

**(RE)POSITIONING  
COMMUNICATION FOR  
ENHANCED MULTIDRUG-  
RESISTANT TUBERCULOSIS  
TREATMENT ADHERENCE IN  
SOUTH AFRICA**

**TOWARDS AN INTEGRATED  
COMMUNICATION MODEL FOR YOUNG  
WOMEN**

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**(Re)positioning communication  
for enhanced multidrug-resistant  
tuberculosis treatment  
adherence in South Africa**

**Towards an integrated  
communication model for young  
women**

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**(Biomedical Research Protocol BREC 379/17)**

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In fulfilment of the requirements for the degree  
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## DECLARATION – PLAGIARISM

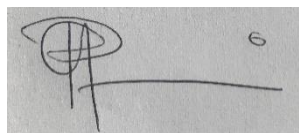
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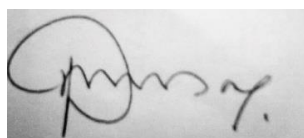


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## **Dedication**

This thesis is dedicated to every woman, man and child who has been treated for drug-resistant tuberculosis and completed treatment.

Not all heroes wear capes.

And to Naniso Y. and Amadika. K. Because of you, I dream.

## ABSTRACT

Tuberculosis (TB) is a significant public health threat in South Africa, which has been the leading cause of natural mortality over many years (Statistics South Africa 2018; Statistics South Africa 2017; ENCA 2015a). Although TB has been largely eradicated in the Global North and available literature explains how this was achieved, in developing countries like South Africa incidence of not only TB, but drug-resistant forms of the disease continue to grow (Shah *et al.* 2017). There are many explanations for these trends, including unavailability of less noxious anti-TB medications, serious side effects and lengthy treatment timelines, drug stock-outs, context-determined structural, socioeconomic, cultural and gender-based barriers to treatment adherence and inadequate or ineffective patient and community education about the disease (Shringarpure *et al.* 2016). Concerns occur on the backdrop of health systems that overly privilege biomedical responses to TB, to the detriment of all other interventions. Scholars protest that 'The TB literature is written almost entirely from a biomedical perspective, while recent studies show that it is imperative to understand lay perceptions to determine why people who seek treatment may stop taking treatment' (Cramm *et al.* 2010:2). Extant literature acknowledges the unsuitability, on its own, of the biomedical approach to reducing burdens of TB in epidemic countries like South Africa (Daftary *et al.* 2015). This recognition is accompanied by impetus to develop and apply theory-based strategies to encourage long-term adherence to TB treatment. Scholars insist that there are several health behaviour theories with potential to improve understanding in this area (Daftary *et al.* 2015; Munro *et al.* 2007).

This research responds to the question of *how* health communication and promotion strategies can practically contribute to improving multidrug-resistant TB (MDR-TB) treatment adherence and clinical outcomes among a defined vulnerable population in KwaZulu-Natal province, South Africa. It aims to contribute knowledge to the under-researched area of non-biomedical responses to sub-optimal adherence to long-term DR-TB treatment in high TB/HIV burden areas (O'Donnell *et al.* 2017). Primary qualitative data was collected through focus group discussions and key respondent interviews with 20 purposefully selected participants in eThekweni Metro, KwaZulu-Natal, from March to September 2018. Ten of the participants comprised the case study of this research; culture-sharing young women, many of them isiZulu-speaking, aged 18 to 34 years from low socioeconomic communities being treated for MDR-TB at one public hospital in the Metro. The study proposes a 'how to' for MDR-TB health promotion in high burden areas.

It finds that vulnerable young women's sub-optimal adherence to MDR-TB treatment is exacerbated by patriarchy, stigma and cultural beliefs and practices. Culturally prescribed family collaborative approaches to health-seeking among Zulu people urge for the incorporation of female elders, intimate male partners and older children into young women's treatment. In contexts like eThekweni Metro where many MDR-TB patients demonstrate strong cultural beliefs and practices, emphasising biomedical treatment for individual patients as the denominator of treatment requires reconsideration. Findings also suggest that MDR-TB programmes would benefit from borrowing from HIV communication interventions by implementing standardised individual, couples' and family counselling at intervals during the nine to 36 months of treatment to enhance patients' adherence. Consideration should also be given to engaging traditional health practitioners as important partners in health promotion. Further, educating patients and communities about MDR-TB treatment should be bolstered through health promotion and communication via school curricula, culturally proximate television and radio (soap operas, dramas and hard news) programmes and Facebook and WhatsApp. Social media is important because it allows for low-cost group, one-on-one and anonymous exchanges and discussions of health information.

**Keywords:** *MDR-TB, KwaZulu-Natal, treatment adherence, vulnerable populations, young women, health communication, health promotion, integrated communication, mass media, social media*

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## ACRONYMS

ACSM	Advocacy, Communication and Social Mobilisation
AIDS	Acquired Immune Deficiency Syndrome
BCC	Behaviour Change Communication
BREC	Biomedical Research Ethics Committee
CCG	Community Care Giver
CCMDD	Centralised Chronic Medicines Dispensing and Distribution
CD4	Cluster of Differentiation 4
DoH	Department of Health
DOTS	Directly Observed Treatment Short-Course
DR-TB	Drug-Resistant Tuberculosis
DS-TB	Drug-Susceptible Tuberculosis
EDR.Web	Electronic Drug-Resistant Software
HIV	Human Immunodeficiency Virus
IPC/C	Interpersonal Communication and Counselling
KAP	Knowledge, Attitudes and Practices
MDR-TB	Multidrug-Resistant Tuberculosis
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NHLS	National Health Laboratory Service
NIMDRT	Nurse-Initiated Drug-Resistant TB Treatment
NSP	National Strategic Plan on HIV, Tuberculosis and Sexually Transmitted Infections
NTP	National Tuberculosis Programme
PCC	Patient-Centred Care
PLHIV	People Living With HIV
PSAs	Public Service Announcement
SABC	South African Broadcasting Corporation
SANAC	South African National AIDS Council
SBCC	Social and Behaviour Change Communication
SDGs	Sustainable Development Goals
SMS	Short Message Service
STI	Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations

VPCM	Vulnerable Populations Conceptual Model
WHO	World Health Organization
XDR-TB	Extremely Drug-Resistant Tuberculosis
X-Ray	X-Radiation



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See what God has done!

# CHAPTER ONE

## INTRODUCTION

Even though it has the dubious honour of being the first infectious disease declared a public health emergency by the World Health Organization (WHO) in 1993 (Mishra *et al.* 2014), tuberculosis (TB) is perhaps the most underrated of all existing communicable diseases. Although TB is much older and more contagious, scholars deplore that the disease failed to rouse the same panic globally as diseases such as HIV (Metcalfe 1991), a finding which significantly influenced this study. While TB has been largely eradicated in countries in the Global North and extant literature explains how this was achieved, in developing countries like South Africa incidence of not only TB, but drug-resistant TB (DR-TB<sup>1</sup>) continues to grow (Shah *et al.* 2017).

Tuberculosis is an airborne disease caused by *Mycobacterium Tuberculosis* which has been the leading cause of natural mortality in South Africa over many years (Statistics South Africa 2018; Statistics South Africa 2017; ENCA 2015a). Even though the National Tuberculosis Programme (NTP) utilises some of the most advanced biomedical anti-TB treatment in the world, TB remains a significant public health concern. Indeed, DR-TB in marginalised communities in contemporary South Africa has more deadly consequences than during the 19<sup>th</sup> century when the rest, careful nutrition and fresh air of sanatorium care was the most effective treatment available. The fact that DR-TB kills more people in contemporary times than 20 years ago when it first became of national concern illustrates the magnitude of the DR-TB problem and the urgent need to address it.

Drug-resistant TB is a blanket term for *Rifampicin* resistant TB (RR-TB), multidrug-resistant TB (MDR-TB) (which is the focus of this study) pre-extremely drug-resistant TB (Pre-XDR) and extremely drug-resistant TB (XDR-TB) (Hughes and Osman 2014; Klopper *et al.* 2013; Schmidt 2008). Multidrug-resistant TB is impervious to the drugs *Isoniazid* and *Rifampicin* and XDR-TB is resistant to practically every known drug indicated for the treatment of TB (Klopper *et al.* 2013; Schmidt 2008). The genesis of XDR-TB is traced to South Africa's KwaZulu-Natal province in the 1950s (Health24 2015) and the largest recorded outbreak occurred in 2005 at Church of Scotland Hospital in Tugela Ferry, KwaZulu-Natal, killing 52 out of 53 infected people (Schmidt 2008). This and other literature discussed in this chapter support the need for

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<sup>1</sup> DR-TB is a blanket term that incorporates RR-TB, MDR-TB, pre-XDR-TB and XDR-TB.

research to contribute to decisively addressing DR-TB, the outpost of TB treatment in KwaZulu-Natal, to protect public health.

Resistance to anti-TB antibiotics or chemotherapy develops because potent drugs eradicate susceptible bacteria, leaving resistant ones to re-infect the patient, becoming stronger in the process (Klopper *et al.* 2013). Different philosophies about the genesis of DR-TB exist. In the first, scholars argue that drug-resistance emerged because TB patients did not scrupulously adhere to treatment, essentially marking DR-TB a man-made disease (Kerantzas and Jacobs 2017; Shah *et al.* 2017; Maharaj *et al.* 2016; Klopper *et al.* 2013; Brennan 2003; Espinal 2003 in van Rensburg *et al.* 2005). Discussions in Chapter Two about the introduction of the anti-TB drug *Streptomycin* in 1944 and studies published as early as 1948 which demonstrated that resistance to this drug developed almost as soon as it was introduced, however, challenge this notion (Arnadottir 2009).

