



SCHOOL OF APPLIED HUMAN SCIENCES

An Emic Perspective of the Health-Seeking Behaviour of Adult Extensively Drug-Resistant Tuberculosis In-Patients in a Public Health Setting in KwaZulu-Natal

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2024

Supervisor: Dr S. Valjee

Submitted in partial fulfilment of the requirements for the degree:

Master of Social Science (Clinical Psychology)

Department of Psychology

School of Applied Human Sciences

College of Humanities

University of KwaZulu-Natal, Howard College

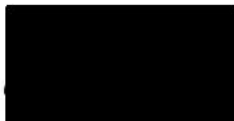
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An Emic Perspective of the Health-Seeking Behaviour of Adult Extensively Drug-Resistant
Tuberculosis In-Patients in a Public Health Setting in KwaZulu-Natal

by

Kavita Soni (Student No:981180239)

Dissertation (article format)

Submitted in partial fulfilment of the requirements for the degree

MASTER OF SOCIAL SCIENCES IN

(CLINICAL PSYCHOLOGY)

in the

FACULTY OF HUMANITIES

at the

UNIVERSITY OF KWAZULU-NATAL (HOWARD COLLEGE)

Supervisor: Dr Sachet Valjee

Date of submission : 25 December 2023



Acknowledgements

Jai Ambe, Jai Swaminarayan

“Education coupled with values will safeguard society” (Shree Pramukh Swami Maharaj)

I offer a prayer of gratitude to Mataji, for the countless blessings that have enabled me to complete this paper.

My heartfelt salutations to my Guru, for his kind encouragement and boons of confidence. This would not be possible without You.

A huge thank you to my supervisor, Dr Sachet Valjee. I am grateful for the privilege to contribute to your primary research project. Thank you for your guidance, support, encouragement, and unwavering commitment to the completion of my research.

Thank you also to the University of Kwa-Zulu Natal for giving me this opportunity to conduct and complete this research. I appreciate the resources available and the dedication of the staff in the Department of Psychology. You were an essential part of this journey.

My obeisance to my parents - to my dad who was the epitome of strength and courage, and to my mum for her blessings and encouragement.

A huge thank you to my husband, Shivan Soni, for his commitment to my progress and his love and support throughout this process. I dedicate this dissertation to my children, Arushi and Drishna who are a tangible reminder of the value of perseverance.

Finally, thank you to all my friends and family for your heartfelt support and motivation to overcome challenges.

Summary

An Emic Perspective of the Health-Seeking Behaviour of Adult Extensively Drug-Resistant Tuberculosis (TB) In-Patients in a Public Health Setting in KwaZulu-Natal.

Globally, tuberculosis (TB) control initiatives face challenges due to multi-drug resistant TB (MDR-TB) and extensively drug resistant TB (XDR-TB). South Africa's public health care systems underperform, with high default and non-adherence rates among patients. Kwa Zulu Natal is the epicentre of the TB, XDR-TB, and human immunodeficiency virus/ acquired immunodeficiency syndrome (HIV/AIDS) crises.

The present study is qualitative and uses an emic perspective to gain an understanding of the unique challenges and factors influencing health-seeking decisions in this region.

This researcher acquired a secondary data set from an overarching research project: MDR-TB treatment adherence in KZN, and a cohort of patients who were identified as treatment-resistant from the original study who went on to develop XDR-TB. Focus groups were conducted with adult XDR TB in-patients. An integration of the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA) suggests that individuals are likely to engage in health seeking behaviour, with favourable levels of health motivation and self-efficacy, if they perceive their susceptibility (likelihood of developing XDR-TB), severity of the illness (XDR-TB prognosis), and believe that taking the recommended health action (seeking medical care) will effectively mitigate the threat (improve their health status/benefit) without any negative consequences (barriers). Furthermore, individuals' intention to seek health care is influenced by expectations of the community and the perceived approval or disapproval of significant others.

What has emerged from this study is that patients in the community conceal their diagnosis and delay seeking treatment. This, in addition to dual-healing systems, compromises treatment adherence for MDR-TB, increasing the probability of the development of XDR-TB. Although the Directly Observed Therapy (DOT) strategy aims to improve treatment adherence, it can be counterintuitive to patients' health-seeking behaviour. Once hospitalised patients fear the worst and are overwhelmed by the poor prognosis of their condition, the disempowering and dehumanising culture within healthcare facilities further exacerbates the

psychological distress of the patient and results in negative health outcomes for patients individually, and the community at large.

Keywords: (TB), (MDR-TB), (XDR-TB), (DR-TB), non-adherence, health-seeking behaviour, (DOT), (HIV/AIDS).

Abbreviations

ART	antiretroviral therapy
Covid-19	coronavirus disease 2019
DMT	District Management Team
DOT	Directly Observed Therapy
DR-TB	drug-resistant tuberculosis
DS-TB	drug-sensitive tuberculosis
DST	drug susceptibility testing
HIV	human immunodeficiency virus
KZN	KwaZulu-Natal Province
LMIC	low and middle-income countries
LTFU	Loss to Follow-Up
MDR-TB	multi-drug resistant tuberculosis
MDT	multi-disciplinary team
NdoH	National Department of Health
NGO	non-governmental organisation
OPD	Outpatient Department
PHC	Primary Health Care
PWDR-TB	people with drug-resistant tuberculosis
PLWH	people living with HIV
TB	tuberculosis
XDR-TB	extensively drug-resistant tuberculosis
WC	Western Cape Province
WHO	World Health Organisation

Table of contents

Acknowledgments.....	2
Summary.....	3
Abbreviations.....	5
1. Preface.....	7
1.1 Article Format.....	7
1.2. Selected Journal.....	7
1.3 Permission from co-authors.....	7
2. Author Guidelines and Manuscript.....	9
3. Manuscript.....	18
4. Abstract.....	19
5. Introduction.....	21
6. Theoretical Framework.....	28
7. Research Methods.....	32
7.1 Research context.....	32
7.2 Research participants.....	33
7.3 Method of data collection: Focus groups.....	34
7.4 Procedure.....	34
8. Ethical considerations.....	35
9. Results.....	36
10. Discussion.....	55
11. Limitations and challenges for further research.....	57
12. Conclusion.....	57
13. References.....	59
APPENDIX A: Transcripts from focus groups.....	73
APPENDIX B: Ethical approval letter.....	100
APPENDIX C: Permission letter.....	102

1. Preface

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This mini-dissertation was completed in article format as indicated by the guidelines of the University of KwaZulu-Natal (Howard College).

1.2 Selected journal

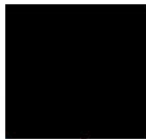
The targeted journal for publication is the South African Journal of Psychology. A shortened version of the manuscript will be submitted to the journal in accordance with the journal's guidelines. The referencing style and editorial approach for this manuscript is in line with the Publication Manual of the American Psychological Association (APA, 7th edition, 2019), except where otherwise specified by the South African Journal of Psychology's guidelines. For the purposes of this mini-dissertation, the pages are numbered consecutively. For submission to the above-mentioned journal, pages will be numbered according to the journal's requirements and thus start from the title page of the manuscript.

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Letter of Consent

I, the co-author, hereby give consent that Kavita Soni may submit the manuscript *An Emic Perspective of the Health-Seeking Behaviour of Adult Extensive Drug Resistant Tuberculosis In-Patients in a Public Health Setting in KwaZulu-Natal* for purposes of a mini-dissertation in partial fulfilment for the degree Master of Social Sciences in Clinical Psychology. It may also be submitted to the South African Journal of Psychology for review.



Dr S. Valjee

Co-Author and Supervisor

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An Emic Perspective of the Health-Seeking Behaviour of Adult Extensively Drug-Resistant Tuberculosis In-Patients in a Public Health Setting in KwaZulu-Natal

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Abstract

Kavita, Soni.2023.An Emic Perspective of the Health Seeking Behaviour of Adult Extensively Drug-Resistant Tuberculosis In-Patients in a Public Health Setting.

Master's Dissertation in Clinical Psychology. University of Kwa Zulu Natal (Howard College). School of Applied Human Science. College of Humanities. 103 pages.

Across the globe and in South Africa specifically, there have been myriad research findings that have contributed to the reduction of TB. However, despite these innovative approaches, health service researchers concur that gains in tuberculosis control are threatened by the emergence of resistance to anti-tuberculosis drugs (Dheda et al., 2017), namely multidrug-resistant (MDR) and extensively drug-resistant (XDR) tuberculosis. In this article, we examine the health-seeking behaviour of adult in-patients with XDR-TB (previous history of MDR-TB) in a public health sector setting. Data transcripts were acquired from an overarching research study (MDR TB treatment non-adherence in KwaZulu-Natal Project - Principal Investigator, Dr S. Valjee) conducted in a district hospital in Durban. The data transcripts were subjected to theme analysis, with comparisons between gender were explored. According to the findings in this research, a range of individual, community, and institutional-based characteristics, which have historically been described as "treatment delay" and "poor patient adherence," impact health-seeking behaviors. This situation is aggravated by the widespread lack of information and knowledge regarding MDR -TB and XDRTB, lack of insight into the model of decentralized primary care, mistrust of information received, social stigma and community's' failure to recognise symptoms. Cultural beliefs that influence individuals' use of dual healing systems, and multiple treatments further compound this predicament. As a consequence, tuberculosis patients develop MDR-TB and/or XDR-TB. The "ivory tower" of medical administration evident at the institutional level that subjects patients to an antagonistic, disempowering experience, further undermines adherence behavior and positive health actions. Practical staff-centered and patient-centered treatments are proposed in the context of many systemic recommendations. This is followed by a discussion of the study's shortcomings and recommendations for further investigation.

Keywords: tuberculosis (TB), multidrug-resistant (MDR-TB) tuberculosis, extensively drug-resistant (XDR) tuberculosis, Drug-resistant (DR-TB) tuberculosis, non-adherence, health-seeking behaviour, Directly Observed Therapy (DOT), human immunodeficiency virus (HIV/AIDS).

Introduction

Tuberculosis (TB) is a communicable disease that affects millions of people across the world. TB is caused by the bacillus *Mycobacterium Tuberculosis* (WHO, 2022). The World Health Organization's Global Tuberculosis Report (WHO, 2022) indicates that approximately

85% of individuals who contract tuberculosis can be cured and further transmission of the infection can be reduced with a timely diagnosis and six months of treatment with first-line antibiotics.

From a global perspective, although preventable and treatable, TB remains a public health epidemic. According to the World Health Organization (WHO, 2022), the annual incidence of tuberculosis is around 10.4 million new cases and 1.8 million deaths. Approximately 3 million new cases, or one-third, remain undiagnosed by the health system, and a significant number of them do not get appropriate treatment (Holmes et al., 2017). TB has a particularly devastating effect in the developing world, where more than 95% of all reported cases of TB occur (Bloom, 2020), having the greatest infection and mortality rates located mostly in low-income, developing nations (Miggiano et al., 2020).

The COVID-19 pandemic has had a devastating impact on the burden of TB disease globally (Chanda-Kapata et al., 2022). Prior to the coronavirus pandemic (COVID-19), TB surpassed the Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS) as the predominant infectious disease-related cause of mortality (WHO, 2022). Globally, adults account for 88% of people with TB (Chakaya et al., 2021). It is suggested that most people (about 90%) who develop the disease are adults between the ages of 15 and 65 years (WHO, 2022), with more cases among men than women (McQuaid et al., 2022). Although deaths from TB have fallen substantively over the past twenty years, with the exception of sub-Saharan Africa (Dheda et al., 2017), the incidence globally, has been declining gradually (Bloom, 2020). Despite some advances, TB control has been threatened by the advent of resistance to anti-tuberculosis drugs (DR-TB) (Dheda et al., 2017).

The emergence of DR-TB as a public health concern may be attributed to decades of ineffective TB programs. Multiple routes exist via which individuals acquire DR-TB. Primary resistance arises via transfer of a drug-resistant strain during infection, while secondary or acquired resistance is the consequence of insufficient treatment of drug-susceptible tuberculosis (DS-TB). (Dheda et al., 2017). The WHO Global TB Report (2022) indicates that DR-TB continues to rise worldwide and as a result, this disease continues to be a significant public health issue due to the vast outbreak of XDR-TB (extensively drug-resistant tuberculosis), a very fatal variant of drug-resistant tuberculosis (Shah et al., 2017). Specifically, Dheda et al., 2017, highlight that in many countries, this expansion of resistance has evolved to drug-incurable tuberculosis (totally drug-resistant tuberculosis).

A South African study, which used networks to document XDR TB cases and map transmission clusters, discovered that 75% of occurrences of drug-resistant tuberculosis are due to transmission as opposed to poor treatment.(Shah et al., 2017). According to the WHO’s categorization, (WHO, 2021) the five groups of DR-TB are distinguished by drug susceptibility testing (DST):

Table 1 : WHO drug susceptibility testing(DST)

Classification	Resistance Type	Medication
isoniazid-resistant TB	isoniazid-resistant TB	resistant to isoniazid and susceptible to rifampicin
rifampicin-resistant TB	(RR-TB)	resistant to rifampicin and susceptible to isoniazid, regardless of resistance to other drugs
multi-drug resistant TB	(MDR-TB)	resistant to isoniazid and rifampicin
pre-extensively drug-resistant TB	(pre-XDR-TB)	resistant to rifampicin and any fluoroquinolone (a class of second-line anti-TB drug)
extensively drug-resistant TB	(XDR-TB)	resistant to rifampicin, plus any fluoroquinolone, plus at least one additional group A drug*
Totally Drug-resistant TB	Drug-incurable TB	Programmatically incurable TB

*The group A drugs are currently levofloxacin or moxifloxacin, bedaquiline and linezolid; therefore, XDR-TB is MDR/RR-TB that is resistant to a fluoroquinolone and either bedaquiline or linezolid (or both). The group A drugs may change in the future; therefore, the terminology “group A” is appropriate here and will apply to any group A drugs in the future (WHO, 2021).recent

Based on the findings of the WHO Global TB Report (2022), resistance testing identified 141 953 cases of MDR/RR-TB and 25 038 instances of pre-XDR-TB or XDR-TB among 2.4 million individuals with confirmed TB in 2021. Initiation of therapy is still below acceptable levels, and 161,746 individuals with MDR/RR-TB were enrolled in treatment globally. Since 2018, the WHO has introduced an all-oral regimen for the treatment of MDR/RR-TB. An estimate suggests that among the percentage of patients that began treatment in 2019, (latest available data), the treatment success rate was 60% for MDR/RR. Treatment for XDR-TB has been challenging with low treatment success rates. Pedersen et al.,(2023), report a global success rate of 44.2% for XDR-TB treatment within the context of WHO's updated definition (see Table 1) of XDR-TB (in 2021)and the recommendation for an all-oral, 6-month regimen for DR-TB treatment (in 2022). The authors conclude that although new treatment developments are promising, access to drugs and acquired drug resistance still present obstacles to managing this disease.

