ3	Trouble falling or staying asleep, or sleeping too much				
PHQ4	Feeling tired or having little energy				
PHQ5	Poor appetite or overeating				
PHQ6	Feeling bad about yourself – or that you are a failure or have let yourself or your family down				
PHQ7	Trouble concentrating on things, such as reading the newspaper or watching television				
PHQ8	Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety (uneasy) or restless that you have been moving around a lot more than usual				
PHQ9	Thoughts that you would be better off dead, or of hurting yourself				

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all _____ Somewhat difficult _____ Very difficult _____ Extremely difficult_____

Appendix 9: UCLA LONELINESS SCALE VERSION 3

Now, I want to ask some questions to assess how lonely you feel in the past two weeks

Nos	Questions	Never	Rarely	Sometimes	Always
UCLA 1	Do you feel that you are "in tune" with the people around you?				
UCLA 2	Do you feel that you lack companionship?				
UCLA 3	Do you feel that there is no one you can turn to?				
UCLA 4	Do you feel alone?				
UCLA 5	Do you feel part of a group of friends?				
UCLA 6	Do you feel that you have a lot in common with the people around you?				
UCLA 7	How often do you feel that you are no longer close to anyone?				
UCLA 8	Do you feel that your interests and ideas are not shared by those around you?				
UCLA 9	Do you feel outgoing and friendly?				
UCLA 10	Do you feel close to people?				
UCLA 11	Do you feel left out				
UCLA 12	Do you feel that your relationships with others are not meaningful?				
UCLA 13	Do you feel that no one really knows you well?				
UCLA 14	Do you feel isolated from others?				
UCLA 15	Do you fee1 you can find companionship when you want it?				
UCLA 16	Do you feel that there are people who understand you?				
UCLA 17	Do you feel shy?				
UCLA 18	Do you feel that people are around you but not with you?				
UCLA 19	Do you feel that there are people you can talk to?				

UCLA 20	Do you feel that there are people you can turn to?				

Appendix 10: Oslo Social Support Scale (OSSS3)

Now I want you to think about the important people in your life and about the support you receive from them.

OSS 1	How many people are so close to you that you can count on them if you have great personal problems?	1 = none 2 = 1–2 3 = 3–5 4= 5+’
OSS 2	How much interest and concern do people show in what you do?	1= none 2 = little 3 = uncertain 4 = some 5 = A lot
OSS 3	How easy is it to get practical help from neighbours if you should need it?	1 = very difficult 2 = difficult 3 = Possible 4 = Easy 5 = very easy

Instruction: This scale comprises a list of statements, each of which may or may not be true about you. For each statement, circle "definitely true" if you are sure, it is true about you and "probably true" if you think it is true but are not certain. Similarly, you should circle "definitely false" if you are sure the statement is false and "probably false" if you think it is false but are not certain.

Appendix 11: Multidimensional Scale of Perceived Social Support

This scale is made up of a list of statements, each of which may or may not be true about you. I am interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement (VSDA= very strongly disagree, SDA = Strongly disagree, DA - Disagree, SA= Strongly agree)

Nos	Questions	VSDA	SDA	Mildly DA	Neutral	Mildly Agree	Strongly y Agree	Very SA
MSPSS1	There is a special person who is around when I am in need							
MSPSS 2	There is a special person with whom I can share my joy and sorrows							
MSPSS 3	My family really tries to help me							
MSPSS 4	I get the emotional help and support I need from my family.							
MSPSS 5	I have a special person who is a real comfort source.							
MSPSS 6	My friends try to help me.							
MSPSS 7	I can count on my friends when things go wrong.							
MSPSS 8	I can talk about my problems with my family.							
MSPSS 9	I have friends with whom I can share my joys and sorrows.							
MSPSS 10	There is a special person in my life who cares about my feelings.							
MSPSS 11	My family is willing to help me make decisions.							
MSPSS 12	I can talk about my problems with my friends.							