While it cannot be denied that TB patients who fail to adhere to treatment precipitate mutations of TB bacterium until they are resistant to treatment, there is overwhelming evidence that most new DR-TB cases in South Africa result from ‘primary resistance’, where already drug-resistant TB strains are passed from infected persons to others (Shah *et al.* 2017; Kapwata *et al.* 2017; Hughes and Osman 2014; Klopper *et al.* 2013; Müller *et al.* 2013). Maharaj *et al.* (2016) found that 49 per cent of MDR-TB patients contributing to research in KwaZulu-Natal had no history of TB or prior exposure to anti-TB drugs. Shah *et al.* (2017) found that of 404 XDR-TB<sup>2</sup> patients who contributed to a four-year study (2011 to 2014), 280 (69 per cent) had never been treated for MDR-TB. High rates of primary infection suggested by these findings suggest poor knowledge about TB prevention and the necessity of implementing infection control practices in households and congregate settings where people with TB are present. Scholars insist that as well as diagnosing people with MDR-TB and treating them, addressing patients’ sub-optimal adherence to treatment is most critical to efforts to curb new infections (Fangudze *et al.* 2016; Maharaj *et al.* 2016, Mohr 2015; Padayatchi and Friedland 2008, Munro *et al.* 2007).

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<sup>2</sup> XDR-TB is the most serious form of TB. Often resulting from a failure of MDR-TB treatment, but also increasingly passed from person-to-person (called transmitted resistance) in South Africa, this form of TB is characterised by resistance to at least four first-line and second-line drugs currently available for treating TB (Shah 2017). Inadequate treatment of MDR-TB reportedly accounts for approximately 31 per cent of cases of XDR-TB as a result of transmitted resistance (Shah 2017).

Historically and in contemporary times, MDR-TB management emphasises biomedical and surveillance-type interventions, including mass screening and chest X-Ray campaigns, health systems strengthening, new drugs and vaccines development, investigating the efficacy of varied treatment combinations, new methods of identifying and tracking patients, and mobile health (mHealth) applications for monitoring patients as they take treatment (Bionghi *et al.* 2018; O'Donnell *et al.* 2017; Mazinyo *et al.* 2016; Churchyard *et al.* 2014; Tsodzo 2011). Some complain that overemphasis of biomedical responses hampers the significance of other approaches to respond to TB in South Africa (Thomas *et al.* 2016; Daftary *et al.* 2015; Daku and Gibbs 2012), similarly to the situation with HIV responses until the 1990s (Parker 2004). A school of thought maintains that the TB and DR-TB epidemics in South Africa result from inadequate patient counselling and treatment education and communication with patients in healthcare facilities being either too narrow or weak (Matebesi and Timmerman 2012, Ndjeka *et al.* 2008). Some insist that developing evidence-based multi-sectoral responses (Academy of Science of South Africa 2011), particularly ones which prioritise improving patients' adherence to treatment is the key to 'turning off the tap of new infections' (Shah 2017: 252). Encouragingly, growing acknowledgement of the unsuitability on its own, of the biomedical approach to TB management in recent times supports attempts to identify alternative strategies (Munro *et al.* 2007), including by studies such as this one.

There is growing consensus among scholars about the importance of considering social aspects like socioeconomic status, patient education, knowledge and changing attitudes to impact sub-optimal adherence to treatment among MDR-TB patients (Maharaj *et al.* 2016; Mohr *et al.* 2015; O'Donnell *et al.* 2014). In spite of this, however, the importance of patient knowledge and attitudes towards the disease and their influence on treatment adherence is under-researched (WHO 2013), even as there is agreement that patients' better understanding of their illness and treatment is central to effective TB programmes (Mohr 2015; Padayatchi and Friedland 2008). Indeed, studies find that treatment is often abandoned because of perceptions that it is too much trouble to take. For Matebesi and Timmerman (2012) this owes to inadequate or ineffectual health education and communication interventions.

This study aspires to contribute to public health communication scholarship and literature in South Africa. It privileges the primacy of treatment literacy in long-term adherence to MDR-TB treatment in investigating how health communication and promotion can be (re)positioned to enhance the biomedical MDR-TB treatment

programme as it benefits vulnerable populations (Flaskerud and Winslow 1998). The study aims to answer the question *how* communication strategies can be practicably implemented to improve vulnerable young women's treatment literacy for improved adherence and clinical outcomes as they are being treated at a public hospital in eThekweni Metro, KwaZulu-Natal province, South Africa. To do this, the study concerns itself with addressing the following questions:

1. What are the main challenges articulated by vulnerable young women receiving treatment at public hospitals in low socioeconomic settings in eThekweni Metro that affect their ability to fully adhere to MDR-TB treatment until completion?
2. How do young women in eThekweni Metro receive information about MDR-TB accessed via television and radio and interpersonal communication?
3. How can health communication be relayed and targeted to ensure attention to and reach of information by vulnerable young women receiving treatment for MDR-TB in eThekweni Metro?

The objectives of the study are to:

1. Assess the socioeconomic, structural, cultural and gendered issues that drive primary MDR-TB infection and hamper infection prevention efforts and treatment adherence among vulnerable young women in low socioeconomic contexts in eThekweni Metro.
2. Establish forms of mass mediated messages frequently accessed by young women on treatment for MDR-TB and their contacts in eThekweni Metro.
3. Ascertain which people, or groups of people, in contact with vulnerable young women receiving treatment for MDR-TB via public health facilities have the most reported influence in terms of communicating behaviour change and health information.
4. Develop a model that repositions, both epistemologically and practically, mass-mediated and interpersonal communication approaches to MDR-TB in ways that contribute to improvements in the KwaZulu-Natal MDR-TB programme.

An assumption of this research is that public health communication can contribute to protecting investments in biomedical DR-TB treatment in TB, DR-TB and HIV

syndemic countries. This can be achieved by defending the continued effectiveness of the limited drugs available through increasing patient's adherence to treatment until completion. The study launches by acknowledging the consensus in literature that public health communication is central to the success of MDR-TB patient management (Maharaj *et al.* 2016; Mohr *et al.* 2015; O'Donnell *et al.* 2014; Matebesi and Timmerman 2012; Padayatchi and Friedland 2008). It considers that target-specific strategies tailored to enhance communication with patients experiencing challenges with adhering to treatment are pivotal to improving patient experiences with treatment (Shah *et al.* 2017). Unfortunately for South Africa, lack of clear, consistent and current communication about MDR-TB conceivably impedes patients' abilities to adhere to treatment, even where they are willing to. Indeed, a 2016 national study found that information about TB is not commonly or widely available, and that general misconceptions about TB transmission, prevention and treatment are rife, particularly among those not infected or personally affected by the disease (Naidoo *et al.* 2016). These findings inspired this research, to ascertain how communication mediums and strategies could be practicably utilised to reach audiences in low socioeconomic contexts with life-saving information about MDR-TB prevention and treatment.

### **Defining adherence to MDR-TB treatment**

Research in South Africa found that people diagnosed with DR-TB/TB who had lived with someone with TB for a long time still demonstrated significant misconceptions about transmission and treatment (Maharaj *et al.* 2016; Matebesi and Timmerman 2012). If this is the case among re-treatment patients, knowledge among patients being newly treated for MDR-TB could be assumed to be too inadequate to support treatment adherence and positive outcomes. It is important to explain that it is harder, more expensive and takes longer to treat people with DR-TB (from nine to 36 months) with more toxic drugs, and poorer outcomes for patients (Shah *et al.* 2017; O'Donnell *et al.* 2017; Kerantzas and Jacobs 2017; Maharaj *et al.* 2016; Tudor *et al.* 2013; Daku and Gibbs 2012). These and other factors affect patients' willingness and ability to fully adhere to treatment, exacerbating the spread of primary MDR-TB and development of new XDR-TB cases (Shah *et al.* 2017; Maharaj *et al.* 2016).

Incomplete adherence or failure to complete treatment is one of the last frontiers to be conquered for South Africa to achieve national TB targets and contribute to global ones (Dick 1994:3-23 in van Rensburg *et al.* 2005). Research situates completion of individual treatment at the centre of global TB eradication efforts. Scholars contend that adherence 'is the fundamental point for treatment effectiveness' (de Oliveira and

Lefèvre 2017:4), an assertion that is substantiated by findings that without innovative patient support strategies, adherence to anti-TB treatment is approximately 50 per cent in developed countries, and significantly lower in low- and middle-income ones (Arnadottir 2009; Munro *et al.* 2007a) like South Africa. Researchers argue that ‘TB programmes which cannot ensure adequate levels of adherence are worse than no intervention at all’ (Dick 1994:3-23 in van Rensburg *et al.* 2005). This brings concerns that low health communication about MDR-TB contributes to the spread of drug-resistance and precipitates sub-optimal adherence to treatment to the fore, issues which are at the core of this study.

The requirement to improve adherence to MDR-TB treatment is so pressing that instructions in the South African National Tuberculosis Management Guidelines (2014) (South Africa National Department of Health 2014) mandate healthcare workers to adopt a patient-centred approach to uncover individual barriers to adherence and use consultations to educate patients about treatment (South Africa National Department of Health 2014:53). ‘Adherence’ in this study is defined as it relates to understanding the ‘patient perspective’ of taking treatment as prescribed by a healthcare provider (Matebesi and Timmerman 2012). The term ‘adherence’ is juxtaposed with ‘compliance’ to clarify the former’s use in this thesis. Both words are used in medical contexts and health literature to discuss treatment, albeit with different connotations. ‘Adherence’ refers to a patient following health professionals’ recommendations to take medications or engage in other positive actions towards improved health status (de Oliveira and Lefèvre 2017). Conversely, ‘compliance’ connotes a patient’s conformity to follow treatment prescriptions, often in the context of an unequal relationship between the patient and healthcare worker, in which the clinician decides what needs to happen, and the patient’s role is reduced to obeying instructions (de Oliveira and Lefèvre 2017).