'Africa estimated tuberculosis incidence rates', indicates that South Africa, situated in the southern part of the continent, maintains its position among the top ten nations globally with the highest tuberculosis burden, with an expected 554 cases per 100,000 inhabitants in 2020. (Baloyi et al., 2022). In South Africa, where the TB and HIV epidemics have overlapped, incidence of TB-HIV co-infection have contributed to one of the highest rates of DR-TB worldwide. Individuals who are co-infected with tuberculosis and HIV have an increased mortality risk as a result of the synergistic interaction between the two diseases (Lelisho et al., 2022). An estimated 7.5 million individuals are now living with HIV; of these, KwaZulu-Natal (KZN) has the highest co-prevalence of HIV and tuberculosis (TB) in the nation, exceeding 90 percent among XDR TB patients (Kapwata et al., 2017). Additionally, the province bears the greatest burden of drug-resistant tuberculosis, with all eleven districts exhibiting resistance rates that beyond the national norm (NDoH, 2019a).

The epicentre of the TB, XDR-TB, and HIV/AIDS emergence in South Africa lies in KZN. According to the study conducted by Seung et al. (2015), the primary factors contributing to the proliferation of resistant tuberculosis strains include inadequate medical infrastructure, treatment errors that exacerbate resistance, and continuous transmission among institutions and communities. Additional research carried out in South Africa has shown that the

ineffective treatment and cure of MDR-TB patients is a factor in the emergence of XDR-TB (Mlambo et al, 2008; NdoH, 2019a).

The 2018 United Nations High-Level Meeting on the battle against tuberculosis, the Sustainable Development Goals, and the End TB Strategy established objectives that are improbable to be achieved (Monedero-Recuero et al., 2021). Although, the global progress made in tuberculosis control and specifically XDR-TB treatment, has been adversely affected by the unprecedented COVID-19 pandemic, (Monedero-Recuero et al., 2021; Tibmaeri et al., 2022; WHO, 2022), TB programs were already behind schedule prior to the emergence of the pandemic (Sahu et al., 2020; WHO, 2022; Chakaya et al., 2022). In South Africa, Murdoch et al., 2021, show that the public health care systems exhibit suboptimal performance in terms of the effectiveness of tuberculosis control measures, as shown by the country's high rates of patient default and non-adherence.

Historically, the 1980s brought the initial reports of resistance to primary drugs used to treat TB and in the 1990s, individualised regimens based on drug susceptibility tests were used - a shift from the standardised regimens advocated by the DOTS (Directly Observed Therapy strategy) (Cox et al., 2017). However, due to the rapid increase of the DR-TB burden in South Africa, policy guidelines provided by the National TB Programme included individualised or standardised treatment for MDR-TB (Cox et al., 2017). The first cases of XDR-TB, were identified in 2006, following an outbreak in Tugela Ferry in KwaZulu-Natal (Chiposi et al., 2021). This prompted various revisions of treatment guidelines for MDR-TB and XDR-TB patients (Cox et al., 2019).

It has been documented that XDR-TB is a challenging form of the disease as it is associated with diagnostic and treatment complexity, high morbidity rates, and is responsible for mortality rates of around 60%. (Dheda et al., 2017). In this setting, inadequate identification facilities for XDR-TB, a lack of availability of patients' past treatment histories (Dheda et al., 2017), and a general scarcity of healthcare resources have impacted patient care (Iruedo & Pather., 2023; Seloma et al., 2023;).

Decentralised and de-institutionalised care for patients with DR-TB was introduced in South Africa in 2011. This policy entailed the transfer of DR-TB treatment responsibilities to primary care settings, which are outpatients (Pietersen et al., 2023). It is worth noting that patients with XDR-TB may continue to receive hospitalisation. A policy framework on decentralized and deinstitutionalized management for multidrug-resistant tuberculosis in

South Africa was changed in 2019 to specify whether patients will get inpatient, outpatient, or home-based care. However, despite the improvement of treatment procedures brought about by decentralization, treatment results remained low owing to health system obstacles (Loveday et al., 2018). Patients who have actively pursued treatment frequently encounter challenges in managing the economic and social repercussions associated with extended identification and management processes (Murdoch et al., 2021). This can result in adverse health outcomes, including non-compliance with prescribed regimens, which furthers the spread of the disease (Gebremariam et al., 2021). The co-epidemic of HIV and tuberculosis has profound ramifications on the health status and prognosis of patients. In addition to the biomedical complexities associated with co-existing conditions, there is a significant correlation between lay interpretations of XDR-TB and HIV/AIDS (Daftary et al., 2021; Edginton et al., 2002). This association is expected, considering the considerable co-morbidity rates between the two diseases, particularly in KwaZulu-Natal where the co-infection rate exceeds 90 % (Kapwata et al., 2017).

Treatment results have been impacted both positively and negatively by the DOT method. By effectively accomplishing its principal aim of guaranteeing compliance with medication regimens, DOT has significantly contributed to bolstering patients' trust in their capacity to implement beneficial health behaviors (Thomas et al., 2022). Conversely, the DOT intervention seems to fall short in sufficiently attending to patients' need for self-empowerment and motivation in relation to their health condition (Chakaya et al., 2021; Metcalfe et al., 2015). According to the reviewed literature, health practitioners often lack insight into the decision-making processes of their patients (Chittenden, 2022; Molina-Mula & Gallo-Estrada, 2020; Sagbakken et al., 2013). Adherence is not only a two-dimensional concept in which the patient is obligated to comply with the treatment recommendations of the health professional but also a complex journey where the patient's beliefs, lifestyle and social support systems play an important role in achieving successful outcomes. It may be very challenging to predict patients' adherence behavior and guarantee that they are encouraged to take an active part in determining their health outcomes in the absence of consideration for the significant impacts of societal, personal, socioeconomic, and psychological variables (Akeju et al., 2017). Furthermore, systematic reviews show that DOT treatment showed no benefit when compared to self-administered therapy in drug resistance therapy (Dheda et al., 2017). Maraba et al. (2021) evaluated the use of adherence medication

monitoring systems among patients and found that although this system did support patients' adherence, operational challenges such as availability of electronic devices, access to the Internet etc. prevent implementation of this system in South Africa.

Therefore, in conjunction with critical clinical research focused on enhancing the effectiveness of pharmaceuticals, it is imperative that we initiate an investigation into patients' health-seeking behavior to acquire knowledge regarding the obstacles and advantages they perceive in relation to treatment. These insights will contribute to the advancement of information about the determinants that impact patients' health motives, level of effectiveness, and knowledge pertaining to certain health issues (XDR-TB). An invaluable resource for the development and implementation of effective health promotion interventions would be knowledge regarding the processes through which TB/XDR-TB patients define themselves as ill, interpret their symptoms, and assign meaning to the specific social consequences of TB/XDR-TB. Furthermore, this understanding would reveal how these contextual factors influence their decision to seek or adhere to treatment.

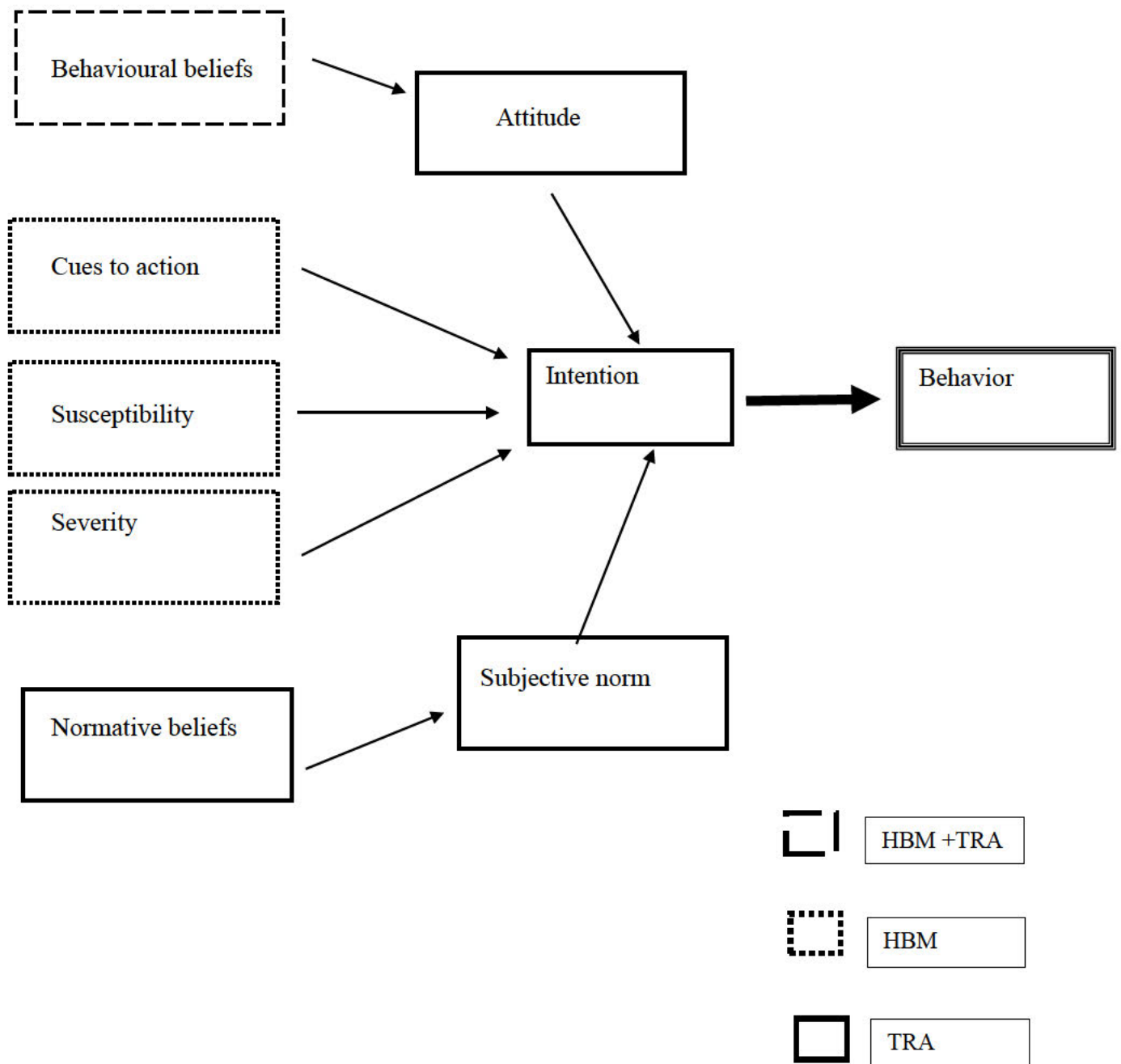
Socio-psychological theories contribute significantly to the comprehension of health behavior by elucidating its dynamics and the consequences of external influences. The HBM assesses all significant aspects of health-seeking behavior using categorical parameters (namely perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers, and self-efficacy). When considering health-seeking behavior, the TRA highlights the significance of intention as a fundamental predictor of such behavior. This focus provides a practical application for researchers. A combination of the HBM and the TRA was used in the context of this research to facilitate a qualitative, culture-centered analysis of the health-seeking behavior of XDR-TB patients. The TRA and the HBM may not be optimal models for explaining health-seeking behaviour, exclusively; however, the application of select constructs provides significant correlation between these models.

The present research

The present study aimed to gain insight into the health-seeking behaviour of adult patients with extensively drug-resistant tuberculosis (XDR-TB). This study aims to examine this phenomenon from the patients' point of view. In light of the potential for age, gender, and ethnic identity to influence the intricacies of patients' health-seeking behaviour, a decision was made to concentrate on a relatively homogeneous cohort of participants who possessed similar attributes that rendered them exceptionally susceptible to the development of extensively drug-resistant tuberculosis (i.e., patients with a history of multidrug-resistant TB, of Black origin). Consistent with the view that health-seeking behaviour for XDR TB patients differs from one person to another and that the reasons for health-seeking of patients are so varied (Bhattacharya et al., 2019), the research involved detailed focus group discussions, with these discussions being designed to explore factors that mediated their health-seeking behaviour at multi-systemic levels.

Theoretical Framework

Figure 1: Theory of Reasoned Action and the Health Belief Model



To get insight into the determinants of an individual's health behavior, one must first establish a clear definition of health behavior itself. Tlou (2009) defines health behavior as any action an individual does to preserve or enhance their health. It is possible to broaden this concept to

include health protective behaviour, which describes actions taken by an individual with the belief that such actions promote or safeguard their health.

The TRA (Fishbein & Ajzen, 1975), which Martin Fishbein and Icek Ajzen developed as a theory of human behavior, postulates that a person's behaviour is influenced by their views (Tlou, 2009). Vallerand et al. (1992) propose, in their interpretation of the TRA, that an individual's action is mostly influenced by two factors: their attitude towards the activity and subjective norms, which are social constructs representing the expected conduct of others. The TRA seeks to explain how an individual's behavior is influenced by the interplay of beliefs, attitudes, and attention. Moreover, the theory posits that humans are rational beings who consciously assess a certain course of action based on the knowledge at their disposal (Poss, 2001).

While the primary objective of the TRA was to understand and predict behavior, it is also a valuable tool in identifying critical intervention target areas that aim to modify health-related behaviours. However, one of the principal criticisms of the TRA is that it explores individuals' intent rather than their behaviour and this conflicts with most healthcare research which aims to understand behaviour. Behaviour is not always driven by an individual's attitude and motivation towards their health but can also be influenced by other aspects (Lauver, 1992). Another criticism of this theory is that it is time-consuming because it requires the researcher to research relevant behavioural and normative beliefs in the sample before developing the instrument (Poss 2001); however, this methodology can be considered a strength as it includes culturally based explanations on behaviour.

The HBM can be used to facilitate a qualitative investigation of the health-seeking behaviour of XDR-TB patients. This model is relevant to the exploration of the health-seeking behaviour of XDR-TB patients as it provides a framework to understand the factors influencing individuals' decisions regarding their health behaviour. The definite constructs of the model include an evaluation of all relevant aspects of health-seeking behaviour (viz. perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers, and self-efficacy), and can be applied to simplify the complex decision-making processes that inform health behaviours. A limitation to HBM is that it does not account for

individual determinants, such as attitudes or beliefs that inform behaviour (Taylor et al, 2006).