Appendix 12: Focus Group Discussion Guide

Introduction: Good morning/afternoon, my name is [Name of interviewer], and I will be interviewing you today. I will start with some general questions, then I will go into more detail about your experiences as a MDR-TB patient. Before we begin, I would like to remind you of how grateful we are for your time and that there are no wrong or right answers. This is a time for you to share your story and your knowledge. This interview will be audio recorded. I would like to reassure you that anything you say will be treated in confidence and that your name will not be on any documents to do with the study. You are allowed to skip questions if you feel uncomfortable or you can ask me to explain a question if it's not clear

Key area of investigation	**Rationale**	**Themes**	**Example Questions**
WARM-UP RAPPORT **Basic background questions**	To learn the basic characteristics of the participant and start to make them feel comfortable	Income Education MDR-TB treatment months Age	Can you tell me a bit about yourself? What do you do for work? How are you feeling this day?
Daily life and social circle	To explore their household and social networks. This will be used to identify potential enacted stigma sources or treatment support networks later in the interview	Household Relationships Social activities	● Can you tell me about your home? Whom do you live with? ● How is your relationship with your partner? How many children do you have? What do you like to do for fun? With whom
BACKSTORY	To identify if the DR-TB is primary or acquired	Diagnostic journey	Can you tell me a bit about your TB story? How did you first get diagnosed? What kinds of thoughts and feelings were foremost in your mind when you found out your TB was drug resistant? What have you learned about TB and TB treatment?

Health facility experiences and treatment	Problems with healthcare facilities can perpetuate stigma and deter patients from commencing or continuing with treatment. Some treatment side effects can cause anxiety and be depressing. This will help to differentiate internal stigma from treatment side effects	How they started the treatment Treatment adherence Healthcare workers Knowledge Personable Side-effects	Why have you decided to get treated at this facility? What do you think about the care being provided? How is your relationship with the health care workers? How do you think HCWs view MDR-TB patients? How long have you been taking treatment? How do the medications affect you? How have these side effects affected your life? Do you feel like the medications are working?
Perceived Stigma (1)	This is to give an insight into the patient's interpretation of	Interpretation of infection control Disclosure	How does it feel to be at the facility? How is the relationship between you and your caregivers at the facility? How did you
Key area of investigation	**Rationale**	**Themes**	**Example Questions**
	infection control policies/practices. It also will identify the relationship between disclosure and stigma.		expect the care to be and how does it compare with the reality?
Experienced Stigma	This topic will explore how the people in their lives treat them regarding their diagnosis. This will be the first aspect of stigma to be discussed as it is more objective then the conversation can go into more depth into the participant's feelings	• Community members • Microaggressions • Friends • Family	• How has your social circle responded to your diagnosis and treatment? Are they aware? How have they engaged with you since they learned? How are the relationships? (Mmm can you tell a bit more specifically what you've felt?) • Since you learned about TB, have you made any changes in your social relationships? • Do people in your community know that you have MDR-TB? • Have you noticed anyone that you don't know very well treat you differently since your diagnosis? • Has your diagnosis impacted your relationship with your family? Friends? Work colleagues? How?

Internalized Stigma	The area focuses on their feelings and the impact of the experienced stigma and MDR-TB has had on them. They may have experienced some forms of mental illness such as anxiety or depression. It will also ask about possible things that helped them	• From diagnosis (intrinsic) • From experiences (extrinsic) Coping mechanisms Blame/shame Mental Illness	•How would you describe your general mood since you learned of your TB diagnosis? (probe: How so?…can you expand on that a bit?) • How do you think this happened? •What about your partner/others? How do they think this happened? •How has the diagnosis affected you as a person? (probe: Can you give some examples?) •Has the experience of having TB changed the way that you think about yourself? (probe: Why do you think that?)
Perceived Stigma (2)	This is the second section of perceived stigma. It will focus on the potential self-imposed isolation due to perceived stigma.	Isolation Loss of Face	• How has MDR-TB affected you? •Do you still attend your normal social events? Why/why not? •Do you feel like you have lost confidence due to your illness? How do you think this happened? •Have you ever tried to hide your symptoms? How did you do this?
Coping	This area will identify any coping mechanisms and also assess the participant's internal stigma by identifying	Coping Aspirations Hopes Plans	•When you think about your future, what do you see for the year ahead? •When you feel low, what kinds of messages or sources of strength do you
Key area of investigation	**Rationale**	**Themes**	**Example Questions**
	'hopelessness' which is a previously identifies feeling for MDR-TB patients		draw on? (probe: Why do believe that these people, ideas, faith, etc. encourage you?) •Has there been anything in your life that has helped you to get through this difficult period in your life? •Do you have any plans for when you have completed treatment? Why/why not? •What would you like to happen next?/What do you think will happen?
Policy	This area is to identify priority areas of programmatic change	Expert advice	•What do you think would have made your MDR-TB treatment easier? •What advice or recommendations do you have for policymakers for improving the quality of TB treatment?