The term adherence is employed in this study as it signifies patients’ greater agency and capacity to act while being supported by health professionals and others to make decisions that support good health (de Oliveira and Lefèvre 2017; Padayatchi and Friedland 2008). ‘Adherence’ connotes better relationships between health professionals and patients, as they enact joint decision-making about treatment (de Oliveira and Lefèvre 2017). Specific to TB treatment, ‘the definition of adherence can be understood as the patient’s consumption of the drug corresponding to the prescribed treatment’ (de Oliveira and Lefèvre 2017:3). Some insist that adherence extends to more health behaviours and practices than just ingesting medications. The



WHO (2003:9), based on earlier writings by Haynes (1979) and Rand (1993) defines adherence as ‘the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider’. There are many ideas about when a patient can be said to be adherent to TB treatment. Quantitatively, acceptable rates range from 90 per cent adherence (WHO 2005; Adane *et al.* 2013) to taking at least 80 per cent of prescribed treatment (Gelmanova *et al.* 2006; Dye *et al.* 2005). South African National TB Management Guidelines (2014:51) are stricter, insisting that adherence means ‘following the recommended course of treatment by taking *all* [emphasis mine] the medication, as prescribed, for the entire length necessary’.

Although I am not contending against the more lenient definitions of adherence, the grave threat to public health posed by DR-TB in South Africa, as well as the difficulty and expense of treating patients with limited drugs calls for stricter adherence. This view is more responsive to the national guidelines’ definition, which demands that all medication doses be taken as prescribed to destroy all TB bacilli, including the drug-resistant ones. The guidelines further articulate the ‘how’ of strict adherence, by proffering strategies that healthcare workers can use to counsel and educate patients about treatment (South Africa National Department of Health 2014:53).

The definitions and position taken above notwithstanding, adherence to prescribed long-term treatment for a serious disease is a complex phenomenon. Studies suggest that most MDR-TB patients struggle to adhere to treatment during the continuation phase (Tola *et al.* 2015; Adane *et al.* 2013; Newell *et al.* 2006), which in South Africa typically starts two to six months post-treatment initiation, depending on the total duration of treatment. Long-term treatment is an ongoing process arranged into three parts: acceptance, execution and discontinuation (Pasma *et al.* 2014). During the acceptance phase patients learn to embrace the necessity of treatment and fit the taking of medication into their daily customs (Pasma *et al.* 2014). This routinisation transitions into the execution of medication intake phase, which is often characterised by experiencing side effects (Pasma *et al.* 2014). Most studies on adherence/non-adherence focus on the execution stage (Pasma *et al.* 2014). This study seeks to understand experiences of MDR-TB patients who have been on treatment for more than six months, are primarily responsible for taking their own medication daily at home and can be perceived as being in the execution stage of treatment.

## **Motivation to research this topic**

I approached this research from a practitioner perspective, applying the lens of one situated in the TB management and health communication field (Berman 2013). Challenges I experienced while employed in a communication role for a South African TB management non-governmental organisation (NGO) motivated this study. I was especially concerned by lack of clear approaches to and documented successes in educating the public in South Africa about TB, and to support patients receiving treatment to fully adhere to their regimens as a form of infection prevention. My team and I frequently encountered difficulties in supporting the work of the NTP, partly because the advocacy, communication and social mobilisation (ACSM) units of the provincial TB directorates were at best understaffed and under-capacitated and, at worst, non-existent. When active, personnel adopted events coordination and pamphlet dissemination roles, particularly around World TB Day commemorations held annually in March. While media engagement and information dissemination increased sharply during this month, focus generally remained on profiling activities, events and political commitments, rather than sharing TB education and communication.

It also appeared that, in policy and practice, government-led TB programmes ranked reacting after TB infections had occurred, instead of prioritising initiatives to prevent new infections and development of drug-resistance. Indeed, while tracing close contacts of TB patients and preventing infection are acknowledged as critical to TB eradication efforts in policies such as the South Africa National Action Plan on HIV, Sexually Transmitted Infections and Tuberculosis (NSP) (2017-2021) and South African National Tuberculosis Management Guidelines (2014), supporting patients to adhere to prescribed treatment as a way of interrupting transmission and preventing new infections is underemphasised. This is despite assertions that the most important consideration in preventing drug-resistant disease is to cure patients at the very first attempt (Matebesi and Timmerman 2012). These concerns piqued my interest in investigating whether health promotion strategies could be better designed and applied to contribute to improving treatment literacy and patients' attitudes and intentions towards MDR-TB treatment, considering assertions that 'for perhaps the first time, the world is faced with a health threat against which the only effective barrier is not only medical, but also behavioural' (Cockerman 2001:31, in Matebesi and Timmerman 2012).

Early in my employment, I puzzled over South Africa's consistent failures to halt the spread of TB and DR-TB with some of the most advanced medicines in use globally and to successfully retain patients on treatment until completion (Munro *et al.* 2007a; Matebesi and Timmerman 2012). I considered these details with reference to evidence that the same country has the largest HIV epidemic in the world and, in the 20-plus years of dealing with HIV since the first two patients were diagnosed in 1982 (Gilbert and Walker 2002), South Africa recorded steady successes in reducing new HIV infections and motivating patients to independently take treatment daily for this incurable disease. I became curious about understanding why, given links and parallels between TB and HIV, similar achievements continued to elude those working on the centuries-old TB challenge in the same environment.

Further, this study's topic of investigation was influenced by my professional contributions to South African interventions to address the growing challenges of high death rates among people with DR-TB and burgeoning numbers of new DR-TB infections recorded among people with no previous history of TB treatment (Kapwata *et al.* 2017; Shah *et al.* 2017; Maharaj *et al.* 2016). From my academic positioning in the social sciences and health communications fields, I perceived South African governmental, non-governmental and private sector stakeholders' insistence on privileging biomedical responses to this socially-determined disease above all other strategies as odd, and I was concerned that it was detrimental to support and funding for non-medical responses to the epidemic (Merrill *et al.* 2016). Additionally, I was convinced that broader public health responses were urgently required, based on scholars' assertions that social advances, including improved food and water safety, sanitation, housing, literacy, socioeconomic status and safer working conditions, not biomedical responses, should be credited with the almost spontaneous historical decline of TB in developed nations (Merrill *et al.* 2016), something I felt countries in the Global South could learn from.

My research interest is in understanding the experiences and motivations of individuals in eThekweni Metro with primary MDR-TB from airborne transmission of the disease, rather than those whose MDR-TB mutated from TB because of incomplete or failed treatment. Two noteworthy articles influenced this focus. In the first, Maharaj *et al.* (2016) present evidence of low TB treatment literacy among patients being re-treated for the disease and those at advanced stages of treatment. I was curious to find out what challenges affect provision of education about MDR-TB treatment and patients' retention and use of it to result in low treatment literacy. This study takes the cue

from Maharaj *et al.*'s (2016) suggestion for additional research to establish how to enhance communication to contribute to the evidence base of effective TB infection prevention strategies.

The second paper demonstrates evidence of a growing XDR-TB epidemic in KwaZulu-Natal and proof that XDR-TB more likely results from transmitted resistance than development due to incomplete treatment or failure of first-line TB treatment (Shah *et al.* 2017). Using genotypic analysis, researchers linked 84 per cent of all XDR-TB patients in KwaZulu-Natal to one of 31 cluster (Shah *et al.* 2017). The study urged for renewed national emphasis on reducing TB infections, tracing patients and initiating and maintaining them on treatment, while simultaneously managing their household contacts. The article, which was published in January 2017, was so significant that it disrupted the South African TB sector and sparked a shift in implementation by the NTP for that year. Notwithstanding this evidence, the NTP's response in action still privileged the identification of new 'missing' TB patients and their clinical management.

The two studies and the national response to the second, to which I contributed through my employment, further flamed my curiosity and informed the nascent ideas that informed the research proposal submitted for this doctoral study. These two articles on the DR-TB problem in KwaZulu-Natal province, literature discussed in Chapter Two explaining how the TB epidemic diminished with negligible clinical intervention in countries in the Global North as those nations became more developed, and South Africa's HIV prevention and management achievements informed some assumptions that influenced this study's conceptual framework and methodological approach, as discussed in Chapters Five and Six.

I considered academics' assertions that research needs to demonstrate to decision-makers that tailored evidence-based approaches to the threat that TB poses to public health in South Africa can be more effective than approaches already in use (Copper 2011) when conceptualising this study. As explained previously, MDR-TB and XDR-TB are under the umbrella term DR-TB. I chose to focus on MDR-TB in this study as a proxy for TB to (i) narrow the research focus from the too-broad and often convoluted topic of TB treatment in South Africa, (ii) specifically contribute knowledge to the emerging topic of primary MDR-TB in eThekweni Metro, (iii) refine the case study of this research, and (iv) restrict and narrow the research questions to be more specific. I chose to focus on women for the same reasons.