In the context of extensively drug-resistant tuberculosis (XDR TB) inpatients in KwaZulu-Natal (KZN), the integration of the HBM and the TRA can provide insights into their health-seeking behaviour. According to the HBM, individuals are more likely to seek health care if they perceive the severity of XDR TB and believe that the recommended actions, such as adhering to treatment, will effectively address the threat. For instance, if an XDR TB patient understands the severe consequences of untreated disease, such as increased mortality or further transmission, they are more inclined to seek medical assistance and adhere to treatment. However, a limitation of the HBM is that it does not consider the perceived significance of social factors that may reduce health motivation and contribute to poor adherence to treatment. The TRA introduces the influence of subjective norms and individual attitudes. In the case of XDR TB inpatients, societal expectations and the perceived approval or disapproval of significant others can affect their intention to seek health care. For example, if the community places a high value on prompt and comprehensive medical care for TB, individuals are more likely to act in accordance with those social norms. Therefore, the integrated argument suggests that the health-seeking behaviour of XDR TB inpatients in KZN is influenced by their perceptions of disease severity, beliefs in the efficacy of recommended actions, and social norms that shape their attitudes toward seeking medical help. This comprehensive understanding can guide interventions and healthcare strategies tailored to the specific dynamics of the local context.

A strength of the combined model is that the HBM focuses on individual perceptions and beliefs about health risks and benefits, while the TRA considers the social influences and subjective norms. Combining the two allows for a more holistic understanding of both individual and social factors that shape health behaviour.

Several studies based on TRA or the HBM have incorporated variables from one model into the other, as these two theories have common characteristics. Firstly, according to Poss (2001), both HBM and TRA assert that an individual's behaviour is determined by the perceived value and likelihood that a particular action will yield the anticipated result. Secondly, both models propose that behavior can be predicted by beliefs regarding the outcomes of the action. It can be hypothesised that combining variables from one model with another may result in shortcomings in the context of cross-cultural research. Poss (2001)

submits that by integrating the two models, several concepts may be coalesced to improve parsimony in research. This synthesised theoretical framework may address concerns over models that have been used to explore health-seeking behaviour that may not be suitable for studying participants from diverse cultural backgrounds, as is the case in the current study.

Research Methods

Research Context

This researcher acquired a secondary data set from an overarching research project: MDR-TB treatment adherence in KZN. Written consent was obtained from the principal investigator, Dr S. Valjee (see Appendix C), for the purpose of generating the prepared publication.

The current research included a consolidated interpretation of themes derived from the primary data. This flexibility allows researchers to generate novel insights or evaluate new but similar hypotheses without the need for extensive data collection efforts (Long-Sutecall et al., 2011).

There are distinct reasons for using a secondary data set in research (Long-Sutecall et al., 2011). In order to do further analysis of an initial dataset or a subset thereof, secondary analysis was therefore implemented in this study (Heaton, 1998; Hinds et al., 1997).

In a study by Long-Sutecall et al. (2011) exploring the secondary analysis of qualitative data, the researchers outline that this method of analysis can be effective when there are barriers to conducting primary research. The Covid pandemic has made accessing an elusive population to conduct health-seeking behaviours in TB patients challenging.

There are numerous benefits to this research method. Cheng & Phillips (2014), suggest that this is a cost-efficient and time-efficient way to make use of data that has already been collected to address new research questions or to refine the results of the primary results from the original study.

Despite the fact that the disease burden of tuberculosis has decreased in the majority of high burden nations throughout the last three decades, meeting the WHO's "End TB Strategy- Global Strategy and Targets for Tuberculosis Prevention, Care and Control After 2015" goals to end TB is still challenging (Ding et al., 2022). This research intends to utilise longitudinal information provided in the secondary data analysis to examine trends, changes in disease patterns, treatment outcomes, and long-term effects of TB interventions.

Research Participants

The primary data set consisted of all adult patients (n=12) diagnosed with MDR TB at a district health center in Durban. Saturation sampling was utilized in this study due to the limited size of the population. Additionally, gender was considered an independent variable in light of established gender disparities on various tuberculosis-related matters, including treatment adherence rates (Lima-Chantre et al., 2022) and social repercussions of the disease (Sudha et al., 2008; Habib et al., 2021; Hatherall et al., 2019; Karim et al., 2011). A cohort of patients who were identified as treatment-resistant from the original study, who went on to develop XDR-TB, were included in the current study (i.e., male; n=6) and female (n=6).

Table 2 : Demographics of respondents in the study

Participant No.	Age	Gender	Highest Level of Education	Employment Status	XDR-TB Diagnosis	History of non-adherence
PxM1	42 years	Male	No Formal Education	Unemployed	Positive	Yes
PxM2	27 years	Male	Grade 8	Unemployed	Positive	Yes
PxM3	30 years	Male	Grade 9	Unemployed	Positive	Yes
PxM4	33 years	Male	Grade 12	Employed	Positive	Yes
PxM5	41 years	Male	Grade 12	Part Time Employment	Positive	Yes
PxM6	33 years	Male	Grade 11	Employed	Positive	Yes
PxF7	36 years	Female	Grade 11	Employed	Positive	Yes
PxF8	29 years	Female	Grade 11	Unemployed	Positive	Yes
PxF9	35 years	Female	Grade 11	Unemployed	Positive	Yes
PxF10	33 years	Female	Grade 8	Employed	Positive	Yes
PxF11	39 years	Female	Grade 12	Employed	Positive	Yes
PxF12	41 years	Female	Grade 12	Employed	Positive	Yes

Method of data collection: Focus Group Discussions

Qualitative data collection was achieved through the use of focus group discussions in order to attain a more profound comprehension of patients' interpretations of their illnesses, the precipitating events that led to their illnesses and hospitalization, their treatment pathways, and perceived socio-economic barriers to treatment efficacy. To fulfill the aims of the primary research, a 90-minute semi-structured focus group program was developed and data from a

cohort of XDR-TB patients was included (See Appendix A). The development of the focus group's core themes was informed by a review of pertinent empirical literature (Hatherall et al., 2019; Lima-Chantre et al., 2022; Moodley et al., 2020), consultation with recognized experts in research methodology and XDR-TB at the national and international levels, and two semi-structured interviews with key management personnel at the district health care facility (i.e. the Deputy Medical Superintendent, and the head matron).

Procedure

In addition to the written consent obtained from Dr. Valjee (Principal Investigator – MDR TB treatment non-adherence in KwaZulu-Natal Project), ethical clearance for the study was obtained from the Humanities and Social Science Ethics Committee at the University of KwaZulu-Natal (HSSREC/00006219/2023).

Four focus groups were completed with in-patients with adult XDR TB who had a documented history of MDR-TB in the past. Each focus group consisted of male and female participants. All study participants that were identified were Black African, and their first language was isiZulu. Consequently, every focus group conversation was carried out in IsiZulu and recorded in audio format. Two isiZulu-speaking fieldworkers (University of KwaZulu-Natal-trained clinical psychologists) facilitated the data collection. These individuals had completed rigorous focus group training and were engaged as data collectors for the core research investigation.

In addition to seminars on focus group tactics and skills, the training provided fieldworkers with knowledge from the evaluated literature about major elements of tuberculosis, MDR-TB, and XDR TB.

The researchers assumed the responsibility of co-facilitating the session, documenting field observations, overseeing the audio equipment, and providing clarifications to concerns expressed by members in the focus group.

In accordance with the primary research project, after completing thematic analysis, the data was refined through a series of meetings between the researchers and the data collection team.

Ethical considerations

Ethical clearance for the study was obtained from the University of KwaZulu-Natal's Humanities and Social Sciences Ethics Committee. The Centre for Applied Psychology at the University of KwaZulu-Natal was consulted for approval. Informed consent was obtained from each participant, and participants were provided with details of the nature and objectives of the research study. Each participant was made aware of their privilege to withdraw their participation from the study at any stage without any negative consequences. Confidentiality was assured as pseudonyms were used on the interview transcripts. Permission from each participant to audio-record the interview was sought.

When considering ethical issues in the use of secondary data, Omari (2021) highlights that in the context of the need for revised data ethics, the use of secondary de-identifying data can protect participants' confidentiality. Although Long-Suthehall et al. (2011) highlight that although informed permission cannot be assumed in secondary analysis, the agreement obtained in the main research is enough provided the research questions posed in this study are relevant to the purpose of the original research.

Results

The HBM offers a comprehensive framework for examining the health-seeking behavior shown by individuals with XDR-TB. However, in order to enhance our understanding of patients' health behavior, elucidate the complexity of the behaviour as well as the impact that external pressures have on their behaviour, a new model developed by Poss (2001) representing a synthesis of the HBM and the TRA was also included in the discussion.

Perceived susceptibility

Multiple inferences can be drawn concerning the perceived susceptibility of patients to XDR-TB. Male and female participants both had insufficient understanding of XDR-TB in regard

to patients' knowledge. Patients exhibited comprehension of the distinctions between MDR-TB and XDR-TB as follows: a) medication: recommended treatment for XDR-TB patients is an all oral regimen replacing the injectable-based regimen; b) the duration of admission: patients with XDR-TB can remain in the hospital for an unknown period during the acute phase of treatment, and once stable discharged to home or community-based care; c) the virus's potency: they perceived the XDR-TB virus to be considerably more potent and potentially more life threatening than the 'strong TB', MDR-TB virus.

PxM1 (male): I had tuberculosis for six months and got treatment for it, but I didn't feel better because I kept feeling weak. Once I got to the hospital after six months of treatment, I continued to be weak and not eat. I was sent there for a long time. People told me I had XDR-TB, but I still got the same treatment.

A considerable proportion of male respondents attributed the distinctions between MDR-TB and XDR-TB to variations in treatment approaches for each disease. Male respondents gave no prior awareness of XDR-TB prior to their hospitalization. Both male and female participants identified their ignorance of the disease as a substantial factor influencing their behavior. Consequently, they experienced a lack of concern regarding their prognosis prior to receiving treatment and they only developed an understanding of the gravity of the condition during treatment. A substantial percentage of male participants ascribed the differences between MDR-TB and XDR-TB to discrepancies in treatment regimens. The majority of male patients stated that their susceptibility to XDR-TB was heightened due to their dependence on alcohol and tobacco. Male patients admitted to being unaware of XDR-TB prior to their admission to the hospital. Both the male and female participants cited their limited understanding of the condition as a significant determinant in shaping their behaviours. Consequently, they were unconcerned about their prognosis prior to treatment, and it was only through available drug-susceptibility testing that was an indicator of XDR-TB, and the commencement of their treatment, that they realised the severity of their prognosis.

PxM4 (male): XDR-TB is a type of TB which does not respond to tablets and requires different treatment. I came to this hospital now, but prior to coming here, I stayed for 6 months in another hospital where I was being treated for MDR-TB. When my coughs did not stop, they transferred me.

PxM3 (male): I haven't been taking good care of myself. I used to smoke cigarettes and drink alcohol until recently. When I felt better, I drank a lot, which made my condition worse. I think drinking made me weak and open to getting sick from germs and viruses.

Furthermore, patients ascribed the healthcare provider's failure to provide sufficient information regarding the necessity of lifestyle modifications as an oversight, thereby attributing the development of their health condition to the institution itself. Hence, these perceptions suggest that these individuals consider their health to be predetermined and beyond their own influence and subject to external factors, which would inevitably lead to negative health behaviours and outcomes (Obadiora, 2016; Wallston et al., 1978). Secondly, patients' understanding of the methods by which they could contract XDR-TB provided insight into their subjective perceptions of the risk of contracting the disease. Male respondents detailed a range of methods by which they contracted multidrug-resistant tuberculosis, including hospital-acquired transmission, working in very dusty conditions, and obtaining the illness while in hospital (e.g. via blankets, food intake and toilets). Female participants shared the sentiments of their male counterparts regarding inadequate hygiene control in the hospital setting, particularly regarding sanitation. The residents complained of unsanitary conditions in the wards and that they had to use contaminated utensils and ablution facilities. They claimed that these conditions increased their susceptibility to developing XDR-TB.

If valid, the patients' accounts of inadequate environmental and sanitary management at the hospital are concerning. Many of these patients showed misinformed perceptions about ways in which this disease is transmitted and consequently inaccurate assumptions about how to curb the spread of this disease. Fana et. al (2019), report on the stigma of TB. The authors describe the stigma of TB and its correlations with "dirt." Furthermore, these authors show that low perceived susceptibility and lack of knowledge regarding prevention practices of the disease has implications for the continued transmission of this disease. With regards to perceived susceptibility, patients poor knowledge of what puts them at risk for transmission of XDR-TB highlights a sense of helplessness and lack of acceptance of their diagnosis. Therefore, those respondents who did not adhere to the previous prescribed treatment

regimen, attributed their illness to “external forces” without acknowledging the role of their behaviour towards their health status (Halimi et al., 2010; Wallston et al., 1978).

Perceived severity

PxM2 (male): To begin, you must get treatment for six months. You have to keep taking it for another 18 months if you don't get better. It's for two years only. You never know if you'll get better or not.

With regard to patients' assessments of the gravity of XDR-TB, a considerable percentage of male and female respondents expressed increased degrees of apprehension over treatment protocols and the possibility of a poor prognosis. A correlation was observed between severity and patients' perceptions of symptom remission, as the former served as an indicator for patients to discern whether the treatment was effectively improving their health status.

PxF9(female): The fact that I was told I had XDR-TB didn't bother me much because I didn't know what it was. It's what I call "extra TB."

Patients showed a limited understanding of XDR-TB and consequently lacked awareness regarding the severity of the diagnosis, regarding it exclusively as "extra TB." Male and female patients alike frequently mentioned this term, doing so in connection with XDR-TB and tuberculosis that failed to improve despite treatment. A lack of knowledge regarding the circumstances resulted in a reduced recognition of the severity of XDR-TB prior to admission. A male participant expressed his feelings regarding the disease using the idiom "akukho mango ongenaliba", which translates to "there is no hillside without a grave and death is inevitable." This statement provides an understanding of how the disease is perceived as a "death sentence" and the associated emotions of hopelessness and helplessness. Related to the issue of powerlessness, a considerable proportion of male respondents concurred that healthcare practitioners demonstrated inadequate awareness of their social obligations and duties, as exemplified, for instance, by the uniformity of pass-out durations for every patient.

PxM6 (male): I was working before I went to the hospital, but since I've been there, my employers have stopped paying me. So, I couldn't take care of my family and

felt like I had been left behind. In fact, being in the hospital is like being locked up.

This general complaint not only signifies patients' inadequate comprehension of the severity of XDR-TB and its transmission, but also highlights the dearth of social support systems for individuals undergoing treatment for an extended period. These circumstances necessitate that patients make complex decisions regarding whether to comply with in-patient treatment or abscond from the ward to deal with their personal and familial obligations. In a study by Daftary et al. (2021), newly diagnosed drug-resistant TB patients felt fear, confusion and destabilized. Many patients 'ducked' treatment in order to fulfil their personal responsibilities.