Closing	Close on less emotive subjects- prepare them for follow-up.	• Expressing gratitude for their time so far • Final additions • Express gratitude again	•We're nearly done, so thank you for your time in this interview. It has been really interesting and I have already learned a lot that will be very helpful for our study. •Is there anything else that you think I should know about or that you would like to share with me for this research?

Closing: Thank you for participating in this study. Thank them for letting me be privileged to hear your story. We appreciate you taking the time to talk to us about this sensitive and very important issue. This interview will be analyzed together with other interviews to gain an understanding of how stigma impacts MDR-TB patients, to be able to measure stigma and reduce stigma through improved MDR-TB services.

Appendix 13: Information letter to participants

LETTER OF INFORMATION

Title of the Research Study: Effects and Modifiers of experienced stigma among people living with drug-resistant tuberculosis in Lagos, Nigeria

Principal Investigator/s/researcher: (Adejumo Adedeji Olusola, MBBS, MPH)

Co-Investigator/s/supervisor/s: (Firoza Haffejee (PhD), Olusoji Daniel (PhD), Jinabhai CC (PhD))

Brief Introduction and Purpose of the Study:

This study aims to better understand discrimination or stigma experienced by people with drug- resistant tuberculosis. Its purpose is to describe how common stigma is, how people cope with it, its effects, and how to reduce its harmful effects among people with drug-resistant tuberculosis. This understanding will help reduce the stigma experienced by people with drug- resistant tuberculosis in Lagos, Nigeria.

Hello, Good morning, I am a student in the Faculty of Health Sciences at the Durban University of Technology (DUT), South Africa, doing research for my PhD.

I am inviting you to participate in this study. Before you decide whether to participate, I will explain what is expected of you and the risks and benefits. This form gives you the necessary information about the study to be discussed. Once you understand the study and agree to take part, you will be asked to sign your name or make a mark on this form.

Research is a systematic search for new knowledge. You are free to ask as many questions as you wish because you must understand the study before you agree to

participate. You are also free to discuss this with your family and friends, and you are not under any pressure to agree to participate at this stage. For this purpose, you will be given a copy of the Letter of information document to take home.

Outline of the study procedures: If you are eligible and decide to participate, a research assistant will assist you in completing the questions. You are expected to answer all the questions to the best of your ability. You are free to decline to answer any question you are uncomfortable with. The questionnaire should take about 45 minutes to complete. If you wish, I would like you to join our focus group discussion with other people. I envisage that each group will comprise 8-12 people. A trained person will guide the discussion process. You do not have to join if you don't wish to. However, if you do, you are requested not to mention your name or the name of any person, as the identity of participants must be kept anonymous. The discussion will not exceed one hour. I anticipate that about 200 people will be involved in completing the questionnaires, and about 40 people will be involved in focus group discussions. People who will participate will be drawn from five DR-TB treatment centres.

Risks or Discomforts of the study: I do not see any form of risks or discomfort this study may cause you. If, however, there is a potential risk that you envisage and you wish not to continue in this study, please share it with the research assistant. We will be happy to ensure your safety in all possible ways. Also, a clinical psychologist will offer you free counselling if you feel you need this while participating in the study.