I was curious about women's experiences with MDR-TB treatment because there are few studies in this area. While it may seem superfluous to apply a gender lens to TB studies because transmission is airborne and generally there is parity in infection rates among women and men for both DS-TB and DR-TB (Shah *et al.* 2017; Fagundez *et al.* 2016; Maharaj *et al.* 2016), some argue that mainstreaming gender considerations lends depth to public health studies (Theobald *et al.* 2017). Gender is the social construct of being a man or woman, which is prescribed by socially determined norms, roles of, and relationships between groups of women and men in-context (SADC 2011; Vlasoff 2007). Conceptions of gender vary from society to society; they are dynamic and can change *within* the same society over time. Differences in roles and responsibilities of men and women in different communities determine vulnerability to illness and infections, health status, burden of ill-health, quality of care, access to health resources, information and preventive and curative measures (SADC 2011). Biological differences alone cannot adequately explain health behaviour; understanding the social and economic factors that, in turn, are influenced by cultural and political conditions in particular societies is key (Vlasoff 2007), as discussed in Chapter Four.

Scholars insist that social, economic and biological determinants and consequences of communicable diseases are mediated through gender, resulting in different approaches to disease prevention, treatment, coping mechanisms and health outcomes among men and women in specific contexts (Theobald *et al.* 2017; Vlasoff 2007). It is anticipated that incorporating gender considerations into this study will result in richer findings and analysis that contributes to understanding young women's vulnerability to MDR-TB – on top of being more susceptible to the comorbid disease HIV – in low socioeconomic contexts. It will also contextualise young women's gendered experiences of barriers and opportunities to healthcare within a defined historical, structural, socioeconomic and cultural context.

Discussions in this thesis are also influenced by encouragements to consider 'the shaping force of the cultural context when trying to understand differences in health behaviours' (Leclerc-Madlala 2009:554). Scholars explain the panoptic influence of culture and its importance in studies such as this one because:

Culture extends to issues of power, control, resistance and defiance as well, and anthropology seeks to understand the links between social stratification (gender, ethnicity, social class), access to material and immaterial goods (food, water, health services, education), illness representations, cultural

constructions of femininity and masculinity, attitudes to health promotion, and health behaviour (Krumeich *et al.* 2001:122).

Meanings made from this research are mediated through understanding of isiZulu-speaking people's cultural beliefs and practices, and the context of data collection as it impacts vulnerable young women's experiences with MDR-TB treatment (de Chesney *et al.* 2008). This study heeds cautions against indiscriminately applying Western-centric theories to understanding health-seeking behaviour and healthcare service uptake among populations in settings other than those where these theories were developed (Leclerc-Madlala 2009; Krumeich *et al.* 2001). Understanding the culture of the researched and situating the case study of this research within its confines as findings of the study were analysed helped guard against this pitfall.

In the findings chapters, I attempt to link the cultural milieu and customs, and health beliefs and practices, of vulnerable isiZulu-speaking young women and others in their communities, and their experiences with MDR-TB treatment in an urban area, considering assertions that 'The lived experience of a particular disease in a Durban township, for example, may be considerably different to that found in a northern KwaZulu (sic) rural area' (Leclerc-Madlala 2009:557). Context-specificity is critical to understanding reasons for non-adherence to MDR-TB treatment among the case study of this study, and how to potentially mitigate them through enhanced health communication.

### **Research procedures and key findings**

This study is undertaken in the qualitative research methodology and is framed as a single descriptive case study (Verschuren 2011 in Simmons 2009; Yin 1984) comprising women aged 18 to 34 years from marginalised communities receiving treatment for primary MDR-TB via a public health facility in an urban area. Data was collected during fieldwork in eThekweni Metro between 6 March and 29 September 2018 through eight in-depth interviews and three focus-group discussions with between four and five (total of 10) women predominantly from the same cultural background. People aged 18 to 34 years are most affected by TB and are estimated to lose incomes equivalent to up to half of their earnings during treatment (WHO 2017). Their families are correspondingly most at risk of experiencing 'catastrophic economic costs' associated with TB infection, since the highest number of people with active disease are in the most economically active age-groups (WHO 2014; Kigozi *et al.* 2017; Lönnroth and Raviglione 2016).

Findings presented in Chapters Seven, Eight and Nine also include insights from three family members of women being treated for MDR-TB at the time of data collection as well as healthcare providers from King Dinuzulu Hospital, and KwaZulu-Natal Provincial Department of Health personnel, to ensure triangulation of data and support the validity of findings of this research. In total, 20 participants contributed to this study.

## **Organisation of work**

The ten discrete chapters in this thesis are interconnected by their aim to address the study's three research questions within the borders of the conceptual framework advanced in Chapter Five. Chapter Two presents an historical account of TB globally and in South Africa. I assume a position on the contested aetiology of TB and explain the point at which resistance to anti-TB drugs first emerged, to support my argument that South Africa's overreliance on biomedical treatment to the DR-TB epidemic is bound to fail, particularly in areas like eThekweni Metro where TB and DR-TB management challenges are exacerbated by the concurrent HIV epidemic.

Chapter Three discusses the historical development of health communications from multiple fields of study and its emergence as a distinct discipline in the 1970s and 80s. It audits seminal and contemporary health communications literature to understand the effectiveness of mass media, interpersonal communication and social media in encouraging public health on a variety of health challenges in theory and practice. The chapter assesses impacts of health communication on knowledge, attitudes, intentions and behaviour, and examines contributions of social and behaviour change communication (SBCC) ideas to this study. It concludes by auditing mass mediated TB/MDR-TB communication broadcast from 2015 to 2018 in South Africa, covering the last two years of the third National Strategic Plan on HIV, Tuberculosis and Sexually Transmitted Infections (NSP) (2012-2016) and the first two years of the fourth NSP (2017-2021).

Chapter Four outlines multi-faceted challenges that hamper vulnerable young women's adherence to MDR-TB treatment in eThekweni and communication's potential to improve patient's treatment literacy and abilities to adhere to treatment long-term. It demonstrates the centrality of adherence to MDR-TB treatment and appraise the varied factors which influence young women's attitudes and intentions towards MDR-TB treatment. The chapter also presents extant literature about multi-

layered challenges that dilute this vulnerable populations' intentions to adhere to treatment.

This study's conceptual framework, which is based on a constructed epistemological approach in the qualitative research tradition, is presented in Chapter Five. This chapter discusses how cogent literature, select theories and my professional experience in the fields of health communication and media were merged to construct an edifice through which to investigate the potential of health promotion strategies to impact sub-optimal adherence among women in low socioeconomic contexts with strong cultural beliefs. Discussions of the Vulnerable Populations Conceptual Model (Flaskerud and Winslow 1998), Knowledge Gap Theory (Tichenor, Donohue and Olien 1970), Two-Step Flow (Lazarsfeld and Katz 1955) and Multi-Step Flow Theory and select health behaviour theories within the frame of Cross *et al.*'s (2017) constructed health communication approach help to theoretically triangulate the study, which is complemented by the methodological pluralism adopted in Chapter Six.

Chapter Six presents the study's methodological framework, which utilised a qualitative research design. Data collection was triangulated through use of a multi-pronged recruitment strategy and multiple data collection methods to emerge with detailed primary data gathered during fieldwork in eThekweni Metro. Elements of grounded theory are incorporated for their contribution to the inductive approach to research sampling, data collection, analysis and presentation adopted for this qualitative research. The methodology of this research was designed to support this study's objective of developing a practicable situated health communication model derived from analysis of empirical data about vulnerable young women's reasons for sub-adherence to MDR-TB treatment. Developing a communication model is Objective 4 of this research as discussed earlier.

Chapter Seven carries descriptions of the six-step thematic analysis process which was applied to the reading and analysis of findings of this research. Through this process, significant broad clusters were identified to explain reasons for MDR-TB patient's sub-adherence to treatment. Emerging broad themes analysed in this chapter include cultural beliefs and practices, environment and socioeconomic status, biomedical and structural considerations, and intrapersonal and relational factors.

Findings presented in Chapter Eight address research question one: What are the main challenges articulated by vulnerable young women receiving treatment through



public hospitals in low socioeconomic settings in eThekweni Metro that affect their ability to fully adhere to MDR-TB treatment until completion? I make associations in the findings to explain why young women from communities with strong cultures and traditions who reside in metropolitan communities may fail to fully adhere to prescribed MDR-TB treatment. Findings presented respond to lived realities of a defined vulnerable population affected by the TB, MDR-TB and HIV syndemic in eThekweni. They are advanced to identify opportunities to improve targeting, quality and quantity of treatment education and health promotion interventions for the benefit of vulnerable populations, their families and residents of high MDR-TB burdened areas.

Findings presented in Chapter Nine, the penultimate chapter of this thesis, address the study's second and final research questions: (ii) How do young women access information about MDR-TB? and (iii) How can health communication best be relayed and targeted to ensure attention to and reach of information by vulnerable young women with MDR-TB? The chapter proposes practicable approaches to contribute to improving MDR-TB treatment literacy among patients and increasing flow of information to the public in eThekweni Metro, KwaZulu-Natal, so supportive environments with reduced stigma can be built around patients and their families.

The answers to all three research questions inform the integrated communication strategy that is developed and proffered Chapter Ten. Discussions in this chapter responds to academic' calls for research that develops context-specific strategies to improve treatment adherence in high TB-burden areas. This chapter also concludes. It sums up discussions in this thesis, explains major conclusions reached and consolidates potential areas for further research, some of which were out of the scope of this study to address. Limitations of the study are also appraised in this chapter.