According to other studies female and male patients who saw a decline in their interpersonal relationships ascribed this to a pervasive ignorance of the condition among the general population (e.g., Javed et al., 2016; Onyango et al., 2020; Sima et al., 2019; Suwarni et al., 2020).

PxM5 (male): Government should teach people about DOT because some people who get tuberculosis think they are cursed. There is not enough information for the people in the communities.

According to previous research (e.g., Sudha et al., 2008; Hatherall et al., 2019; Karim et al., 2010), female TB/XDR-TB patients experience more peer rejection than males as a result of the social stigma associated with the disease. However, in the present study, male participants reported more severe interpersonal relationship conflict with their partners than females. This was attributed to prolonged hospitalization and the inability to provide a sustainable income to support their families. Related to the socio-economic challenges of patients, a study in the Eastern Cape Province, reported high perceived severity of DR-TB respondents and the consequences of untreated DR-TB; however, almost half of the participants were unconcerned with the diagnosis as they viewed their condition as a source of income via disability grants (Fana et al., 2019). This is an example of the systemic influences that the HBM fails to account for. In general, adverse social outcomes have more extensive ramifications due to the stigmatization and rejection of patients by their families and communities (Datiko et al., 2020; Edginton, 2002; Sommerland, 2020). This further amplifies

the severity of their conditions, particularly in light of the protracted treatment that patients endure.

PxF11 (female): My family didn't want to see me at first. Over time, they started coming to see me here more often. Some family who used to get along great with me have dropped me and never come to see me here. Some people in my family think I might have HIV.

Health Motivation

Concerning this construct of the HBM, the results of this investigation raise several significant concerns. The initial concern pertains to participants perceived lack of autonomy in decisions about their health. Most male and female patients described their encounters with healthcare settings, such as outpatient clinic consultations, DOT, and in-patient treatment, as inherently disempowering.

PxM2 (male): I'm not told ahead of time if my medication doses change. It scares me to question the staff because I'm afraid they'll push me away.

PxF7 (female): Other people treat you badly because it makes you feel less responsible.

Most male participants indicated they were not sufficiently apprised of their health condition throughout treatment. They attributed this deficiency to inadequate patient-professional communication.

PxM6 (male): From January to November, I took my tablets daily as directed, but they didn't work. I was moved to the hospital. The nursing sister, not my doctor, told me I had XDR-TB.

On many occasions, it was evident that patients were not given the opportunity to make decisions about their own treatment. This may occur if medical experts attribute the patient's existing condition to noncompliance with the prescribed treatment regimen. Consequently, patients who have developed the condition may have been less motivated to take their medication and less able to adhere to their treatment programs due to the physicians' presumptions. This is because medical professionals believe that such beliefs result in

patients non-compliance with prescribed medication and subsequent exacerbation of their disease (e.g. potential delays in diagnosis, mismanagement of tuberculosis cases, sociocultural influences, etc.).

Most of the participants (male and female) indicated that XDR-TB does not discriminate among individuals and that non-adherence of treatment regimens does *not* correlate with an increased risk of contracting the disease.

PxM1 (male): XDR-TB doesn't care who you are; anyone can get it.

Despite participant accounts indicating that medical practitioners had advised them that non-compliance with the treatment was a significant factor in developing XDR-TB, this perspective continued to dominate. According to the participants, health care professionals frequently erred in their presumption that they failed to comply with prescribed treatment plans. Furthermore, even when this assumption was accurate, health care professionals exhibited a limited comprehension of valid reasons for patients' non-compliance, such as adverse medication reactions, social and familial circumstances, inadequate patient knowledge regarding XDR-TB and the treatment protocol, and detrimental side effects of medication. This led to adverse and occasionally antagonistic attitudes and conduct on the part of healthcare practitioners, diminishing patients' accountability for their own treatment. To compound an already demanding situation, patients reported that engaging in productive discussions with health workers about these issues was an extremely difficult task.

It has been reported that ineffective patient-provider communication is a significant barrier to favourable health outcomes, such as treatment adherence (Akeju et al., 2017; Arakelyan et al., 2021; Gashu et al., 2021; Molina-Mula & Gallo-Estrada, 2020). It is imperative to acknowledge that treatment adherence research has predominantly been conducted from the standpoint of healthcare professionals, with limited consideration for patients' decision-making processes. (Chittenden, 2022; Moodley et al., 2020; Sagbakken, 2013).

PxM4 (male): We were told that not getting treatment when you should have been what causes XDR-TB when we got here. We feel bad because we're being blamed for it.

There is a natural predisposition to attribute blame and label patients as "problematic" (Dheda et al., 2017; Nathavitharana et al., 2017) without taking into account the cognitive process through which patients evaluate various aspects, including treatment side effects, financial and social costs, and the long-term ramifications of their health decisions (Dheda et al., 2017). Conventionally, therefore, "treatment adherence" denoted that patients were to comply with the wishes of their healthcare providers and had little choice but to follow the instructions they were given (Molina-Mula & Gallo-Estrada, 2020). The influence of patients' personal and social circumstances, in addition to their perceptions, on their health-seeking behaviour and decision-making processes has been demonstrated to be significant (Akeju et al., 2017; Shatil et al., 2019). In order to greatly enhance patient adherence to therapeutic regimens, it is critical to foster supportive patient-provider relationships (Gashu et al., 2021), which empower patients to take an active role in their healthcare (Myburgh et al., 2023) and cultivate a sense of control over their health outcomes (Moodley et al., 2020).

In summary, health motivation overall of patients in this research was significantly low, which led to unfavourable prognostic and therapeutic outcomes. Patients' lack of health motivation stems from two primary factors: a sense of fundamental disempowerment inflicted by institutional health care providers and the externalisation of the responsibility for their healthcare decisions to the community via the DOTS strategy. The WHO endorsed Global Plan to End TB 2023–2030 emphasises, 'people-centred care' as a priority. (WHO, 2022). The document advocates improvements to TB care programs that entail changing the program's focus from its historical focus on disease control to one that acknowledges TB patients' needs, seeks to empower them, and builds relationships of trust between patients and health care providers. (Myburgh et al., 2023).

Perceived Benefits

Male participants in the study expected their health to improve when they followed treatment protocols rigorously. Particularly regarding the correlation between medication duration and symptom remission, such responses demonstrate a lack of comprehension of the treatment protocol. Due to the absence of a rapid improvement in their health status, several participants failed to perceive the treatment as potentially effective.

PxM3 (male): I went through treatment for six months. After three months, I stopped coughing and didn't feel so weak all the time. I stopped taking my medicine at that point because I thought if I felt better, there was no reason to keep taking it.

Solanki et al. (2022) have shown that non-compliance with tuberculosis medication can be attributed to several factors. These include the perception of improved health status upon symptom resolution, limited knowledge regarding the disease and its treatment options, apprehension regarding potential side effects, the substantial number of pills to be taken, and resistance to adhering to a long-term drug regimen. Fekadu et al. (2022) shows that the conventional injectable based regimens for XDR-TB treatment and long treatment duration showed a low success rate. Updated WHO treatment guidelines recommend an all-oral drug regimen for DR-TB which includes the novel drug Bedaquiline (WHO, 2022). Although positive treatment outcomes with Bedaquiline have been described (Ndjeka et al., 2022), adverse effects of the drug require additional treatment. This increases the 'already' high pill burden and may influence patients' adherence to treatment (Gaida et al., 2020). Morkbak et al. (2017) provide an alternative interpretation of adherence by contending that individuals attribute significance to current-day results. This 'present-bias' is one conceivable way by which non-adherence may occur (Irvine et al., 2022). Given this, one might postulate that individuals who had predicted that adhering to treatment plans would result in "rapid" symptomatic relief (as they did during tuberculosis treatment), would hold the same expectation while undergoing XDR-TB treatment. Consequently, the absence of a rapid amelioration in their symptoms resulted in their negative assessment of the advantages of their present plan of action.

Predominantly male patients attributed the onset of XDR-TB to a deficiency in the initial diagnosis and provision of suitable treatment by healthcare practitioners, which failed to prevent complications of the disease.

PxM5 (male): Ukungaphathwa kahle ngokunakekelwa kwezempilo (mismanagement by health care workers) especially when it comes to treatment as a cause of the disease. If my treatment had been geared toward XDR-TB from the start, I would have gotten better quickly.

PxF8 (female): At first, I thought I had the flu, so I went to a nearby clinic for help. There, they gave me cough syrup and tablets. I didn't show any signs of getting better. After that, it was determined that I had MDR and was put on treatment for four months. When my condition did not improve, I was transferred to the hospital...my new physician diagnosed me as suffering from XDR-TB.

The participants held a firm belief that the delay in diagnosis had potentially compromised their health status. According to the TRA, these individuals attribute their beliefs to the influence of *powerful others*; for instance, they may hold a firm conviction regarding the healthcare facilities' capacity to cure any illness and, as a result, ignore health promotion communications. Therefore, although there may have been a few instances of delayed diagnosis leading to the development of XDR-TB, inadequate treatment adherence for the initial tuberculosis condition accounted for the majority of cases.

In the context of the limited availability of healthcare services, Chiposi et al. (2021) address the issue of diagnostic delays by arguing that patients frequently delay seeking help at distant health facilities owing to the difficulty associated with waiting in line for a few minutes to visit a physician. It follows that the severity of the sickness will be the only determinant of health-seeking behavior in such a setting, and the inclination to seek medical attention for disease or illness screening is frequently quite low; therefore, it is not unusual for traditional or alternative medicine to be utilised in such situations. Determining where and by whom illness or disease is treated may be influenced by sociocultural factors and financial constraints when treatment options are being evaluated (Mbuthia et al., 2018; Steen et al., 1999).

Based on our multicultural dynamics, incorporating one's cultural understanding of patients' illnesses need to be addressed before advocating pharmaceutical interventions. This has been identified both nationally (Mbuthia et al., 2018; Steen et al., 1999) and internationally (Edginton et al., 2002; Kleinman, 1980).

The cultural beliefs and knowledge of tuberculosis that patients possess have an impact on their choices concerning the timing and source of assistance, frequently leading to treatment setbacks that patients have historically neglected to report. (Edginton et al., 2002; Mbuthia et al., 2018). In Kenya, for instance, attributing tuberculosis symptoms to witchcraft has been linked to delays in seeking professional treatment and exceptionally high rates of non-

compliance after treatment has occurred (Juma et al., 2022). By contrast, Edginton et al. (2002) describes beliefs in a rural district of South Africa about two types of TB, namely, 'Tindzaka', believed to be caused by breaking traditional rules, and 'Western TB'- characterised by cough. According to them, instances of delay were ascribed to patients' convictions that their condition ("Tindzaka") was incapable of being diagnosed or treated by a medical professional. As a consequence, some resorted to self-medication using "over-the-counter medications.". A considerable proportion male patients included in this research indicated that they had sought the advice of a traditional healer either before or during their biomedical treatment. The justifications for implementing this health intervention encompassed the necessity to complement biomedical treatment, the belief that traditional consultation could provide valuable insights into probable causes of the illness (such as sorcery or witchcraft), and the requirement to establish an unequivocal diagnosis.

PxMI (male): When I was sick for the first time, I saw a traditional healer. Traditional medicine really helped me when I was in hospital stays. I felt a lot better when I went back to the hospital.

Individuals' perceptions of how they experience their illness are described by explanatory models, which may inform culturally appropriate treatment. Kleinman's explanatory model has been extensively used to assist researchers in investigating the illness experiences of people (Kleinman, 1980; McSweeney et al., 1997). This model of illness explains how patients choose to deal with their condition and how they understand their symptoms in terms of the cause, nature, expected course, treatment, and ability to get better. Stonbraker et al. (2022) found that nurses and other clinicians are well-placed to provide culturally meaningful person-centered care that fosters enduring, trusting, and mutually respectful partnerships with patients, leading to improved health outcomes, by comprehending and honoring cultural beliefs concerning illness experiences and treatment preferences, and integrating this knowledge into their care. Steen et al. (1999) explain that a Western physician would explore the disease's mode of transmission. In contrast, a traditional healer would attribute a "meaning" to the disease (e.g., witchcraft), thereby identifying the "source" of the illness/disease, which would determine the specific course of action pursued. Morgan et al. (2012) suggest that healthcare providers adopt a “holistic bio-psychosocial-spiritual” approach when treating patients to urge patients to actively engage in their treatment and for clinicians to gain a deeper understanding of patients’ traditional beliefs.

These cultural systems also significantly impact community members regarding treatment choices. As a result, patients frequently turn to traditional methods of 'curing' illnesses, such as home remedies and traditional medicine, which frequently result in treatment setbacks and deteriorating health conditions. Modern health care, grounded in the bio-psycho-social framework, often addresses social concerns cursorily, failing to understand the significance of patients' health-seeking behaviours that are often categorised as "high-risk behaviour" and "non-adherence." Hence, it is critical to implement holistic interventions and interpretations to foster patient engagement in healthcare and guarantee positive health outcomes.

Notably, a considerable number of study participants who sought treatment from traditional healers to understand the 'true' cause of their ailments discontinued the recommended treatment because such measures failed to mitigate the disease's threat. Subsequently, these patients pursued biomedical intervention, perceiving it as potentially effective due to the persistence or worsening of symptoms. Although these results offer valuable insights into the combined use of traditional and biomedical services, they ultimately limit the perceived benefits of both immediate and prolonged biomedical care, which leads to adverse health outcomes.

Mbuthia et al. (2018) provide insight into how patients adopt combined treatment options. It was observed that individuals often began their health care journey with home or self-treatment, which was subsequently followed by medical treatment at a health facility. In cases where supernatural 'causes' were suspected, indigenous practitioners (known as 'Chepsakitian') were sought out almost continuously throughout the illness episode to provide additional support. As demonstrated in this research, the inability to attain prompt outcomes with the selected treatment approach, frequently prompted patients to transition to alternative treatment modalities. Given that the majority of respondents in this research indicated that they sought treatment for TB at medical facilities, it is important to consider that healthcare providers with similar cultural perspectives on diseases frequently explain illness in terms of biomedical systems, emphasising disease identification and treatment. Variations in interpretation have the potential to intensify mistrust and conflict between the healthcare provider and the patient, ultimately resulting in the patient perceiving the treatment as "inadequate." Although it is important to understand the cultural context of a patient's health-seeking behaviour., Nguyen et al. (2003) describe the “violence of inequality” when they examine the relationship between social inequality and health outcomes. They argue that

structural dynamics, such as poverty, social inequality, racism etc. and their social consequences inform disease patterns in society. Parker (2002) concurs with this as he argues that structural inequalities fuel the HIV/AIDS pandemic as it is within the context of poverty, gender inequality and racism that this disease continues to rage. As a result, cultural explanations of illness and the impacts of structural forces must be emphasized as potentially powerful elements that affect global health, patients' health-seeking behavior choices, and, ultimately, their health status and results.