Reason you may be withdrawn from the study: You may withdraw from the study if you are not comfortable in any way. There will be no adverse consequence to you if you withdraw.

Benefits of the study: One of the benefits of taking part in this study is that you will receive information about the outcome of this study. The outcome of this study will also be communicated to various stakeholders. I hope this will inform the organization of TB services in the future in Lagos State.

Remuneration: You will not receive any remuneration for participating. You will be given a light refreshment and a token of 1500 naira to cover your transport for coming all the way to participate in this study.

Costs of the Study: There are no costs involved in participating in the study.

Confidentiality: Efforts will be made to keep your personal information confidential. Your name or any information that identifies you personally will not be on any form where your responses are recorded. Your details, such as name or address, will not be linked with any information. All records of your interviews will be kept in a safe place under lock and key. Your records may be reviewed by authorised study staff only.

Results: The results of this research will be communicated with the Lagos State Ministry of Health and the Lagos State Tuberculosis and Leprosy Control officer. In addition, findings will be communicated to you through any means that are convenient for you.

Research-related Injury: I do not envisage any research-related injury. However, if you experience one, please share it with the research assistants and appropriate treatment will be provided at no cost to you.

Storage of all electronic and hard copies, including tape recordings: Questionnaires, transcripts, and audio recordings of focus groups will be stored on a dedicated laptop and backed up on a flash drive. The data will also be stored in my email. All files will be password-protected and stored for 5 years, after which all electronic files will be permanently deleted. All paper- based questionnaires will be stored in a locked cupboard in my office for a period of 5 years, after which they will be shredded and disposed of. Only I and a research assistant will have access to the data.

Persons to contact in the Event of Any Problems or Queries: If you ever have any questions about the study, or if you have research-related harm, you should contact me Dr. Adejumo Olusola at General Hospital Agbowa Lagos State (08033502773), my co-supervisor Prof Olusoji Daniel at Ogun State University Teaching Hospital (OSUTH) Sagamu (08145825999) or the DUT-Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Acting Director of research and Postgraduate Support at researchdirector@dut.ac.za

Appendix 14: Consent form for participants

CONSENT

Full Title of the Study: Effects and modifiers of experienced stigma among people living with drug-resistant tuberculosis in Lagos, Nigeria.

Names of Researcher/s: Dr. Adejumo Adedeji Olusola

Statement of Agreement to Participate in the Research Study:

I hereby confirm that I have been informed by the researcher, Dr. Adejumo Adedeji Olusola , about the nature, conduct, benefits, and risks of this study - Research Ethics Clearance Number: IREC 066/ 23

I have also received, read, and understood the above- written information (Participant Letter of Information) regarding the study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials, and diagnosis, will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant **Date** **Time** **Signature/Right Thumbprint**

I Dr Adejumo Adedeji Olusola herewith confirm that the above participant has been fully informed about the nature, conduct, and risks of the above study

Full Name of Researcher	**Date**	**Signature**
Full Name of Witness (If applicable)	**Date**	**Signature**
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Appendix 15: DUT IREC Approval

Institutional Research Ethics Committee Research and Postgraduate Support Directorate 2nd Floor, Berwyn Court
Gate 1, Steve Biko
Campus Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

20 September 2023

Dr O A Adejumo
P.O. Box 855
Sagamu Ogun State
Nigeria

Dear Dr Adejumo

Effects and modifiers of experienced stigma among people living with drug-resistant tuberculosis in Lagos, Nigeria.
Ethics Clearance Number: IREC 066/23

The DUT-Institutional Research Ethics Committee acknowledges receipt of your final data collection tool for review.

We are pleased to inform you that the data collection tool has been approved. Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the DUT-IREC acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the DUT-IREC according to the DUT-IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the DUT-IREC as outlined in the DUT-IREC SOP's.

It is compulsory for a student or researcher to apply for recertification on an annual basis. The failure to do so will result in withdrawal of ethics clearance. It is the responsibility of the researcher and the supervisor to apply for recertification.

Please note that you are required to submit a Notification of Completion of Study form together with an abstract to the DUT-IREC office on completion of your study.