## CHAPTER TWO

# HISTORICAL DEVELOPMENT OF DRUG-RESISTANT TB AND CONTEMPORARY CHALLENGES OF MANAGING THE DISEASE IN ETHEKWINI METRO

### Introduction

This chapter establishes the aetiology of TB and probes the global rationale for making medicine the fulcrum of a disease which, as demonstrated here, is largely determined by patients' socioeconomic statuses. Tracing the rise, ebb and flow of TB through the centuries helps to establish the point at which drug-resistance first emerged and elucidate that early treatment with far less sophisticated drugs than are available today was to an extent effective. This knowledge raises pertinent questions about responses to MDR-TB in contemporary South Africa. These include why MDR-TB reached epidemic proportions in the first instance, and why the disease is as obdurate as it is. It also suggests the ineffectuality of prioritising eradicating MDR-TB using biomedical treatment for patients without their full involvement.

The history of the rise of TB, its treatment and eradication in parts of the Global North presented in this chapter challenges us to view MDR-TB as a polyhedral product of history and, accordingly, to question those who privilege its biomedical management. This includes interventions which, among others, merely provide TB information and hopes it sticks. Extant responses to MDR-TB overlook its multidimensional morphology, which historically unfolded in a specific socioeconomic, political and cultural context, as explained here. A detailed reflection on the sociology of TB in relation to its epidemiological as well as social and cultural history may help us to understand shortcomings of strategies in use and gain insights to support development of effective responses to the disease. These discussions are also presented in this chapter.

In latter sections, the scale of the contemporary threat posed by MDR-TB to public health in South Africa is introduced. The chapter further discusses the epidemiology of MDR-TB and explains how leakages of patients along all steps of the TB/DR-TB care cascade result in significant numbers of people with TB lacking appropriate treatment and likely remaining infections, with dire consequences for infection prevention efforts. It describes the context of the study; eThekweni Metro, KwaZulu-Natal province, argues for the importance of countries such as South Africa in achieving global MDR-TB eradication targets, and urges that prioritising social

responses to the DR-TB epidemic to support biomedical treatment is the best approach.

### **Sociological dimensions of tuberculosis**

Facts about the origin and development of TB in humans are disputed. Some scholars trace the emergence of the disease to 10,000 years ago, during a period known as the Neolithic Transition in Africa (Chisholm *et al.* 2016; Gagneux 2012). This time was characterised by humans venturing into agriculture and the domestication of animals. Declarations from this camp, which are widely contested, are that *Mycobacterium Tuberculosis* originated in animals and passed to humans (Chisholm *et al.* 2016; Gagneux 2012; Comas *et al.* 2005). Other studies date the emergence of TB to 20-35,000 years ago (Bynum 2012).

In their influential writings, Sebastien Gagneux and his colleagues insist that TB emerged much earlier, around 70,000 years ago, and that it originated in humans (Gagneux 2012; Comas *et al.* 2005). Here the advent of TB in humans is linked to the discovery and use of controlled fire by early people about 300-400,000 years ago (Chisholm *et al.* 2016). This ostensibly created ideal conditions for bacterium to pass from person-to-person as communities huddled around fires in close proximity (Chisholm *et al.* 2016). In this argument, inhaled smoke damaged lungs and created favourable conditions for human infection with pulmonary TB (Chisholm *et al.* 2016).

Taking into consideration these different theses and setting aside uncertainty about exactly how TB first emerged, there is strong evidence that the TB bacilli in its current form originated in East Africa (Barberis *et al.* 2017; Chisholm *et al.* 2012; Daniel 2006), although archaeological evidence to prove this is generally lacking in the region, (Bynum 2012; Daniel 2006). Evidence in Egypt, North Africa, however, traces TB back more than 5,000 years as evidenced by skeletal abnormalities consistent with TB infection which were discovered in Egyptian mummies and are depicted in early Egyptian art (Barberis *et al.* 2017; Daniel 2006).

From Africa, TB spread to China, Europe, and India predominantly via human migration (Gagneux 2012). These regions experienced huge population growths and, with it, exponential increases in the numbers of people with TB, who facilitated its spread as they too migrated further afield (Gagneux 2012). The first written records on TB are from 2,300 and 3,300 years ago, in China and India respectively (Barberis *et al.* 2017). Unlike other ancient diseases, TB has been in existence for so long without a cure, and the bacterium has managed to reinvent itself into more virulent forms over

centuries and millennia. The threat of TB to public health urgently requires multi-sectorial responses, beyond the predominantly biomedical ones in current use. Literature strongly suggests that improving socioeconomic status and enhancing patient knowledge and attitudes contributes to strengthening TB control efforts. We will return to this point below, which is the pith of this study and is well-illustrated by accounts of the natural decline of TB as countries became more developed during the Industrial Revolution (1760-1840).

Indeed, assertions that social determinants of TB infection may be more important than medical causes are supported by findings that during the Industrial Revolution, city dwellers and beneficiaries of its attendant developments continued to succumb to TB at alarming rates (Daniel 2006). Even during the early days of the progression of TB into a fully-fledged epidemic, there was some understanding and acknowledgement of the links between poverty and hardship, particularly caused by overcrowding, poor nutrition and harsh working conditions (Daniel 2006). Tuberculosis' associations with low socioeconomic status arguably informed early responses to manage and treat the disease (van Rensburg *et al.* 2005; Daniel 2006) and is key to contemporary arguments advanced in this thesis that TB is ill-suited to being addressed via biomedical means alone.

### **Early forms of tuberculosis treatment**

Tuberculosis has long been the leading cause of death of people of all ages, but young people especially (Daniel 2006). The disease has been known as 'consumption', 'phthisis', 'scrofula', 'Pott's disease', 'White plague', 'Captain of all these men of death', 'graveyard cough' and the 'robber of youth' at various points and places in history (Frith 2014). In ancient times, so grave was TB's impact on youth that in his writings the ancient Greek philosopher Hippocrates (active sometime between 450 BCE and 380 BCE), mentions a wasting disease, then known as phthisis, that mostly afflicted people aged 18 to 35 years (Barberis *et al.* 2017; Frith 2014; Coar 1982 in Daniel 2006; van Rensburg *et al.* 2005). In contemporary times, the End TB Strategy notes that TB affects most economically active age groups and urges for interventions to mitigate 'catastrophic costs of TB' on households (WHO 2014).

Tuberculosis reached epidemic proportions in the rapidly industrialising nations of Europe and North America during the 18<sup>th</sup> and 19<sup>th</sup> centuries, affecting both young and old, and rich and poor (Daniel 2006). The early 20<sup>th</sup> century witnessed escalation of efforts to find effective TB diagnosis, infection control and treatment options

(Barberis *et al.* 2017). Discussions in this section focus on the TB epidemic in Europe, for its impact on the spread of the disease to South Africa and for contributions of countries in the Global North to TB research and biomedical advances. The discussions also demonstrate that successes in treating TB were recorded before the advent and widespread use of anti-TB drugs, as the launching point to establish that other interventions can contribute to ending TB in developing countries in contemporary times.

### ***Pneumothorax***

The first recorded treatment for pulmonary TB in the early 19<sup>th</sup> century was pneumothorax. Dr James Carson, an English physician, established that injecting air into the pleural cavity could collapse the lung, giving it rest and permitting it to heal. The exercise did not catch on at the time (Bynum 2012), but it was rediscovered by C. Forlianini in 1882 and became the standard treatment for those with pulmonary TB for some time. Although painful and debilitating, pneumothorax achieved improvements in some patients, and was favoured because it reduced the production of sputum and chances that treated TB patients would infect others (Bynum 2012).

### ***Sanatorium cure***

The first major development in TB treatment was ‘sanatorium cure’, pioneered by TB survivor and physician Hermann Brehmer, who found that he was cured of the disease when he went to the Himalayas in search of a healthier climate on the advice of this doctor (Barberis *et al.* 2017; Daniel 2011; Sandhu 2011). In 1854 Brehmer presented his auto-biographical medical dissertation with the dramatic title *Tuberculosis is a curable disease* (Barberis *et al.* 2017). He thereafter opened an in-patient hospital where TB patients, surrounded by trees and fed a nutritious diet, were exposed to continuous fresh air (Barberis *et al.* 2017; Sandhu 2011). The first of these, Heilanstalt, in the Himalayas, treated 958 patients in its first decade, recording a mortality rate of only 4.8 per cent, an impressive feat for the times (Daniel 2011). Indeed, contemporary TB treatment programmes set 5 per cent as the maximum acceptable mortality rate.

Brehmer’s approach became the prototype for subsequent sanatoria built during that period (Daniel 2011). Sanatorium care: expensive, inaccessible to the majority of those with TB, but effective considering that no medicines were involved, was the go-to TB treatment for a century (1840-1950) (Daniel 2011; van Rensburg *et al.* 2005; Daniel 2006). That it was possible to cure TB and, in the case of countries in the Global

North, come close to eradicating the disease in the absence of large-scale biomedical treatment programmes suggests that environments where TB treatment occurs and the behaviours of patients within these environments, rather than medicines dispensed, is more important for cure.

Around the time sanatorium care was declining in the 1950s, initiatives to test the effectiveness of public health campaigns in supporting mass TB screening campaigns were increasing. The Greenock Survey (1953-1954) partly aimed to test effectiveness of communication in encouraging residents of Glasgow, Scotland, to be screened for TB and resulted in the diagnosis and treatment of many infected people. Officials noted the 'apparent success of [TB] propaganda ... Over 3,500 people attended 20 meetings under a variety of auspices at which talks, demonstrations and films on the subject were given ... as a result of the press publicity that the local daily newspapers gave to the campaign day by day we had a very great success. To be effective campaigns needed unqualified local institutional support' (Levitt 2003:7-8). However, subsequent campaigns in the city were hampered by delayed implementation, because of concerns about their cost, relative to the numbers of new TB patients identified (Levitt 2003). Thus, as early as the 1950s public health communication about TB was already beginning to be linked to notions that it needed to yield TB patients, instead of being a standalone strategy useful for preventing new infections or encouraging positive TB treatment behaviours. The situation deteriorated through the decades and persists in contemporary TB health communication practice in South Africa. It is also worth noting that this period coincided with rapid discoveries of several new anti-TB medications in the 1940s and '50s, which may have further hampered advances in the budding TB health communication field, as stakeholders turned their focus to promises of effective biomedical treatment capable of eradicating TB.