Perceived Barriers

Perceived barriers are the adverse attributes of a certain health activity that have the potential to hinder the adoption of the suggested behavior. According to Carpenter (2010), this concept is a process in which an individual evaluates the anticipated advantages of a particular action in comparison to the perceived drawbacks, such as the action being costly, dangerous (with adverse consequences), distressing (distressing, challenging, or unsettling), inconvenient or requiring considerable time, and so forth. There have been several variables identified as barriers to the adoption and enforcement of healthy health behaviours. To begin with, patients showed insufficient knowledge of drug regimens, which had an adverse effect on their ability to endure the side effects of treatment. The situation was further complicated by few or no updates concerning their well-being throughout treatment, which once more detrimentally affected their judgment of the prescribed treatment's effectiveness. To quote:

PxM6 (male): Even if the doses of my medicines change, I'm not told ahead of time.

Questioning the staff would make me nervous, and I don't want them to leave me.

The female participants indicated that the uncomfortable side effects of their treatment for XDR-TB were unanticipated and had an adverse impact on their health behaviours. One might postulate that these individuals initially assessed the anticipated efficacy of their health interventions (biomedical treatment) with insufficient knowledge regarding the side-effects associated with the prescribed drug regimen.

PxF10 (female): I don't want to eat because of that strong pill. I'm really tired. It hurts my stomach sometimes.

PxF12 (female): It's impossible for me not to throw up after taking the medicine. My hearing is getting worse, and I have trouble seeing sometimes.

This would account for the participants' profoundly adverse impressions of treatment effects, which had an influence on their compliance with treatment protocols. Following this, Solanki et al. (2022) demonstrated a significant correlation between perceived obstacles to action patients face regarding medical regimens and their potential side effects and adherence. XDR-TB drug regimens are extensive, and treatment may include invasive surgical procedures and involve participants who are unaware of the associated side effects of drug regimens; as a result, they have a detrimental impact with respect to patient expectations about their treatment and its effects. Similarly, most of the male participants reported never being adequately informed about the effects of their medication.

PxF5 (male): We understand better when the treatment is explained to us.

Additionally, these respondents said that the diagnosis had no impact on them, attributing it to limited knowledge about the medication and potential side effects. In cases where health professionals warned participants of a few adverse effects (visual and auditory disturbances), they asserted that they had not encountered any such effects. This further eroded the confidence of the participants in both the healthcare provider and the treatment they were administered. A male participant proposed that patients be provided with a pamphlet detailing the treatment protocol and potential adverse effects of the medication in order to facilitate their comprehension of the treatment. In addition to patients' limited knowledge about XDR-TB and its treatment, many participants were not informed as to whether they were responding to treatment. They strongly believed that this information was 'deliberately' withheld from them.

PxM4 (male): I had TB for six months and got treatment for it, but I didn't feel better because I was still weak. When I was previously treated, I stayed for six months but kept getting weak and not eating. After that, I was sent to the hospital to stay for five months. I was told I have XDR-TB, but I'm still getting the same treatment.

Furthermore, individuals lacked knowledge about the mechanisms by which the various drugs used in their therapy contributed to the efficacy of their illness management, although they were familiar with the names of the drugs prescribed. Consequently, patients reported inadequate discussions prior to discharge or pass-outs. Kallon et al. (2022) report that patients discharged to primary care facilities for continued care felt anxious, hopeless, and powerless. Health workers' time constraints and high workloads were cited as reasons for the lack of containment for these patients' needs and feelings. These issues presented barriers to treatment adherence, health motivation, and favourable health outcomes. Kilbride et al. (2018,p.1) discuss the concept of 'medical paternalism' and explain that a central tenet of the paternalistic framework was that "doctors knew what was best for the patient". Thus, health care professionals took on a 'parental' role in patient interactions. Horter et al. (2016) argue that this creates asymmetry in the doctor-patient relationship thereby tainting the patients self-awareness and responsibility for their own well-being, subverting the patient's autonomy. Even though there has been a shift towards patient autonomy, informed by the internet and social media, Kilbride et al. (2018) explain that, in practice, healthcare practitioners still retain control over their patients because of the power associated with their medical knowledge and control over medical resources. As an additional obstacle to the treatment process, these social control duties of health care providers discourage patients from taking an active part in the management of their health problems. Mesko et al. (2017,p.1) discuss the concept of 'digital health'. They suggest that the paternalistic model of medicine is transforming to one that views the patient-physician relationship as a partnership. In the context of progressive medical technology, the authors advocate the use of technology that provides patients with the information and tools, which lead to shared decision-making and empowerment of patients. The study, however, outlines the challenges of digital health namely, 'dehumanising care,' risks associated with misinterpreted medical information, regulating un-authorized access to confidential information and the requirement of high health literacy. Delays in treatment and diagnosis were also seen as perceived obstacles to effective health behavior. A considerable proportion of the male participants expressed that the diagnostic procedure was both laborious and ineffectual. Despite adhering to the diagnostic protocol, these participants were not mindful of the potential for being diagnosed with XDR-TB due to their lack of education about the disease.

PxM6 (male): We understand treatment better when it is explained to us.

Therefore, it is possible to hypothesise that the participants had the expectation of timely and easy diagnoses in these cases and held the belief that their health behaviours would benefit and improve their condition. Based on their testimonies, the diagnostic technique fell short of these expectations, and the diagnosis lacked substantiality; thus, this had an adverse effect on their commitment to treatment.

The TRA, proposed by Fishbein and Ajzen in 1975, posits that an individual's behavioural purpose is intrinsically linked to his attitudes about participating in the behavior and the subjective standards he ascribes to it. Therefore, a person who firmly holds convictions of the positive outcome associated with a certain action would have a positive attitude toward that action. Following this, the participants' first views of their health actions were deemed positive as a result of their anticipation of anticipated consequences (i.e. early detection and treatment of their health condition). The following depiction of the prognosis as a life-threatening situation, insufficient explanation or awareness of the problem, and delays in diagnosis were viewed as obstacles to positive health behaviours and results.

Male and female patients who self-reported having little awareness of XDR-TB held the belief that medical professionals themselves had an inadequate comprehension of the illness. Consequently, they felt that substantial time had been lost administering MDR-TB regimens due to practitioners' inability to promptly identify the conditions. It was their conviction that the condition might have been more effectively managed and resolved more rapidly if XDR-TB had been identified as a primary diagnosis, as opposed to being diagnosed only after resistance to conventional therapy had developed. In accordance with Robert Merton's Theory of Global Health (Kleinman,2010) one could hypothesise that the social interventions (policy of decentralised, de-institutionalised care) had unintended consequences (high rates of misdiagnosed TB patients). Dheda et al. (2017) explains that South Africa's rapid transition to community-based TB care programmes occurred without ensuring that these health facilities were well-equipped to diagnose and treat patients effectively. This directly influences patients' confidence in the healthcare system's capacity to effectively manage their condition, thus serving as an additional perceived barrier to positive health outcomes. Thirdly, the manner in which patients responded to the diagnosis of XDR-TB revealed that they were experiencing challenges adjusting to a significant life event, which posed a substantial obstacle to treatment adherence.

PxF7 (female): When the nurse told me I would die from my type of tuberculosis, I was upset. I believed that because a professional nurse told me so. XDR-TB cannot show any symptoms for a while but starts up again in the end.

A considerable proportion of female participants who had received a diagnosis of XDR-TB reported manifesting symptoms consistent with Major Depressive Disorder, including sorrow, despair, tearfulness, and feelings of isolation. Mainga et al. (2022) found that mental health disorders such as depression and anxiety often resulted in poor adherence in patients treated for TB. When the mental health diagnosis preceded their diagnosis of TB, they found that this served as a barrier to seeking health-care. The adverse effects of these psychological consequences on patients' health behaviour (treatment adherence) are evident. When patients lack sufficient support services, they are faced with the difficult decision between the improvement of their quality of life against the risk of not adhering to treatment. Thus, the inability to manage patient distress through adequate supportive services negatively impact patients' capacity to cope with the stress associated with XDR-TB following diagnosis.

Phetlhu et al. (2011) explore the conflictual relationship between health care workers and patients co-infected with HIV and TB. Health workers perceive patients as harsh, stubborn, and difficult to work with. These negative perceptions of health workers may impact patients' access to healthcare. This creates a vicious cycle where unacknowledged and unattended emotions result in defaulting treatment, which exacerbates the situation as clinicians become frustrated.

Matakane et al. (2019) provide valuable insight into this vicious cycle by arguing that health care workers experience psychological stressors that require support and containment within their working environment. It was discovered that health care nurses held concerns regarding their ability to effectively cope with grief and high mortality of patients. These concerns manifested themselves in a hesitancy to deal with patients frustrations and fears and nurses often request that patients be transferred to another hospital. Furthermore, it was found that nurses who care for dying patients may experience psychological distress due to their own beliefs about death and this was compounded by patients own distress due to their illness. Additionally, Cremers et al. (2018) explain how the pessimism and irritation of healthcare professionals stemmed from what they saw to be irresponsible patient behavior. Solely focusing on the causes of patients' apparent non-compliance and the underlying dynamics of their "irresponsible" conduct may jeopardize the provision of appropriate patient care by healthcare professionals. Matakane et al. (2019) suggest that healthcare

professionals require support services and relevant in-service training to better equip healthcare providers to cope with the demands of treating critically ill patients with TB. The points discussed above, have particular significance when considering highly infectious illnesses such as XDR-TB. The apprehension of healthcare professionals regarding XDR-TB, stemming from concerns about occupational transmission, has been linked by Engelbrecht et al. (2019), Probandari et al. (2019), Sima et al. (2019), and Tudor et al. (2013) to uncaring and unsupportive staff attitudes towards patients. Such attitudes have the potential to adversely affect patients' treatment adherence and acceptance. XDR-TB, the most fatal form of tuberculosis, complicates things further by being transmitted by simple inhalation of contaminated air particles, in contrast to HIV/AIDS. Consequently, the imminent risk of patients transmitting MDR/XDR-TB significantly impairs the ability of medical staff to engage with patients and manage their fears.

Self-Efficacy

Concerning patients' self-efficacy, the absence of an appropriate protocol for addressing their concerns about treatment and care is a source of concern. Issues were raised about a lack of communication between health care personnel and patients over in-patient treatment and care, an apparent lack of mutual respect, and patients' concerns of victimization and intimidation by staff when patients expressed their complaints.

PxM3 (male): I want to be treated with respect. I think I was put down, and the staff isn't being nice, and genuine, and they treat us unfairly.

It could be hypothesised that these circumstances negatively impact patients' assurance in their ability to adhere to in-patient treatment procedures, considering that these complaints have been recognized by patients as barriers to developing and sustaining therapeutic relationships with medical personnel. An intriguing discovery linked to the level of trust female patients placed in their capacity to execute favorable health behaviors in response to the way in which they were treated by healthcare workers upon admission. Individuals who experienced a sense of prejudgment throughout the admissions process attributed their feelings to discrepancies in the quality of care provided by medical staff. Incidents such as these highlight concern regarding patients' requirement for continuous support from the moment they are admitted until the completion of their treatment, with the aim of restoring their confidence levels.

At a systemic level, organizational disempowerment is sustained in health care settings through the acceptance of a set of complex and rigid hospital regulations that shield health care professionals from the potential anxiety associated with making creative decisions and deprive them of the chance and fulfillment of resolving their problems (Matakane et al 2019; Cremers et al 2018). The authors describe how the frustrations and anger of health care workers stem from patients they perceive to be unmotivated and irresponsible. These intrapsychic anxieties may be mitigated by transforming the situation into an interpersonal conflict. Hence, it is plausible to propose that this "conflict" has materialized in the form of varying degrees of care that patients perceive throughout their medical care at a health facility, eroding their confidence in their abilities and hindering their complete adherence to their treatment regimen.

A considerable proportion of male participants reported having "decreased belief in themselves" (low self-esteem). This had an adverse effect on their capacity to make appropriate healthcare choices subsequent to becoming ill. Reduced self-esteem poses an additional obstacle to taking healthy actions and may even lead to the development of clinical depression in patients. This underscores the necessity for the institution to offer supplementary psychological and social work services. Rouf et al. (2021) show that in the syndemic relationship between depression and TB, depression in TB patients was a significant risk factor for treatment failure and defaulting treatment. Huque et al. (2020) suggest that depression among drug-resistant in-patients is associated with feelings of isolation and despair. In light of the established high prevalence of psychological distress (including symptoms of sadness and anxiety) among tuberculosis patients in South Africa, (Theron, 2015), it follows that TB management programmes need to include screening and mental health interventions to treat these psychologically distressed patients (Rouf et al., 2021). Consequently, the implementation of a methodical therapeutic intervention would empower healthcare professionals to fortify the patient-system connection, increase patient self-efficacy, and result in improved health outcomes and more efficient patient management.

Culturally diverse groups' health behaviours and beliefs have been effectively investigated through the application of the HBM, the TRA, and a model that combines the two (Poss, 2001). The TRA and the HBM share certain traits. Both are predicated on the notion that an individual's behaviour is determined by the value they assign to a specific outcome and their conviction that a particular action will lead to that outcome. As a result, both models propose

that attitudes regarding the consequences of actions ought to influence actions (Firouzbakht et al., 2021).

A normative component of the TRA looks at the fundamental issues and viewpoints of the group under investigation (Poss, 2001). In designing the present study, it was noted that in isiZulu society illness is believed to be caused by ancestral spirits of bewitchment ('Idliso'). Traditional healers play a crucial role in traditional healthcare. Based on this, Poss (2001) suggests that the concept of normative beliefs is essential in understanding intention and behaviour as it also helps to overcome the failure of the HBM to include culturally relevant constructs.

Discussion

To comprehend the health-seeking behavior of patients, a framework comprised of the HBM and the TRA was integrated. An amalgamation of the HBM and the TRA posits that persons who possess positive levels of health motivation and self-efficacy are more inclined to participate in health-seeking behavior if they perceive the susceptibility (likelihood of developing XDR-TB), severity of the illness (XDR-TB prognosis), and believe that taking the recommended health action (seeking medical care) will effectively mitigate the threat (improve their health status/benefit) without any negative consequences (barriers). Furthermore, individuals' intention to seek health care is influenced by expectations of the community and the perceived approval or disapproval of significant others.