Yours Sincerely

Prof J K Adam
Chairperson: DUT-IREC

Appendix 16: Lagos State University Teaching Hospital HREC Approval

LAGOS STATE GOVERNMENT

LAGOS STATE UNIVERSITY TEACHING HOSPITAL, IKEJA

HEALTH RESEARCH AND ETHICS COMMITTEE
REG.NO. NHREC04/04/2008
(www.nhrec.net)

PROIECT TITLE: EFFECTS AND MODIFIERS OF EXPERIENCED STIGMA AMONG PEOPLE LIVING WITH DRUG-RESISTANT TUBERCULOSIS IN LAGOS, NIGERIA
REF. NO.: LREC/06/10/2179
PRINCIPAL INVESTIGATOR: ADEJUMO ADEDEJI OLUSOLA
ADDRESS: DEPT. OF COMMUNITY HEALTH, GENERAL HOSPITAL AGBOWA
DATE OF RECIEPT OF VALID APPLICATION: 14/06/23
DATE OF APPROVAL: 20/06/23

PROF. A. O. FABAMWO
MB.Ch.B, FMCOG, FWACS, FICS
Chief Medical Director
08037787788

PROF. ADEBOWALE O. ADEKOYA
MB.BS, MSC, FMCP, DTM&H, PhD, PGCE
CMAC / Director Of Clinical Services and Training
08033812199

PROF. YETUNDE KUYINU
MBBS, MPH, MD, FMCPH
Prof. Public Health & Community Medicine
Chairman, LASUTH IHREC
08023207440

NOTICE OF APPROVAL

This is to inform you that the research described here in the submitted protocol, the consent forms, advertisements and other participant information materials have been reviewed and given full approval by the Health Research and Ethics Committee of LASUTH (LREC)

This approval dates from 20/06/2023 to 19/03/2024. If there is any delay in starting the Research, please inform the HREC LASUTH so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. All informed consent forms used in this study must carry the HREC LASUTH assigned number and duration of HREC approval. In a multiyear research, endeavor to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

THE NATIONAL CODE FOR HEALTH RESEARCH AND ETHICS (www.nhrec.net) REQUIRES YOU TO COMPLY WITH ALL INSTITUTIONAL GUIDELINES, RULES AND REGULATIONS AND WITH THE TENETS OF THE CODE INCLUDING ENSURING THAT ALL ADVERSE EVENTS ARE REPORTED PROMPTLY TO THE HREC. NO CHANGES ARE PERMITTED IN THE RESEARCH WITHOUT PRIOR APPROVAL BY HREC LASUTH EXCEPT IN CIRCUMSTANCES OUTLINED IN THE CODE.THE LREC RESERVES THE RIGHT TO CONDUCT COMPLIANCE VISIT TO YOUR RESEARCH SITE WITHOUT PREVIOUS NOTIFICATION.

PROF. Y.A. KUYINU

Appendix 17: Lagos State Ministry of Health Administrative Approval

LAGOS STATE GOVERNMENT

LSMH/6902/I/160

10th July, 2023

Dr. Adejumo Adedeji Olusola,
Consultant Public Health Physician,
General Hospital Agbowa,
Agbowa Ikosi,
Lagos.

RE: REQUEST FOR ADMINISTRATIVE/SOCIAL APPROVAL

I hereby convey the approval of the Ministry of Health for you to conduct a research on the topic: ***"Effects and Modifiers of Experienced Stigma among People Living with Drug-Resistant Tuberculosis in Lagos, Nigeria"***.

The approval is being granted following a review of your research protocol and requested documents: Ethical approval and Letters of Introduction from both your Institution and the Public Service Office, Alausa Secretariat, which have been found satisfactory.

Please note that the Ministry expects to receive monthly progress reports of this study. This should be sent via e-mail to: lagresunit@gmail.com, copying: **ibidun.lajide@lagosstate.gov.ng, hussein.abdur-razzaq@lagosstate.gov.ng** and **adepase.abiola1@lagosstate.gov.ng**.

Thank you.