### **The 'selective immigration' to and management of tuberculosis in South Africa (1890-1994)**

As TB flourished in the Global North, the disease soon returned to Africa through mass immigration, with devastating consequences for countries such as South Africa. Prevalence of TB in 19<sup>th</sup> century Europe was so high that many abandoned urban locales for treatment in rural sanatoria. Some moved further afield, off the continent altogether to countries like South Africa with perceived favourable climates to support recovery and cure from TB (van Rensburg *et al.* 2005). Van Rensburg *et al.* (2005) refer to this as the 'selective immigration' of TB to South Africa and explain that many of the migrants were already so ill by the time they arrived that they were unable to

travel far from the port of landing. The concentration of early immigrants in coastal regions meant that South Africa's inland areas remained relatively TB-free for longer (van Rensburg *et al.* 2005; Packard 1989, Metcalf 1991), although port cities like Natal, (now known as Durban, which is part of eThekweni Metro)<sup>3</sup> bore the brunt of the disease almost immediately.

Incidence of TB remains high in major cities in coastal areas of South Africa. This is because of 'social, economic and environmental conditions created by apartheid in the form of overcrowded squatter settlements, migrant labour and deliberately under-developed health services for Blacks' (Karim *et al.* 2009:936). The threat that the legions of newcomers with TB posed to inhabitants who, with little previous exposure to the bacteria, had little biological resistance to it, was grave, although this was not considered before 1895 (van Rensburg *et al.* 2005; Packard 1989, Metcalf 1991), because the infectious nature of TB was only established in 1884 as discussed below.

### ***Introduction of TB to rural areas and setting the stage for the development of drug-resistance***

While TB first established itself in urban areas, it soon moved inland. Although there is evidence of very low levels of TB in South Africa when the first Dutch settlers arrived in 1652, incidence was not at the epidemic levels recorded following the landing of immigrants during the 1890s (van Rensburg *et al.* 2005). The years 1895 to 1910 were characterised by rapid increases in TB infections, particularly among the impoverished majority Black population (van Rensburg *et al.* 2005, Packard 1989). The discovery of diamonds in 1867 and gold in 1886 sparked TB importation with the emigration of mineworkers and fortune-seekers from Europe (Rees *et al.* 2010; Karim *et al.* 2009; van Rensburg *et al.* 2005). Even the consumptives among them went directly into mining, a sector highlighted as particularly burdened by TB transmission in South Africa, even in contemporary times (van Rensburg *et al.* 2005).

The new arrivals were soon joined on the mines by the original inhabitants of the country who, together with immigrants from neighbouring nations, served as cheap labour for fixed periods (Lurie and Williams 2014; Rees *et al.* 2010). Poorly ventilated working and living conditions, constant exposure to silica dust, and the often-chronic

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<sup>3</sup> Portuguese explorer Vasco da Gama, arrived on the KwaZulu-Natal coast on Christmas 1497 and named the area Terra do Natal, or Christmas Country in Portuguese. In 1824 a settlement, which was initially named Port Natal, was established in the area. On 23 June 1835 Port Natal was renamed Durban in honour of Sir Benjamin D'Urban, governor of the Cape Colony from 1834 to 1837 (South African History Online 2011).

underprivileged nutritional status of local mineworkers made them particularly prone to contracting TB (Karim *et al.* 2009; van Rensburg *et al.* 2005). Scholars explain that mining in the 1800s was an effective conduit for TB transmission to masses of Black people over a short period (Packard 1989). The system assembled thousands of young Black men in high-risk environments for TB infection, before dispatching them back to their rural communities within South Africa and neighbouring countries and hiring new recruits to take their place when they became too ill to work (Lurie and Williams 2014; Rees *et al.* 2010; Karim *et al.* 2009; van Rensburg *et al.* 2005). In this process, termed 'oscillating migration', TB was gradually introduced to rural communities, where it spread unchecked due to poor or no health services (Rees *et al.* 2010; Karim *et al.* 2009, Packard 1989). Former miners who returned to rural communities with TB often failed to complete treatment they had started taking while working, if they had been prescribed it at all (Rees *et al.* 2010). This contributed to the spread of TB in hitherto unaffected areas and development of DR-TB, until South Africa was faced with an epidemic. Indeed, studies show that by the 1920s, TB infection was so commonplace in some inland rural areas in South Africa that returning mineworkers with TB no longer posed a significant threat to the public health of communities (Packard 1989).

### ***Colonial and apartheid governance systems and inequities in TB treatment***

It is worth noting that TB was declared a notifiable disease, with compulsory registration of all patients, in what are now the coastal provinces of Western Cape and KwaZulu-Natal in 1904, while the policy rolled out nationally 15 years later, in 1919 (van Rensburg *et al.* 2005). In 1905 a Special Committee appointed by the South African Medical Congress raised concerns about rising prevalence of TB in Coloured towns (van Rensburg *et al.* 2005). Similarly to Europe and North America during this period, sanatorium care was the principal method of treatment in South Africa. The country's first sanatorium was opened in Cape Town in 1907. This option was, however, only available to the White population, hampering infection control measures across the board and sustaining the threat to public health (van Rensburg *et al.* 2005). By the 1940s, TB was characterised by huge disparities in incidence and mortality in the different population groups; incidence rates among Blacks increased steeply, while they gradually declined among Whites (van Rensburg *et al.* 2005; Packard 1989).



The establishment of apartheid as the governance system in 1948 introduced and sustained numerous socioeconomic, political and demographic conditions conducive to heightened incidence and rapid escalation of the TB epidemic nationally (van Rensburg *et al.* 2005). Analogously to all other facets of life in the country at the time, health policy and legislation in apartheid South Africa favoured the White population, with resources and services disbursed along racial, geographical, sectoral and class lines (Packard 1989). The consequence was huge disparities in the health status of different population groups, inequalities that persevere (van Rensburg *et al.* 2005). Understanding these inequalities is integral to appreciating why the Black population in South Africa is so disproportionately affected by TB, other infectious diseases, and non-communicable diseases that are linked to lower socioeconomic status, such as Diabetes Mellitus (van Rensburg *et al.* 2005, Packard 1989).

Scholars contend that failures of national TB control efforts during apartheid, and even after, result from significant disparities in living standards of different racial groups; inefficient treatment programmes attributable to fragmented, uncoordinated services; and shortages of health resources and services for the Black population (Rees *et al.* 2010; van Rensburg *et al.* 2005; Packard 1989). Under-reporting and non-notification of TB cases also contributed to high numbers of unconfirmed TB patients who consequently remained untreated, and infectious (van Rensburg *et al.* 2005). These challenges persisted well after 1994 when South Africa attained democracy (Packard 1989). It is also significant that because of apartheid, from 1948 to 1994 South Africa was excluded from the international community and missed out on benefitting from advances in the management of TB in the international health system; particularly the work of the WHO and International Union Against TB and Lung Disease (van Rensburg *et al.* 2005). This forfeiture contributed to South Africa significantly lagging in TB management efforts. It is ironic that South Africa re-joined the international arena a year after the WHO declared TB a public health emergency.

### **One hundred years of biomedical advances in tuberculosis diagnosis, treatment and control in Europe (1865-1965)**

Major breakthroughs in the TB field and development of effective treatment in Europe corresponded with South Africa's colonisation, the influx of consumptives to the country and the advent of apartheid. One of the most significant events occurred in 1865, two years before the discovery of gold in South Africa, when French physician Jean-Antoine Villemin demonstrated that TB was an infectious disease (Barberis *et al.* 2017; Daniel 2015). His conclusion arose from observation that TB was more

common among soldiers stationed in the barracks than among those out in the field (Barberis *et al.* 2017). Villemin also noted that crowded urban areas tended to record higher incidence of TB (Barberis *et al.* 2017). This breakthrough was notable because before then, medical theory was that each case of consumption arose spontaneously in predisposed people (Barberis *et al.* 2017). This finding paved way for the use of basic TB infection prevention methods and allowed other scholars to research systems to more accurately diagnose TB and explore treatment options.

Seventeen years later Hermann Heinrich Robert Koch identified the tubercule bacillus as the agent causing TB disease and established the infectious nature of the illness in 1882 (Barberis *et al.* 2017; Daniel 2015; Frith 2014; Daniel 2006; Van Rensburg 2005). This important discovery supported, among others, development and implementation of public health measures to halt the spread of TB (Daniel 2006). Koch was awarded the Nobel Prize in Medicine or Physiology in 1905 for his explanation of the aetiology of TB (Barberis *et al.* 2017; Daniel 2006). In his acceptance speech, he alluded to the work of a colleague and fellow bacteriologist, Carl Flügge, who proposed that bacilli found in droplets from a cough could be the possible mode of transmission of TB (Frith 2014).