The topic of health seeking behavior in MDR patients has been discussed in the primary study, demonstrating “pre-admission, admission, and post-admission” behaviour of patients. To advance knowledge this discussion has been constructed in terms of community, institutional and individual variables. This classification demonstrates that the health-seeking behaviour of XDR patients is heterogeneous and context dependent.

We found that for patients in the community, multiple factors contribute to patients’ diminished levels of perceived severity towards their health status. These causes encompass widespread lack of information and knowledge regarding MDR-TB and XDR-TB, lack of understanding of the decentralized primary care model, mistrust of information received, social stigma and community’s’ failure to recognise symptoms. Many patients felt defined by their condition and fear of stigma as well as cultural dynamics served to diminish their health motivation as the perceived obstacles outweighed the perceived benefits of seeking health care. This often resulted in patients hiding their symptoms and delayed health-seeking. Culturally rooted beliefs about illness add a layer of complexity to health seeking pathways. Prevailing cultural beliefs inform who (traditional healers, spiritual or western medicine) is consulted for health care depending on the meaning attached to symptoms, and the availability and accessibility of care. The use of multiple remedies and healing systems further challenges the management of this disease. Consequently, poor adherence to MDR-TB treatment can be linked to the development of XDR-TB. Although the DOT strategy aims to improve treatment adherence, it can be counterintuitive to patients’ health-seeking behaviour, as patients perceive DOT as depriving them of their agency over their health.

Once hospitalised, patients fear the worst and are overwhelmed by the narrative that conveys a poor prognosis of their condition. Hospitals do not achieve patient-centred care. Instead of providing a supportive, containing environment, this notion of ‘finality’ increased perceived susceptibility and further increased their perceived severity of their condition. Although according to the HBM, it could be predicted that this would lead to greater health motivation, patients’ dysfunctional coping mechanisms to deal with anxiety and fear result in denial or avoidance and thus, diminished health motivation. In addition, given the significant perceived barriers to health actions, patients are less motivated to overcome those barriers. The disempowering and dogmatic culture within healthcare facilities further exacerbates the psychological distress of the patient and results in negative health outcomes for patients individually, and the community at large.

Within the context of the decentralised and de-institutionalised DR-TB care model in South Africa, patients with XDR-TB may be admitted for acute treatment until they are stabilised and thereafter, they may be referred to de-centralised units for follow-up and further management. This means that patients are discharged if their condition improves, not ‘cured.’ It is expected that these patients leave the hospital with a poor prognosis and a profound belief that their illness is “terminal.” The attitude of patients discharged may vary widely, however; given the low health motivation, anxiety, dire socio-economic barriers, and fear of stigma in the family and/or community, many patients are unlikely to follow-up at their primary care units. Furthermore, poor patient-health provider dynamics result in lack of support and containment for patients’ needs and feelings. This has severe implications for public health in South Africa as it contributes to drug-resistant strains and the perpetuation of this disease. It is necessary to revise healthcare policy and practice to include initiatives that evaluate patients’ needs, improve education (specifically drug-resistance) in the community, and deliver healthcare that meets individual needs. This study concludes that it is not the development of new drugs for the treatment of DR-TB that will turn the tide, but rather an understanding of the community, and institutional and individual dynamics that impact patients’ health-seeking behaviour. The implementation (not just development) of patient-centred care models based on these findings aim to promote positive treatment outcomes.

Limitations of this study and challenges for further research

Although the facilitators made efforts to keep discussions open and encouraged the group to give their own truthful responses, (Habib et al, 2021) state that a common limitation of focus groups as a data collection method may create group bias where the opinion of one participant may influence that of another.

Halcombe et al (2007), suggest that some cultures may embrace the focus group technique given that they align with cultural norms found in oral culture.

A limitation of qualitative research is that it provides insights at a specific time. The temporal changes of health seeking behaviour among XDR-TB patients are dynamic and change over time. Therefore, a strength of this study is the use of longitudinal information provided in the secondary data analysis to examine trends, changes in disease patterns, treatment outcomes, and long-term effects of TB interventions. Another limitation is that our findings, while valuable, may be unique to the social cultural context of KZN and may limit broader applicability. Furthermore, this research only explored the experiences of patients prior to and

during admission. It is suggested that future research explores the behaviour of patients after referral to community care units. Finally, transition in outcomes contributed to adjustments in the researchers' position concerning the efficacy around treatment.

Conclusion

The health-seeking behaviour of MDR patients is heterogeneous and context-dependent, with factors such as lack of information, mistrust of information, social stigma, and community failure to recognize symptoms contributing to diminished levels of perceived severity towards XDR-health motivation. Cultural dynamics, fear of stigma, and multiple remedies and healing systems further complicate health-seeking pathways. Poor adherence to MDR-TB treatment can be linked to the development of XDR-TB. Hospitals do not provide patient-centred care, leading to dysfunctional coping mechanisms and diminished health motivation for patients. The disempowering and dogmatic culture within healthcare facilities further exacerbates psychological distress, leading to negative health outcomes for patients and the community.

In South Africa, patients with XDR-TB may be admitted for acute treatment until stabilised, then referred to de-centralised units for follow-up and further management. Poor patient-health provider dynamics result in lack of support and containment for patients' needs and feelings, contributing to drug-resistant strains and perpetuation of the disease. Implementing patient-centred care models based on these findings aims to promote positive treatment outcomes.

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APPENDIX A: Focus Group Transcripts from Primary Project

1.

- One participant said, "When we arrive here, we are told that MDR-TB is caused by defaulting treatment." He further mentioned that he initially sweated, lost weight and persistently coughed. After a month he was told that he had TB and then now he is told that he had the type of TB, which resists to other treatment. He started taking treatment in July 1999 and has to take it up to 16 months.
- Another participant stated that he was initially told that he had TB and was subsequently put on treatment. When his condition showed no sign of improvement, he then went to see a physician who scolded at him and said that he did not allow his treatment enough time to take effect. He nonetheless referred him to the hospital. He was admitted for 2 months and was discharged to his home. He claimed that his spits were still positive at that time. His condition persisted and he went back to hospital. He was finally transferred to KGV.
- Another participant said that he is not sure about his condition because he initially took acetic treatment. However, later on it was discovered that he had TB. He took treatment for TB for 6 months. On examination, it was found that he had not improved adequately. Later, he was diagnosed with "strong TB."
- Another participant stated that in 1998 started coughing. Physicians that he consulted said that he had fever. After 3 months his condition persisted and he sought treatment from the local clinic. The nurse referred to the "chest clinic" where they said he was healthy due to his physical structure. He insisted that they should investigate him. It was discovered that he had TB. He was then treated for TB for 9 months. His condition persisted and was later diagnosed with MDR-TB.
- Another participant said, "Sometime when you present to the clinic with TB, you receive fever treatment. At a later stage X-Rays are done. Until then you get wrong treatment." In his situation, he got sick and received treatment for flu until X-Rays were done and then it was discovered that he had TB. He was hospitalized for 2 months and then got transferred to another hospital where he stayed for 6 months receiving treatment for TB. He was discharge to his home. He got sick again and sought help from the hospital. He was also transferred to another hospital where he

stayed for 6 months. His physician told him that he had MDR-TB last year and was subsequently transferred to KGY. According to him, the difference between MDR-TB and TB is that TB is not as contagious.

- One participant stated, "Chances of survival with MDR-TB are slim to none. However, in my experience, MDR-TB patients recover quicker than TB."
- Another participant felt that treatment for MDR-TB and TB is what explains the difference between the two conditions. All patients agreed with this assertion.
- Another participant said, "MDR-TB are much stronger than TB patients."
- Another participant stated, "Firstly, you have to take treatment for 6 months. If you do not improve, you have to take it for another 18 months and if you do not improve you have to take it for 2 years. If you still do not improve - only God knows."
- One participant said that he initially coughed and that physically there were no changes for a long time. Then, he started sweating. He sought help from the local clinic where his spits were taken for further investigations. The results came back with nothing of note. Finally, X-Rays were done and TB was discovered. He was put on treatment for TB for 5 months. It was noted that tablets were not effective. He was hospitalized and still took the same tablets.
- Another participant stated that he initially sweated and got tired easily. On further examination at the local hospital, it was discovered that he had TB.
- Another participant said that he had been having TB for 2 years. He came to KGY in February 2000.
- Another participant reported that he initially suffered from common cold and pneumonia and sought treatment from a specialist. He could not help him but referred him to the "chest clinic" in 1997. He was given tablets, which were ineffective. After 2 months, he went back to the clinic because he was not improving. The clinic referred him to hospital where he stayed until he was discharged in January 1998. He returned to work but still continued to take his tablets until he was advised to stop them by the "chest clinic." After 2 months of stopping treatment, TB started again. He sought treatment from SANTA where he stayed for 3 months. He got discharged from SANTA because he improved satisfactorily. He nonetheless continued to take his

tablets outside. TB persisted and he went back to the chest clinic. His supervisor told the staff that his tablets were not working. His physician chased him away and he sought treatment from another "chest clinic" where he was told that he had MDR-TB. He had been at KGY for 7 months. He complained that when they are given a pass out, they are not given all their medication.

2.

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All participants agreed that MDR-TB could affect anyone indiscriminately.

One participant said, "We are told that MDR-TB is caused by defaulting treatment, patients are not to blame but clinics. However, we get blamed for it and this hurts us.

" All participants agreed with him.

Another participant stated that other people do get it through defaulting treatment.

Another participant reported that he had been taking his tablets consistently and as instructed between January and November 1999 and they did not work. He was transferred to KGY. His physician did not tell him that he had MDR-TB but the nursing sister.

Another participant said, "Physicians fail to recognize it because they initially treat us for TB and in the meantime the virus establishes itself within us." He felt that MDRTB affected his plans. All participants agreed that MDR-TB affected their life.

One participant said that by now he should have completed his studies. His physician did not allow him to further his studies in the hospital. He abandoned his studies due to MDR-TB only 6 months before he completed them. He was hopeful that he would resume his studies in July 2000.

- Another participant stated that at worked he worked under extremely dusty conditions and suspected that he could have contracted the diseases there.
- Another participant concurred with the above assertion.

- Another participant said that he might have contracted the virus in jail but failed to explain how this could have been possible. Most participants admitted that they had been jailed before.
- Another participant suspected that the blankets at hospital perpetuate it. All participants agreed that the hospital was not a safe "haven" for them as it is possible that the conditions at hospital make the virus thrive.
- Another participant cited that they eat rice and soup constantly and alleged that this maintains the disease.
- Another participant stated that some of the patients do not take their tablets and hide them and, because they are not on treatment, they re-infect them.
- Another participant cited the conditions at the hospital toilets as breeding for the disease to be contracted.
- Another participant mentioned carelessness as playing an important role.
- All participants agreed that there was enough ventilation at the hospital.
- Participants felt that during ward rounds, they were not told about their progress.
- One participant said, "Even if your spit converts to negative, nobody talks about it."
- Another participant stated, "We are not even allowed to view our own files."
- Another participant reported, "We are not allowed to talk to our physicians directly by the nursing staff."

3.

4.

One participant said he had not noticed any progress since he had just been admitted to hospital. He complained that he was not given much information concerning his condition.

Another participant stated that nurses once attempted to inject him without his knowledge.

Another participant reported, "Even if medication doses change, we are not told prior."

Another participant said, "or need to be respected." He felt that he was belittled; the

staff was not being genuine and that it treated them discriminately.

Another participant said that they felt paralyzed to challenge the staff because "of the fear that they may be chased away."

Another participant complained about the carelessness of the nursing staff. He also reported that his family did not believe he had MDR-TB.

All participants did not know anything about MDR-TB prior to their hospitalizations.

One participant said that he asked his physician.

One participant said that if you are on treatment, MDR-TB could be cured.

Two participants stated that for them treatment was helping.

One participant said that he was put off injections but his sputum had not converted to negative.

- Another participant reported, "I want to try traditional medicine."
 - Another participant concurred with the above participant but further elaborated. "I initially saw a traditional healer when I fell ill. I also use traditional medicine between my hospitalizations and when I went back to hospital, I felt much better."
 - Another participant confessed to having seen a traditional healer initially. He claimed that he took traditional medicine but improved in hospital.
 - Another participant said that he did not notice much improvement with traditional medicine.
 - Another participant admitted to having seen a traditional healer. The traditional healer told him that he had idliso. He prescribed some traditional medicine for him. But he did not improve significantly. He only noted significant improvement in hospital.
 - Other participants said that they were cured for idliso and not TB by a traditional healer.
 - Another participant reported that he went to a traditional healer for diagnosis only.
 - One participant said that the only thing he knew about his treatment were the names of his tablets. He self-discovered them. He was never told specifically how they work.
- 5.

One participant said, "I was not much affected by the diagnosis of MDR-TB because I did not know what it was."

Another participant also claimed that he was not affected by the diagnosis of MDRTB.

Another participant stated that he was not affected by the diagnosis of MDR-TB as well because on clarification he realized that it was not so bad.

Another participant reported that he was not affected because when he came to KGY He was told that treatment for MDR-TB affects eyes and ears. However, he has never seen anyone among the patients who have such side effects.

One participant mentioned that DOT occurs when a person is given treatment under supervision and as per the orders.

Four participants were previously on DOT.

One participant found DOT to be helpful for him.

Another participant said that it had a negative impact on him because he became an object of ridicule and he felt dehumanized.

Another participant said, "It makes you feel less responsible."

Three participants felt that DOT could reduce the incidence of TB.

Two participants stated that there are people in the communities who are spreading TB.

Another participant said that other people look down upon them with a condescending attitude.

Another participant stated that TB is not a form of punishment.

Another participant felt that the government needs to teach people about DOT because other people who contract TB think that they are bewitched. There is a clear lack of information in the communities.

- Another participant said that physicians discharge people who default treatment.
- Another participant stated that the government has to be careful.
- Another participant compared his hospitalization to being given a jail sentence.
- Another participant felt that the injection is like a form of punishment.
- Another participant stated that injections affected him.
- Another participant reported that when they report ill treatment by the nurses, they run a risk of being seen as bad people.
- Another participant said, "You have to be silent even if you are being abused."

- Another participant recommended that pamphlets containing information concerning their treatment has to be designed and given to them.
- Another participant felt that there was no respect and communication between them and nurses.

6.

- The majority of the participants felt that their issues are treated according to them individual merits. For example, the pass-out period is standardized for everyone.

7.