Dr. Dayo Lajide
Director, Healthcare Planning, Research, and Statistics
For: Permanent Secretary (Health).

MINISTRY OF HEALTH

Appendix 18: Lagos State Health Service Commission Administrative Approval

LAGOS STATE GOVERNMENT

LSHSC/2222/VOLV/37 — 20th July, 2023

Dr Adejumo Adedeji Olusola.
General Hospital Agbowa,
Agbowa Ikosi,
Lagos.

RE: PERMISSION TO COLLECT DATA AND INTERVIEW DRUG RESISTANT TUBERCULOSIS PATIENTS IN FIVE TREATMENT CENTERS IN LAGOS STATE.

The Commission is in receipt of your letter dated 7th July, 2023 in respect of the above captioned subject.

2. Following the review of your request, I have been directed to convey the Commission's approval for you to carry out your study titled **"EFFECTS AND MODIFIERS OF EXPERIENCED STIGMA AMONG PEOPLE LIVING WITH DRUG RESISTANT TUBERCULOSIS IN LAGOS, NIGERIA"**.
3. Please note that this approval does not preclude you from obtaining individual consent from study participants.
4. Also note that you are mandated to submit a copy of the research findings to the Commission as soon as the study is completed.

10/07/2023
Dr Olugbenga Oyekan
Director Medical Services
For Permanent Secretary (HSC)

cc: MD, Mainland Hospital Yaba
MD, General Hospital Ikorodu
MD, General Hospital Alimosho

HEALTH SERVICE COMMISSION

Appendix 19: Lagos State Primary Health Care Board Administrative Approval

LAGOS STATE GOVERNMENT

LAGOS STATE
PRIMARY HEALTH CARE BOARD

LS/PHCB/DPRS/256/VOL.II/031

30th August 2023

Dr Adejumo Adedeji Olusola
General Hospital Agbowa
Agbowa Ikosi
Lagos

APPROVAL TO COLLECT DATA AND INTERVIEW DRUG RESISTANT TUBERCULOSIS PATIENTS IN AJEROMI-IFELODUN & OJO LGAs OF LAGOS STATE.

This is to acknowledge the receipt of your letter requesting for approval to conduct the above named research and to convey the Board's approval.

2. You have been given approval to access Primary Healthcare centres in the two LGAs above.

3. Kindly note that you will be needed to fill and sign our Data Sharing Policy Document.

3. We must emphasize the necessity of you sharing with us the result of your findings before public dissemination.

4. Thank you.

Dr. Balogun T.K.
Director Healthcare Planning Research & Statistics
For: Permanent Secretary

5, Taylor Drive, Off Edmund Crescent, Yaba. P.M.B. 21007, Ikeja Lagos. Tel: 08183310819
E-mail: lsphcboard2010@yahoo.com

Appendix 20: Approval to collect Data in Tolu and Ojo PHC

LAGOS STATE GOVERNMENT

LSMH/6902/I/162

10th July, 2023

The Permanent Secretary,
Primary Health Care Board,
5, Taylor Drive,
Off Edmund Crescent,
Yaba, Lagos.

Attention: Medical Officers of Health (Ajeromi & Ojo LGAs)

ADMINISTRATIVE APPROVAL

This is to inform you that the Ministry has granted social approval **Dr. Adejumo Adedeji Olusola**, a Consultant Public Health Physician, General Hospital Agbowa, Lagos, to carry out a study on the topic: ***"Effects and Modifiers of Experienced Stigma among People Living with Drug-Resistant Tuberculosis in Lagos, Nigeria".***

The project comprises both quantitative and qualitative data collection from selected Drug Resistant-Tuberculosis (DR-TB) patients in the selected Primary Healthcare Centres (PHCs), using a structured questionnaire.
A Focus Group Discussion (FGD) involving consenting participants will also be conducted.

The Selected PHCs are:

- Tolu PHC (Ajeromi LGA)
- Ojo PHC (Ojo LGA)

Kindly help facilitate the process.

Thank you.