### ***Discovery of antibiotics for the treatment of TB and development of drug-resistance***

Once the aetiology and mode of transmission of TB were established, efforts turned to finding effective treatments. The discovery of *Penicillin*, the first true antibiotic in 1928 and *Sulfonamide*, the first effective therapy against bacterial diseases in 1935, were major medical breakthroughs that sparked races to discover what diseases they could cure (Ryan 1992). Unfortunately, TB was not one of them (Kerantzas and Jacobs 2017; Ryan 1992). A year later *Actinomycin* proved effective against TB invitro, but it was regrettably too poisonous for both humans and animals (Kerantzas and Jacobs 2017).

The 1940s heralded a period of rapid development and testing of biomedical interventions that registered some successes (Kerantzas and Jacobs 2017; van Rensburg *et al.* 2005). *Streptomycin* was the panacea drug that researchers had long sought, combining as it did low toxicity with high inhibitory effects (Kerantzas and Jacobs 2017; Daniel 2006). The first critically ill TB patient was initiated on the drug in late 1944, with dramatically good results (Kerantzas and Jacobs 2017; Daniel 2006). Several other anti-TB drugs followed. They were important because therapy with a

single drug soon sparked resistant TB strains (Kerantzas and Jacobs 2017). Of significance to this research is that resistance to *Streptomycin* developed soon after it was first used, and the introduction of all subsequent drugs was eventually similarly afflicted (Kerantzas and Jacobs 2017; van Rensburg *et al.* 2005). Multi-drug therapy helped circumvent this problem and was quite effective when taken continually in regular doses for six to eight months (Kerantzas and Jacobs 2017).

*Isoniazid*, the first oral anti-TB drug, was initially used in 1952, closely followed by the discovery of *Rifampicin* in 1957 and its launch in the late 1960s (Kerantzas and Jacobs 2017; Daniel 2006). *Pyrazinamide* was discovered in 1952 and added to existing treatment regimens. Combined with *Isoniazid*, *Pyrazinamide* achieved the shortest duration of treatment for sputum conversion, but it was, unfortunately, also highly toxic (Kerantzas and Jacobs 2017). *Ethambutol* was discovered in 1961 and shown to be more potent than *Streptomycin* (Kerantzas and Jacobs 2017).

These drugs made it possible for patients to take anti-TB drugs for between 18 and 24 months without being hospitalised (van Rensburg *et al.* 2005). Furthermore, research during this period established the basis of modern TB treatment regimens, by demonstrating that treatment with an intensive phase using combined *Isoniazid*, *Rifampicin*, and *Pyrazinamide* and a continuation phase on *Isoniazid* and *Rifampicin* was more efficacious (Kerantzas and Jacobs 2017). These combinations demonstrated that six months of treatment was equivalent to nine months of the same on different drugs (Kerantzas and Jacobs 2017). They further significantly lowered infectivity of patients on treatment, leading to reduced new infections and death rates, and increased cure rates (Kerantzas and Jacobs 2017; van Rensburg *et al.* 2005). Notwithstanding these successes, however, sub-optimal adherence to treatment was already a concern as early as the 1940s. Leeming-Latham (2015:176) explains that once anti-TB drugs ‘as a stand-alone treatment for TB became established, ensuring that drugs were taken reliably on a long-term basis emerged as one of the most difficult aspects of clinical management. Experiences were that home treatment, unless highly supervised, could fail’, urging for support for patients to enhance adherence. Apart from studies that associate the challenge with the introduction of longer treatment regimens and patients spending less time being treated while hospitalised in the 1950s (Leeming-Latham 2015), literature that explicitly documents when sub-optimal adherence first emerged is scarce.

A long hiatus in TB drugs research occurred from the 1960s to 2000s. *Bedaquiline* and *Delamanid* are the first new anti-TB drugs approved for use in over 40 years; both are prioritised for inclusion in MDR-TB treatment regimens (Bionghi *et al.* 2018; Sotgiu *et al.* 2017; Bridgen *et al.* 2015; Deoghare 2013). It is significant that *Bedaquiline* made injection-free DR-TB treatment regimens possible for the first time. Based on experience and concerns that sub-optimal adherence would instigate resistance, the WHO provided 'conditional stringent regulatory approval' to use the new drugs between 2011 and early 2017 (Bridgen *et al.* 2015:367). In this arrangement, *Bedaquiline* and *Delamanid* were initially available only on a compassionate basis or prescribed to patients with XDR-TB, or MDR-TB patients whose four-drug regimens could not be constituted with existing options because they were resistant to one or more of them (Sotgiu *et al.* 2017; Bridgen *et al.* 2015). *Delamanid* was launched at Sizwe Hospital, Johannesburg, during commemorations of World TB Day in 2016, although its use was restricted to few categories of MDR-TB patients: adolescent, children and complicated cases with limited treatment options (Medicines Sans Frontiers 2017).

There is urgency to increase adherence to these new drugs, to minimise chances that further DR-TB mutations would render them ineffective, similarly to other medications in the past (Bionghi *et al.* 2018). Losing the new drugs would negate recent advances in the response to DR-TB and cripple efforts to halt the surging global and national epidemics. Indeed, a promising area for further research could focus on measuring DR-TB or DR-TB/HIV co-infected patients' adherence to treatment regimens that include *Bedaquiline*, since the drug is lauded for reducing length of treatment. Considering patients' mixed reviews about whether side effects are worse or better on this drug as discussed in Chapter Eight, this topic is worth investigating further as it is outside the scope of this study to explore.

South Africa was among three (together with Armenia and France) of the first countries with the largest number of patients eligible to roll-out *Bedaquiline* via compassionate use programmes which simultaneously had the necessary policy framework and mechanisms for implementation. The drug was available for controlled use with select patients in 2013 and 2014 (Bridgen *et al.* 2015) but was only launched for wider use in South Africa in 2017. KwaZulu-Natal province launched use of *Bedaquiline* in November 2017, benefitting some of the participants to this study, and necessitating adjustments to some assumptions of this research, as explained in Chapters Seven and Eight.

While it is not disputed that the advent of antibiotics vastly improved TB treatment, excessive focus on the effectiveness of biomedical treatment, almost to the exclusion of other explanations for declining TB incidence rates is criticised in literature (Arnold 2012, van Rensburg *et al.* 2005). Indeed, reasons for significant reductions in TB incidence in the Global North are debated (Daniel 2006). While some laud advances in biomedical research and use of more effective treatment, others contend that better health and hygiene standards and implementation of basic personal TB prevention methods led to declining TB-related mortality rates (Arnold 2012, van Rensburg *et al.* 2005). In support of this position, Van Rensburg *et al.* (2005:5) maintain that:

The conquest of TB in the Western World had been largely accomplished by the 1980s, with the decline having commenced well before the use of isolation, surgical procedures, BCG vaccination<sup>4</sup> and anti-TB therapy. Historians associate this decline with improved nutrition and sanitary infrastructures, as well as elevated standards of living.

The premise is that poor socioeconomic status and hardship compromise individuals' immune systems, galvanizing latent TB into active disease (Arnold 2012; Rees 2010; Schmidt 2008). Thus, if socioeconomic factors improve, it becomes likely that the war against TB can be won (Schmidt 2008). In support of this idea, some studies show that by the time antibiotics and a TB vaccine first came into wide use in the 1940s, better housing, less crowded accommodations and improved sanitation and nutrition had lowered TB incidence in England and Wales to fewer than 50 deaths per 100,000 (Schmidt 2008). Vynnycky and Fine (1999) agree and expound that reductions in new infections were due to TB patients having fewer contacts to whom they could pass TB, which they linked to the availability of more effective treatment and improved socioeconomic and living conditions. In 1900 each TB patient had 22 contacts with whom they had sustained enough contact to transmit TB to, a figure that dropped to about 10 in 1950, and down further to 1 by 1990 (Vynnycky and Fine 1999). This finding is vital to this study, which seeks to uncover how enhanced communication and MDR-TB treatment literacy can contribute to improving adherence to treatment and suppressing infectiousness in contexts where patients and their (many) contacts

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<sup>4</sup> Bacillus Calmette–Guérin (BCG) is a vaccine primarily used against TB. It is the only vaccine for TB currently available, which is given to babies at birth in many countries as it has been found to be most effective in preventing TB, particularly TB Meningitis, in children.

often live, socialise and work in close proximity for sustained periods of time in crowded conditions.

By the 1970s, 20 years of treating TB with more advanced treatment combinations and more hygienic living environments in the Global North sparked the decline of TB until it looked like the disease could be eradicated (Anderson *et al.* 2017; Schmidt 2008). At this peak however, reduced attention and funding, and lack of systematic monitoring of drug resistance over another 20-year period slowed progress (Schmidt 2008). The tide turned dramatically with the advent and spread of HIV in the 1980s, leading to increased TB transmission and MDR-TB outbreaks around the globe (Karim *et al.* 2009; Schmidt 2008). As explained earlier, HIV is the single most important factor contributing to increasing incidence of TB in Africa since 1990 (WHO 2012).