- One participant said, "Except medication, there is not much activity within the hospital and no special treatment."
- Another participant stated that MDR-TB patients should have special treatment because they spent the longest period of time in the hospital.
- Another participant reported that he had been working prior to hospitalization. Her employers have discontinued paying him his wages. Consequently, he could not support his family and felt left behind in life. In fact, he likened his hospitalization to be imprisoned.
- Another participant identified with the previous participant in that his employers also paid him his salary up to a certain period. Consequently, his children have since stopped attending school due to his TB. He understood that, from a business point of view it would not make business sense for his employers to continue paying him his wages because he was no longer productive.
- Another participant who identified with the previous two participants also reported, "My Company told me that there is nothing they could do for me any longer." They arranged a pension fund for him.
- Another participant felt bad because "I am sending money home, instead I expect them to send me money."

8.

All participants agreed that their hospitalization resulted in the breakup of their social relationship with their partners.

One participant who was married said that his wife went away following his

hospitalization spanning back to 1997. His children are now with his extended family. Another participant stated that he separated from his girlfriend as a result of his hospitalization.

9.

- One participant cited physician deterioration as a contributing factor toward the break up of relationships.
- Another participant said, "abantu bathi ngingathanda ibhokisi (how can I love a coffin)."
- Another participant reported, "Following such attitude, we default treatment."

10.

- If they take Inkunzi/sh011 tempered- strongest tablet - cannot eat. All participants agreed. It was also thought to cause "isilungilelo".
- One participant advised that it helps to take it before sleep.
- Another participant said that he just cannot help it but vomits.

11.

- One participant said that his family depends on him and does not need to go to hospital.
- Another participant reported that he has had no visits from family.
- Another participant cited that lack of motivation leads to alcohol indulgence.

12.

- One participant said that he defaulted on treatment for TB. He was told to take treatment for a 6-month period and stopped taking treatment on his own when the 6-month period lapsed.

13.

- One participant said that MDR-TB is not known in the communities. He felt that he had never experienced discrimination personally as a result of his condition but agreed that other patients had experienced it firsthand.
- Another participant stated, "People say I am HIV/Aids positive. Some of my family members say subtle statements and look down upon me."
- Another participant mentioned that when goes out on a pass-out, his children want to

come in close contact with him. He is forced to scare them away from him for fear that they may contract the disease from him.

- Another participant reported that given the duration of treatment, other people get demotivated and tempted to try criminal ways to survive.
- Another participant said that he thought that his future was in sports. He used to be a good athlete.

14.

- One participant stated that some people adhere to and comply with their treatment and other activities while others do not.
- Another participant said that he felt discriminated against at work.

15.

- One participant said that fear affected his treatment. (All participants concurred with him). He further elaborated, "From experience, I took my treatment with no apparent improvement."
- All the participants felt that the strict controls at hospital affected them negatively and tended to liken their hospitalization to imprisonment.
- Some participants complained about meals citing that their diet habits differ. But that is not taken into consideration and the assumption is that their diet habits are the same.

1.

- She said that MDR-TB is a type of TB, which does not respond to tablets and requires an injection for 9 months. She was admitted to KGV in December 1999. Prior to coming to KGV, she stayed for 6 months in another hospital where she was being treated for TB. When her coughs showed no sign of abating, she was transferred to KGV.
- She was initially hospitalized and treated for TB with tablets for 3 months. She was discharged but soon came back as her condition persisted. She stated that she worked for the TB center. She also said, "MDR-TB affects a person who defaults on treatment for TB."
- She initially took tablets for TB as well and was allergic to some of them. Every time

She ingested them, she found that she shivered; her eyes reddened and had rash. Her physician discovered that she had hepatitis-B but did not disclose the diagnosis to her. She consulted another physician who, upon learning about her allergy, promptly discontinued some of the tablets she was taking. Nurses pressured her to take all the tablets including the ones the physician had discontinued. She took them in their presence. On her way back home, her allergy started. As her condition persisted, she was transferred to KGV. She still was not aware that she had MDR-TB at this stage. Her allergy started once again at KGV. She was then put on a depo (injection) preparation. She felt that the injection did not help her significantly and it was discontinued. She has been told that her sputum is negative. She felt that her condition has improved.

- Initially, she had been suffering from TB since 1995. She did not completely recover from it and was transferred to KGV in March 2000. The improvement of her condition has been very erratic. She has just been told that she suffers from MDR-TB.

- She said, "I have a stubborn virus caused by defaulting TB treatment."

- She was diagnosed with TB in June 1998 and subsequently took treatment for it. Her physician discontinued her treatment when she showed signs of improvement. In December 1998, her physical complaints started again. Her physician diagnosed her as suffering from pneumonia and was treated for it. In May 1999, her illness started again. Her physician put her on treatment and she improved. He nonetheless changed her tablets after 3 months of taking them. Her illness got worse. She sought help in a public hospital where she was told that her "lung had a hole." The hospital contacted her private physician who had been treating her all along. Her physician rudely told them that he was professional and could not be told by anyone how to treat his patients. In January 2000, she was told that her "lung is finished." She was subsequently transferred to KGV. At KGV, she was told that she has "strong TB that is resistant to drugs."

- She did not believe that MDR is caused by defaulting treatment.

2.

- He said, "MDR-TB does not discriminate." Other participants concurred with her.

- She stated, "MDR-TB can be caused by defaulting and other ways, but I did not default treatment because I was not taking TB treatment. I suspect that I might have contracted it from someone who had it."
 - She mentioned, "In March 1998, I suddenly started coughing and sought treatment from the local clinic. I was given tablets. However, coughing persisted after 1 month of taking tablets and referred to the hospital for further management. At hospital I was given tablets and an injection and a follow-up date. On my follow-up at hospital, the physician requested to invest me for TB and TB was discovered. I was referred to the TB clinic where I was put on tablets. No X-Rays or any other tests were done. After 3 months of taking treatment my spit was still positive and I was not improving. On 21 February 2000, I was admitted to another hospital until 03 March 2000. The physician told me that I had strong TB and that one of my lungs was damaged." (She looked very distraught).
 - She said, "I initially thought I had idliso (she thought she was bewitched by family members." She refused to take treatment. However, she no longer adhered to the belief that she was bewitched.
 - Initially, her family thought she had idliso. However, they now believe that she has TB.
- 3.
- She said, "I was very hurt" and further elaborated that one nurse said to her "you have a kind of TB that is incurable and eventually you will die from this disease." She further said that she believed that because the person that told her this was a professional nurse. She stated that the nurse also told that "even if it (MDR-TB) is cured, it can be asymptomatic or remission for a while but eventually starts again."
 - She admitted to feeling very hurt upon learning about the diagnosis of MDR-TB. She sought an explanation of the condition from a nurse. She initially became very hopeless but is not hopeful about the prospects of her conditions.
 - She said that she was told by her physician that she had MDR-TB and that she would have to be hospitalized and secluded in her own ward. She appeared to be hopeful about the prospects of her condition.

4.

She said that she could not see a traditional healer, although she would have liked to see one, owing to fact that her chest was very painful. Family members ascribed her illness to idliso. She sought treatment from the local clinic at her own peril.

Another participant said that community health workers advised her that if she coughed excessively and continuously she should go to the hospital.

Another participant stated that one of her family members had TB and that helped her understand her condition better.

5.

- One participant was put on DOT through community health workers.
- Another participant said that her sister who is a teacher administered her DOT.
- Another participant stated that her DOT was managed at work.
- Another participant declared that her brother managed her DOT.
- Another participant cited the local clinic as having been responsible for her DOT.

6.

- One participant felt that DOT helped her a great deal as would not be able take her tablets regularly on her own. The supervision aspect of DOT helped her because of it. ensured that she took her tablets as per the instructions.
- Another participant felt that she did not think DOT was a great idea as it made her realize that she was not being trusted.
- Another participant stated that she benefited from DOT because it made her withstand the difficulty in swallowing the tablets.
- Another participant concurred with the above participant and further elaborated that Had it not been for DOT she would have definitely defaulted treatment. She mentioned a gray tablet - commonly known as imbongolo (donkey) among the patients as very being very difficult to swallow. Other patients agreed with her.
- Another participant also found the DOT to be helpful in that she "would have nearly vomited them all. The mere presence of another person helped me a great deal."
- Another participant stated that she found the DOT to be helpful in that "my family would never believe that [am taking my tablets on my own."

7.

- One participant said that she arrived at KGY at 7 a.m. At approximately 8 a.m. she was handed over to the admitting staff. The admitting nurse said that she had not come on the admission date. She had to travel with other patients in an ambulance that brought her to hospital to other hospitals. She was very sick at the time. She returned to KGY in the afternoon and the staff that dealt with her then received her warmly (it is quite possible that nurses had changed shifts - the staff that dealt with her in the morning was probably off duty).
- Another participant stated that she was well received. She further elaborated that she has not felt discriminated against such that she does not see her illness as different from other patients. She feels "at home and normal here."
- Another participant came out clearly and said that she was not happy with treatment at hospital. She claimed that she did not know the time when she should take it medication. She further stated, "If you miss your medication for whatever reason and go to the nurse that distributes medication afterwards, she says, "Never follow me with a chart. She mentioned that she knew her medication very well and that she took it. 8 tablets. One day the nurse gave her 2 tablets. She followed the nurse and insisted on it getting all the tablets. She was ill treated by the nurse.
- Another participant said that they are "treated equally in our ward."
- Another participant stated, "Most of us are not told about our treatment." She felt that she not given adequate explanation about her treatment by the nurses."
- Another participant said that nurses laugh at her when she asks for extra meals.
- Another participant said that nurses are not the same, some are nice, and others are insensitive.
- One participant said that health standards are not good within hospitals. They are asked to wash their dishes in a space near where fesses, urine and spits are dumped. They are also not given good blankets.
- Another participant said that nurses are not the same, some are nice, and others are insensitive.
- Another participant cited facilities as lacking in the hospital.

8.

- One participant recommended that the hospital be renovated because it is dusty and a ways should be sought to combat snakes.

9.

- One participant said that she heard, "If you suffer from MDR-TB, you should not work hard." She further elaborated that she could not work as domestic worker after recovery.
- Another participant stated, "I had to discontinue attending school due to MDR-TB."

10.

- All participants agreed that they were not happy with the duration of their treatment (hospitalization) and depo preparation.
- One participant said that she attended occupational therapy and found it helpful.
- The majority of the participants agreed that they were discriminated against in their respective communities and that community members often attributed their condition to HIV/Aids.
- Most of the participants did not feel discriminated against in their families.
- One participant said that she was treated indiscriminately but she nonetheless has low self-esteem.
- Another participant also felt that she had lost weight as a result she has low self-esteem.
- Another participant said, "It's my sickness, it's my gift from God. I keep telling myself that I'm not different from others."
- Another participant worried that her children were not well looked after and that they were no longer taking their medication.
- Another participant stated, "It's better to be hospitalized - taking treatment collectively helps. Even when you lose your appetite, it helps to see others eating who are in your situation. You get motivated to eat. In fact, life is more important than other things at home."

11.

No response.

1.

- Had TB first, put on treatment for 6 months, went back for follow-up appointment, told that he was resistant to TB medication, continued treatment for 4 months, visiting. Sister told him that he had MDR, went to city and was transferred to KGY.
- Had TB for 6 months, took TB treatment, but no apparent improvement as he continued to feel weak, spent 6 months at SANTA, symptoms (i.e., weakness and not eating) persisted, has been at KGV for 5 months. He has been told that he has MDR. but still receives the same treatment.
- He got diagnosed with "big" TB at KGV. He was initially treated for TB at St Lucia hospital where he stayed for 9 months. When his spit failed to convert and his condition did not improve even with treatment; he was referred to KGV. He has been at KGV for 5 months. He has improved. While at home, he did not know anything about MDR.
- He has been taking treatment for TB since 1996. During this period, he has been defaulting treatment. He has been at KGV for 5 months.
- His improvement from TB has always been erratic. He has been at KGV since November 1999. He is not receiving injection presently. He did not know anything about MDR prior to his hospitalization at KGV.
- He was working for someone when he got sick. His employer sent him to Osindisweni Hospital where he was hospitalized for 2 months. He was diagnosed with TB there. He was then transferred to KGV, where he has been hospitalized for 6 months. He was diagnosed with MDR at KGV hospital. He feels that he is improving. He stated that he was worried because his father was sick. During his treatment, he had problems with his ears and his body was itching. He was sent to KEH for an ear assessment. His TB treatment was reduced.
- He comes from Inanda. He had TB treatment for 6 months. When no apparent improvement noted, he was then transferred to KGV for further management. He was diagnosed as having MDR TB at KGV.

2.

- TB is much better than MDR. "MDR is very strong, it can even cause mental illness." He admitted to experiencing symptoms (e.g., confusion) that suggested that he was.

becoming mentally ill when he came to KGV.

- Other members of the group disagreed with the assertion that MDR can cause mental illness.
- MDR is very strong and incurable.
- MDR is different from TB in terms of treatment. Although he has been sick for 3 months, he has been at KGV for 2 weeks.
- He has been at KGY for 5 months. He has been taking treatment for TB since June 1999. After

completing the course, he was sent to X-Ray, which revealed no positive improvement. He was then transferred to KGY for further management. He was diagnosed with MOR at KGY.

- He has been sick since 1976/7. He was initially seen at Edendale Hospital where he was diagnosed as suffering from TB. He was sent to SANTA where he stayed for 6 months. He was discharged and remained asymptomatic for a year. He started vomiting blood again. He went back to Edendale Hospital and was transferred to Richmond Hospital where he treated for 8 months. Since then, he has never been asymptomatic for longer than a year. He was transferred to KGY on 24 November 1999. He was diagnosed as suffering from MOR at KGY. He still does not know anything about MOR. He has improved. He gets injections twice per week.

3.

- The majority of the respondents agreed that MOR affects everyone.
- One of the respondents disagreed with the majority and stated that they are discriminated against at hospital. He admitted that he has been smoking cigarettes and drinking alcohol but stopped recently. He also confessed that he has been eating food indiscriminately. For these reasons, he suspects that he might have been vulnerable to MDR-TB.
- The other respondent was also doubtful or uncertain. He stated that he has not been looking after himself properly. Until recently, he has been drinking alcohol and smoking cigarettes. He further said that when he got better, he heavily indulged in alcohol. His condition worsened. He felt that alcohol made him weak and vulnerable to viruses and bacteria.

- The majority of the respondents agreed that they also have not been looking after themselves properly as they have been drinking alcohol heavily and smoking cigarettes when their condition improved slightly.
- Only two participants denied a history of alcohol and drugs. One of them was the youngest member of the group. He was 17 years old.
- Generally, those respondents who had a history of alcohol use agreed that they indulged in alcohol and substances once they got better. Sometimes, they tried to make up for the time they spent in hospital by drinking heavily.

4.

5.

One participant admitted to having defaulted on his treatment.

The other participant cited "ubudedengu babezempilo" especially in terms of treatment as a source of their diseases. He declared that if treatment were initially geared towards MOR, he would have recovered speedily.