Dr. Dayo Lajide
Director, Healthcare Planning, Research, and Statistics
For: Permanent Secretary (Health)

Appendix 21: Administrative Approval to Collect Data in Mainland Hospital

LAGOS STATE GOVERNMENT

LSMH/6902/I/161

10th July, 2023

The Medical Director,
Mainland Hospital,
Yaba,
Lagos.

ADMINISTRATIVE APPROVAL

This is to inform you that the Ministry has granted social approval to **Dr. Adejumo Adedeji Olusola**, a Consultant Public Health Physician, General Hospital Agbowa, Lagos, to carry out a study on the topic: ***"Effects and Modifiers of Experienced Stigma among People Living with Drug-Resistant Tuberculosis in Lagos, Nigeria"***.

The project comprises both quantitative and qualitative data collection from selected Drug Resistant-Tuberculosis (DR-TB) patients in your facility using a structured questionnaire. A Focus Group Discussion (FGD) involving consenting participants will also be conducted.

Kindly help facilitate the process.

Thank you.

Dr. Dayo Lajide
Director, Healthcare Planning, Research, and Statistics
For: Permanent Secretary (Health)

MINISTRY OF HEALTH

Appendix 22: Administrative Approval to Collect Data in General Hospital Alimosho

LAGOS STATE GOVERNMENT

LSMH/6902/I/161

10th July, 2023

The Medical Director,
General Hospital Alimosho,
Alimosho,
Lagos.

ADMINISTRATIVE APPROVAL

This is to inform you that the Ministry has granted social approval to **Dr. Adejumo Adedeji Olusola**, a Consultant Public Health Physician, General Hospital Agbowa, Lagos, to carry out a study on the topic: ***"Effects and Modifiers of Experienced Stigma among People Living with Drug-Resistant Tuberculosis in Lagos, Nigeria".***

The project comprises both quantitative and qualitative data collection from selected Drug Resistant-Tuberculosis (DR-TB) patients in your facility using a structured questionnaire. A Focus Group Discussion (FGD) involving consenting participants will also be conducted.

Kindly help facilitate the process.

Thank you.

Dr. Dayo Lajide
Director, Healthcare Planning, Research, and Statistics
For: Permanent Secretary (Health)

MINISTRY OF HEALTH

Appendix 23: Administrative Approval to Collect Data in General Hospital Ikorodu

LAGOS STATE GOVERNMENT

LSMH/6902/I/161

10th July, 2023

The Medical Director,
General Hospital Ikorodu,
Ikorodu,
Lagos.

ADMINISTRATIVE APPROVAL

This is to inform you that the Ministry has granted social approval to **Dr. Adejumo Adedeji Olusola**, a Consultant Public Health Physician, General Hospital Agbowa, Lagos, to carry out a study on the topic: ***"Effects and Modifiers of Experienced Stigma among People Living with Drug-Resistant Tuberculosis in Lagos, Nigeria".***

The project comprises both quantitative and qualitative data collection from selected Drug Resistant-Tuberculosis (DR-TB) patients in your facility using a structured questionnaire. A Focus Group Discussion (FGD) involving consenting participants will also be conducted.

Kindly help facilitate the process.

Thank you.

Dr. Dayo Lajide
Director, Healthcare Planning, Research, and Statistics
For: Permanent Secretary (Health)

MINISTRY OF HEALTH

Appendix 24: Ethics Training Certificate (Introduction to Research Ethics)

TRREE

Zertifikat
Certificat
Certificado
Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Clinical Trials Centre
The University of Hong Kong

Olusola Adejumo

a complété avec succès - has successfully completed

Introduction to Research Ethics

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2023/04/24

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

APPROVED BY
SIWF FMH
ISFM

Foederatio Pharmaceutica Helvetiae
FPH
Programmes de formation postgraduée et continue

Ce programme est soutenu par - This program is supported by :

Appendix 25: Ethics Training Certificate (Research Ethics Evaluation)

TRREE

Zertifikat
Certificat
Certificado
Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Clinical Trials Centre
The University of Hong Kong