All the respondents concurred with the above assertion.

One participant felt that it is not curable.

Two participants stated that people who get better always come back.

One participant said that it is curable but "ukungaziphathi kahle kwethu" results in relapses.

- One participant felt that "either you die or come back to hospital."
- One participant stated that it can only be reduced in severity and referred to it as "Aids number two."
- One participant said that other people get better.
- One participant said that MDR-TB cannot be prevented. Once you get it, behave responsibly.

6.

• He received a call at work from the local clinic and was informed that he had MDRTB. He suspects that the clinic was skeptical to face him with the diagnosis because.

they mismanaged his illness. He further recommended that communities have to be educated about MDR-TB in much the same way they are educated about HIV/Aids.

In that way, the stress associated with MDR-TB diagnosis may be normalized.

- One participant stated that he is "still in the dark". He has been at KGV for one month and has not been fully informed about MDR-TB. He was only told that his life has come to be terminal. He admitted to being very hurt following the diagnosis. He was also told that if he does not improve in hospital he will be discharged to die at home.
- Another participant stated that he is only physically weak and fatigued. Other than that he is well. He is therefore not convinced that he will die. Even if his sleep and dreams, he does not believe that he may not wake up the following day.
- Another participant said, "Physicians can discharge you to die at home." He cited one man, who used to sleep next to him at hospital who was recently discharged without sufficient improvement. He claimed that he was not bothered by the diagnosis.
- The youngest of all the participants stated that he defaulted on his treatment for TB. He took them for 6 months. He mentioned being upon learning about MDR-TB diagnosis. He wondered how he got it because he took, he was too young to contract it.
- This participant stated that the doctor told him that he would have to be hospitalized for at least 9 months. In he did not improve, another 9 months would have to be added.

7.

- Three of the participants agreed to have initially sought help from traditional healers. The rest of participants went straight to the clinic.
- One of those who initially saw a traditional healer said that he thought he has 'izibhobo', 'amahlaba' (sharp pains) and umkwebhelo. For this reason, he thought physicians were not competent in treating these conditions and accordingly sought help from traditional healers. Upon realizing that her condition was not improving, he went to the clinic. He was diagnosed as suffering from TB and instantly hospitalized.
- The participant who sought treatment from traditional healers reported that he has always suffered from several medical conditions including diabetes. When he sought treatment for diabetes, hospital staff said that he was too young to suffer from diabetes. For this reason, he claimed, he sought treatment for diabetes from traditional.

healers and developed skepticism and doubts about clinics. He interchangeably used traditional medicine and western medicine and noted tremendous improvement.

- This participant outwardly declared that he does not believe at all in traditional medicine and cited this as a source of conflict within his family. Since he came to hospital, he once used traditional medicine that used by other patients in hopes that he would improve. However, he did not note any significant improvement.

- He saw a traditional healer first and was helped. He believes that he was bewitched. The traditional healer gave him something to use to get rid of "idliso". He also clearly explained to him how the medication would get rid of "idliso". He warned him that it might even kill him. Upon using the substance given to him by the traditional healer, he literally saw "idliso" coming out. He then went to the clinic because he was feeling weak and bleeding profusely. The doctor told him that his insides, especially his lungs, were damaged. The doctor advised him to go to the hospital where he underwent X-Ray examination. Following the findings of the X-Ray, he was promptly hospitalized.

- His neighbor noted that he was not well physically and gave him money to go to the local clinic for medical attention. He stayed in the clinic for 2 months. When he failed to exhibit any observable improvement on TB medication, he was transferred to Osindisweni hospital. Finally, he was transferred to KGY after 6 months when his TB became resistant to TB medication.

8.

9.

The majority of the participants admitted to having been initially put on the DOT program.

The mentioned a variety of people who signed on their behalf including a father, mother and professional nurse.

One participant stated that the DOT is a good idea. He was concerned that his children could have contracted the MDR-TB from him.

Another participant felt that he would appreciate it very much if his family members could be tested for MDR-TB.

He said that he signed on his behalf.

He stated that the DOT, program is a good idea because there is usually irresponsibility on their part. "Sometimes, if we take treatment without supervision, we are likely to take it for a brief period." In this way, the illness may intensify again. One participant admitted that some of the tablets are fearsome and unpleasant and it helps if they are administered under supervision by another person.

One participant stated that he has been at KGY for I month and has noted that the hospital staff are trying their best. However, he would appreciate it very much if recreational facilities could be expanded and access to shops be extended. He noted that although there is a tuck-shop within the precinct of the hospital, it is insufficient stock.

Another participant complained about blankets. More specifically, he was unhappy about the texture (itches) and condition (dill) of the blankets. He further recommended that patients should be allowed to bring their own blankets to the hospital. He was also not satisfied with food that the hospital provides in terms of amount and nature.

- Another participant said that he was unhappy about that they do not get medication that they ask for from the doctors. Apparently, when they get illnesses such as flu for which they need treatment, they report them to doctors. Doctors prescribe treatment for them, which never get to them. When they enquire with the nurses, they are told that it has been returned.
- Another participant complained about one general assistant who "does not care about us." She distributes food to patients and "if you are not in your bed for whatever reason or asleep, she passes your bed."
- All participants concurred with this participant.
- One participant stated that as far as he is concerned, they do not experience any problems with light and ventilation.
- Another participant said that one nursing sister came to explain their condition to them.
- All participants disagreed with him.

- One participant stated that he once enquired about his tablets from a certain nursing sister who said, "Ask your doctor." He mentioned that he was left hurt by this assertion so much so that he did not bother to ask his doctor.
- All participants felt that they need to be educated about their tablets.
- One participant said, "If you are given drugs, it would be appreciated if I could be told what it is for."
- The majority of the participant felt that they are not respected as responsible adults at hospital.
- One participant stated that some nurses wake them up very early in the morning for no apparent reason.
- Another participant felt that they are treated as children.
- Another participant said that they are not told who to contact when they have complaints.

10.

- One participant said that he sometimes vomits.
- Another participant stated that it helps to have treatment explained to them because that increases their understanding of the treatment.
- Another participant felt that he would appreciate that if they could be given treatment on a full stomach.

11.

- One participant said that he felt better and took his treatment by himself.
- Another participant stated that he did not default his treatment and noted that side effects could lead to defaulting.
- Another participant said that he felt better and defaulted on treatment.

12.

- One participant said, "If you have this disease everybody in the community says whatever they want. They say you have HIV/Aids. I come from a very close and supportive family and that is what has been my pillar of strength" and he called that "isikithi". He further elaborated that his brothers eat from the same plate as him.
- Another participant stated that some members of his community say "why are you

perpetually ill."

13.

- The majority of the participants stated that initially there is an element of "Ukuzenyeza."
- One participant denied such feelings.
- Another participant felt that his making decision has not been affected.

14.

- All participants agreed that this is problematic, especially if working.
- One participant stated that he still has to "fight" informing his employers about his hospitalization.
- Another participant stated that access to social workers has been available.
- Other participants preferred to have more games such as "umlabalaba", snooker, table tennis, soccer, and other recreational facilities.
- One participant said that he recently got a pass-out. He found his girlfriend being pregnant with another man's child. He could not blame her nor did he mind considering the duration of the treatment program.
- The youngest participant said that he had to dropout at standard 9. He felt that he would be left behind and that by the time he goes back to school all his friends would have finished school.

171

1.

- She initially had flu. She sought treatment from the local clinic where she was given cough mixture and tablets. She failed to show satisfactory improvement. Subsequently, she was diagnosed as suffering from TB and was put on treatment for TB for 4 months. When her condition showed no sign of improvement, she was transferred to KGV. She had been in treatment for TB at KGV for 5 months when her physician was changed. Her new physician diagnosed her as suffering from MDRTB. She has been on KGV since May 1999.
- She also initially had flu and coughed severely. She sought treatment from the local clinic. She was given tablets and cough mixture. When she did not improve, she was referred to the hospital for further management. At hospital, she was diagnosed as

having TB and was put on TB treatment for a year. X-Ray examination revealed no significant improvement. She was subsequently diagnosed as suffering from MDRTB. She has been hospitalized at KGV since January 2000.

- She initially had colds and X-Ray examination suggested that she had TB. She was put on TB treatment since April 1999. After 4 months on treatment, she developed diabetes. She was hospitalized at Marrianhill for 6 months. Finally, she was transferred to KGV. Recently, her treatment was changed and a diagnosis of MDRTB made.

- She had flu in January 1999 and was put on treatment. Subsequently, she was diagnosed as suffering from TB in October 1999. When no notable improvement was seen, she was transferred to KGV. At KGV hospital, she was diagnosed with MDRTB and treatment for MDR-TB was started in March 2000.

- Initially, she felt something was moving across her stomach and as if she was pregnant. She started losing weight as well. She did not cough significantly. In 1998, She was treated for TB for a period of six months. Subsequent X-Ray examination revealed that TB had not subsided and treatment for TB was continued. In April 2000, she was hospitalized at the local hospital and further transferred to KGV where she was diagnosed with MDR-TB recently. She has been at KGV since 22 April 2000 and has satisfactorily improved.

- She initially had hot flushes and coughs. X-Ray examination suggested that her lungs were destroyed and this was attributed to TB. She was put on TB treatment for 6 months. She felt as if there was a sore inside her body and coughed "ubomvu". She completed her treatment. However, she was soon put on treatment again for two months. Finally, she was transferred to KGV where she was diagnosed with MDRTB.

173

- Another participant stated, "I was very hurt when I first learnt that I had MDR-TB."

- Another participant said, "I became very sad upon learning about the MDR-TB diagnosis and cried copiously because I was separated from other patients at hospital. I was distraught and helpless because I thought I had a peculiar disease. I felt much better here at KGV because I am always within the company of patients who have the same condition."

- Another participant stated, "The community sister informed the local clinic about me

condition. The local clinic transferred me to KGV.

6.

- The majority of the participants were initially put on DOT.
- One participant said that she worked as a domestic worker. Her employers took her to hospital and were actively involved in her treatment. She expressed that she was happy with them issued her treatment to her because they took good care of her.
- Another participant said that her nephew issued the treatment to her in evening. She stated that she was happy with this arrangement because she would not have the courage to adhere to the instructions.
- Another participant said that the DOT benefited her because she would have not adhered to her treatment on her own. She would become doubtful of her treatment every now and then. She sometimes thought that skipping a dose would not cause any problems.
- All participants agreed that the DOT is an effective alternative.

7.

- One participant said, "Since I have been here, I have had different reactions from the nursing staff. People are never the same."
- Another participant stated, "I have just been told today that I has MDR-TB." (This participant looked very distraught throughout the interview).
- All the participants felt that they would like to know more about their treatment. They also stated that they contend with boredom daily and this prompts them to ruminate about their families.

8.

- One participant said, "In view of the pass-outs constraints, she would like have more pass-outs. "

9.

- None of the participants admitted to having defaulted on their children.

10.

- One participant felt that her interactions with her family members have not changed. She basically avoids people in her neighborhood for fear that they could spread.

rumors about her condition.

- Another participant said that when she initially fell ill, she received treatment with other children from the local clinic who have since recovered from their illness.

Following her failure to recover with them, someone in her community is spreading the rumor that she is HIV positive. As far as she is concerned there is no

discrimination in terms of interactions with her family members.

- Several other participants admitted that they have been labeled as HIV positive or suffering from Aids in their communities.
- One participant said her family members have neglected her. Her husband and brothers have not contacted her since her hospitalization. In fact, the nurses in her local hospital insisted that she should take HIV test. Even at KGV, health professionals insisted that she should be HIV tested. She is presently awaiting findings of that investigation.
- Only one participant said that she has not been discriminated against at home and in the community.
- Another participant stated that she has recently been hospitalized and diagnosed with MDR-TB, she was therefore in no position to comment.

11.

- One participant said, "It is important to make sure that you take your treatment accordingly. "
- One participant stated, "When I initially came here and diagnosed with MDR-TB, I looked down upon myself. I even contemplated escaping from the hospital. But now I have accepted my condition and my family accepted it and no longer feel the way I used to."
- Another participant declared, "Initially, my family did not want to see me. As the time wore on, they gradually started to visit me here. Two of my brothers who used to get along with me very well have neglected me and have never visited me here. Some of my family members suspect I may be HIV positive. They even refuse to believe the HIV test result.
- Another participant also revealed, "My husband has not spoken to me since my hospitalization. Further, none of my family members has been here to see me. I have

tirelessly been trying to contact them to no avail.

- Another participant said, "Only my mother comes to see me here in my family.

12.

- One participant said, "Everybody in my family has accepted my condition. My husband is very supportive and often come to visit me here."
- Another participant felt that other than missing her family, her job was likely to be affected by the duration of her hospitalization.
- Another participant said, "By the time I get out of hospital, my classmates would be far ahead of me."
- Another participant suspected, "In view of the fact that my husband might have not been fully treated for TB, he may be infecting our children with TB at home. In fact, one of my children was given a referral letter to hospital by health professionals who visited his school. He apparently lost the letter. I would appreciate it very much if all my children could be tested for TB."

APPENDIX B: Ethical Clearance Approval Letter



23 October 2023

Kavita Soni (981180239)
School of Applied Human Sc
Howard College Campus

Dear K Soni,

Protocol reference number: HSSREC/00006219/2023

Project title: An emic perspective of the health seeking behavior of adult extensively drug resistant tuberculosis in -patients in a public health setting

Degree: Masters

Approval Notification – Expedited Application

This letter serves to notify you that your application received on 15 September 2023 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

This approval is valid until 23 October 2024.

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

HSSREC is registered with the South African National Health Research Ethics Council (REC-040414-040).

Yours sincerely,



Professor Dipane Hlalele (Chair)

/dd

Humanities and Social Sciences Research Ethics Committee

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Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

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APPENDIX C: Permission Letter



18 March 2023

To Whom it May Concern

Re: Permission for master's by coursework candidate Mrs. Kavita Soni (Reg.no 981180239) to use secondary data set from project (Protocol reference number: HSS/0316/017CA), which has been granted full ethical approval.

The above candidate is applying for ethical clearance for her study titled: : ***An Emic Perspective of the Health Seeking Behavior of Adult Extensively Drug Resistant Tuberculosis In -Patients in a Public Health Setting in Kwa Zulu Natal***, which will be submitted for the completion of a mini-dissertation.

I, the project leader, hereby give consent to the above candidate to access and use transcribed interview data collected as part of the MDR TB treatment non-adherence in KwaZulu-Natal Project.(Protocol reference number: HSS/0316/017CA).

Should you require any further information, please do not hesitate to contact me

Yours sincerely

Dr S.R Valjee (Staff no: 10343)

Lecturer/Supervisor

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