Olusola Adejumo

a complété avec succès - has successfully completed

Research Ethics Evaluation

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2023/04/25

CD: [illegible]

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

APPROVED BY SIWF FMH ISFM

Foederatio Pharmaceutica Helvetiae FPH Programmes de formation postgraduée et continue

Ce programme est soutenu par - This program is supported by :

[illegible]

[illegible]

Appendix 26: Ethics Training Certificate: Informed Consent

Zertifikat
Certificat
Certificado
Certificate

TRREE

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Clinical Trials Centre
The University of Hong Kong

Olusola Adejumo

a complété avec succès - has successfully completed

Informed Consent

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2023/04/29

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

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APPENDIX 27: RECEIPT OF MANUSCRIPT FROM BMC HEALTH SERVICES RESEARCH

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BMC Health Services Research - Receipt of Manuscript ''The way they...'

B BMC Health Services Research<jofferson.ponteres@springernature.

To: O Adejumo (22290751) Mon 4/7/2025 11:14 PM

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and know the content is safe.

Ref: Submission ID 015b2764-da8d-438f-80da-33876fd12f66

Dear Dr Adejumo,

Thank you for submitting your manuscript to BMC Health Services Research.

Your manuscript is now at our initial Technical Check stage, where we look for adherence to our submission guidelines, including any relevant editorial and publishing policies. If there are any points that need to be addressed prior to progressing we will send you a detailed email. Otherwise, your manuscript will proceed into peer review.

You can check on the status of your submission at any time by using the link below and logging in with the account you created for this submission:

https://zaf01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fsubmission.springernature.com%2Fsubmission-details%2F015b2764-da8d-438f-80da-33876fd12f66%3Futm_source%3Dsubmissions%26utm_medium%3Demail%26utm_campaign%3Dconfirmation-email%26journal_id%3D12913&data=05%7C02%7C22290751%40dut4life.ac.za%7C64f500b3f9c4424ccd0208dd76191b9f%7C4b1930d112f440b5b48cbd86117429d8%7C0%7C0%7C638796572422149890%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=h0V8SuHBrYedUYt9CzT5lbHivEJVFxU68JxnatQT%2FJI%3D&reserved=0

Kind regards,

Editorial Assistant
BMC Health Services Research

APPENDIX 28: SUBMISSION CONFIRMATION OF MANUSCRIPT FROM STIGMA AND HEALTH

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STG - A manuscript number has been assigned to The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study - [EMID:df3ca271a66e9e80]

SH

em.stg.0.932166.28668660@editorialmanager.com on behalf of Stigma and Health<em@editorialma

To: O Adejumo (22290751)

Fri 5/2/2025 5:12 PM

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Dear Dr Adejumo,

Your submission "The experiences of people with drug-resistant tuberculosis in Lagos, Nigeria: A qualitative study" has been assigned the following manuscript number: SAH-2025-0105.

You will be able to check on the progress of your paper by logging on to Editorial Manager as an author. The URL is https://zaf01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.editorialmanager.com%2Fstg%2F&data=05%7C02%7C22290751%40dut4life.ac.za%7C682875ec3cd64479d3a708dd898bcc38%7C4b1930d112f440b5b48cbd86117429d8%7C0%7C0%7C638817955720322354%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=G2fXR6E3N%2BlCIIRxP5N1qtFuhetXDdladzNg6nXM9Vo%3D&reserved=0.

Thank you for considering Stigma and Health as an outlet for your work.

Best regards,

Stigma and Health

_____

In compliance with data protection regulations, you may request that we remove your personal registration details at any time. (Use the following URL: https://zaf01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.editorialmanager.com%2Fstg%2Flogin.asp%3Fa%3Dr&data=05%7C02%7C22290751%40dut4life.ac.za%7C682875ec3cd64479d3a708dd898bcc38%7C4b1930d112f440b5b48cbd86117429d8%7C0%7C0%7C638817955720340929%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=Ni7TRDtW5V39a4irwE%2FLfD8gzyJ10LDgJzbBQYW5pqU%3D&reserved=0). Please contact the publication office if you have any questions.

Reply Forward