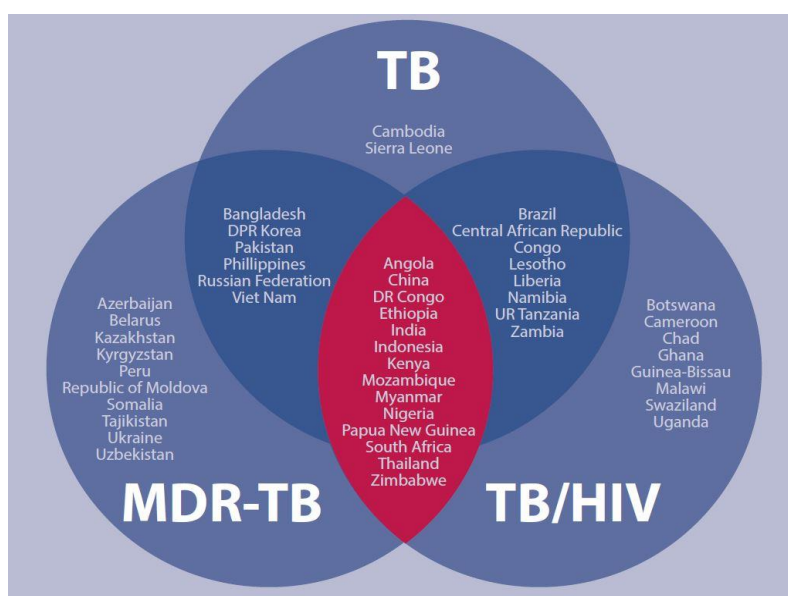
While the battle against TB had been all but won in the Global North by the 1990s, in the developing nations of the Global South, and in Africa in particular, the pervasiveness of TB infection finds explanation in hereditary considerations, and poor socioeconomic circumstances, housing situations and diets that play a role in TB infection progressing to TB disease (Schmidt 2008). Gagneux sums this up succinctly by asserting that ‘TB is the prototype of a disease of poverty’ (Gagneux 2012:850), a position substantiated by findings that most of the two to three million people who die of TB are in developing countries or from poor, urban neighborhoods in wealthier nations (Schmidt 2008; van Rensburg 2005). So significant is the problem that as far back as 1996 the WHO called TB a ‘fire raging out of control’ in developing nations, among the poor, in prisons, and in people with HIV (Saeed 2006). Literature strongly suggests that in poorer countries, of which South Africa has significant pockets, enhancing patient knowledge and impacting attitudes contributes to strengthening TB management efforts. So convincing is this argument that the WHO (2010) included education as an intervention in its TB management priorities, a point which supports the legitimacy of this study. We will return to this idea, which is a major thread running through this thesis.

### **Establishing the global and national MDR-TB problem**

In contemporary times TB is among the top ten causes of death globally, and the leading one from a single infectious agent (WHO 2018). Tuberculosis-related deaths globally increased from 1.5 million in 2014 to 1.8 million in 2015 (WHO 2015), before falling to 1.3 million in 2017 (WHO 2018). Of this number, 0.3 million were people co-infected with HIV and TB (WHO 2018). Among the 22 countries with the highest

burdens of TB, in 2015 South Africa recorded the highest estimated incidence and prevalence of TB, and the second highest number of diagnosed MDR-TB patients (WHO 2016; Churchyard 2014). Additionally, the country has the largest number of HIV-co-infected TB patients worldwide (WHO 2016). South Africa's HIV and growing TB/DR-TB epidemics are inexorably linked, as illustrated in Figure 1. Because of weakened immune systems, people living with HIV (PLHIV) are more susceptible to TB infection and to developing active TB disease than those who are not, and the reverse is true.

Figure 1: High TB/HIV and MDR-TB endemic countries globally



Source: WHO (2018)

South Africa's TB burden continues to grow (Shah *et al.* 2017; Kapwata *et al.* 2017; van Rensburg *et al.* 2005), the country ranked fourth globally for TB incidence in 2014 (Maharaj *et al.* 2016). The following year an estimated 454,000 people developed active TB, 300,000 of whom were initiated on treatment, leaving an estimated 154,000 people missing from care (WHO 2016).<sup>5</sup> Globally, estimates are that 41 per cent of people with TB remained undiagnosed and untreated (WHO 2016). This percentage is lower than that recorded in South Africa, where more than half of people with TB did not receive treatment. Of those receiving treatment, 252,000 were successfully treated and cured, which demonstrates the effectiveness of TB treatment, but only if patients take it faithfully (WHO 2016). Despite these successes, South Africa could not account for 19,500 TB patients lost from care after they were initiated on

<sup>5</sup> Statistics South Africa (2018) mid-year estimates recorded a total national population of 57,73 million.

treatment in 2015 (WHO 2016). Encouragingly, TB incidence globally has registered declines of about 2 per cent annually since 2013 (WHO 2018). However, these successes may be offset by increasing incidence of DR-TB worldwide.

Recent performance in DR-TB diagnosis, treatment and retention in care is no better. Globally, an estimated 558,000 people were newly diagnosed with RR-TB in 2017, of whom 82 per cent had MDR-TB (WHO 2018). In South Africa, of the people with TB recorded in 2017, 14,000 (4.3 per cent) had DR-TB (WHO 2018). For mixed reasons, only 73 per cent started treatment that year, leaving 27 per cent people missing from care in the first instance (WHO 2018). These people were in communities where they remained infectious, actively contributing to the transmission of DR-TB to others (WHO 2018). Considering trends in DR-TB management illustrated in Figure 2 below, the necessity of scaling up responses to reduce the number of people with DR-TB who have not been correctly diagnosed, as well as those detected but not initiated on treatment is foregrounded.

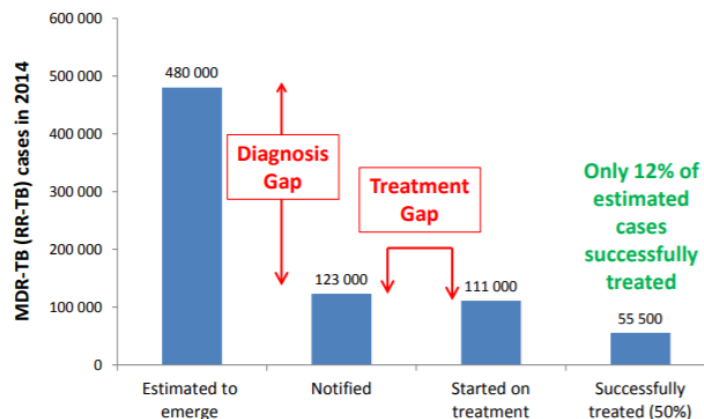
In South Africa, initiation on treatment is not correlated to reduced mortality, however, as only about 49 to 55 per cent of people with DR-TB are cured (Bionghi *et al.* 2018; WHO 2018; WHO 2016; Klopper *et al.* 2013), a figure significantly lower than the 75 per cent global target for treatment success rate. From this figure, we can infer that patients' adherence to treatment is woefully inadequate, which reduces effectiveness of treatment and increases possibilities that the MDR-TB epidemic will further escalate into an XDR-TB one, which will be difficult to address in already compromised environments. These considerations urge for an urgent shift in priorities, from finding new people with MDR-TB and bringing them to care, to ensuring that people already receiving treatment are supported to strictly adhere and complete their regimens. As elaborated later in this chapter, nowhere else in South Africa is this issue more urgent than in eThekweni Metro, because of the centrality of KwaZulu-Natal's TB/HIV and DR-TB syndemic to reducing the scale of the problem nationally (Munro *et al.* 2007a).

Like other countries, South Africa utilises the TB or DR-TB care cascade to track the number of people screened for TB, number with presumptive TB tested, number diagnosed with TB and initiated on treatment, and number of people who successfully complete prescribed treatment (Naidoo *et al.* 2017). Indications are that only 20 to 25 per cent of the estimated number of people with DR-TB globally are properly diagnosed (WHO 2015), largely because of lack of appropriate laboratory



infrastructure in low-income settings, which often record the highest TB figures (Müller *et al.* 2013).

Figure 2: DR-TB diagnosis and treatment cascade: Global



Source: WHO (2015)

Scholars argue that South Africa's DR-TB epidemic is attributable to wide inconsistencies between the numbers of patients diagnosed, those who start treatment and those who successfully complete it (Naidoo *et al.* 2017; WHO 2016; Klopper *et al.* 2013; Narasimooloo and Ross 2012). Put simply, the large number of people who do not know that they have TB and remain infectious because they are not being treated, and the large numbers of patients who do not complete prescribed treatment and risk developing mutation all contribute to the airborne transmission of resistance. In areas like KwaZulu-Natal, alarmingly high incidence of MDR-TB, low diagnosis, a haemorrhaging health service that loses patients at every interval of care, and low implementation of infection prevention measures contribute to significantly impacting public health (Naidoo *et al.* 2017; Klopper *et al.* 2013; Variano 2013; Narasimooloo and Ross 2012)

An objective of this study is to proffer an evidence-based model for how to use communication to improve adherence to MDR-TB treatment, considering assertions that 'preparation of patients to start receiving TB treatment is comparatively minimal and nonstandardized' in South Africa (Dong *et al.* 2007:S494). In this way, it is hoped that this study's contribution to the extant knowledge base can support reducing gaps between the number of people initiated on treatment and the number who successfully complete it without having skipped doses. It argues for the imperative to focus attention on ensuring that those already being treated for DR-TB are retained

in care and supported to take and complete it, to contribute to curtailing new infections. Public health communication can contribute to this endeavour.

### **Context of the study: eThekweni Metro, KwaZulu-Natal province**

Most DR-TB patients in South Africa are diagnosed in impoverished communities of the coastal provinces of Eastern Cape, KwaZulu-Natal and Western Cape, where TB was first introduced with the arrival of immigrants from Europe and America (Klopper *et al.* 2013) as discussed earlier. KwaZulu-Natal, one of nine provinces of South Africa, is located on the country's South-East coast and is the second most populous province in the country. An estimated 10.9 million people live in KwaZulu-Natal, comprising 19.9 per cent of the population (Statistics South Africa 2015). As intimated earlier, KwaZulu-Natal is the epicentre of the TB, MDR-TB and HIV crises in South Africa (Loveday *et al.* 2018; O'Donnell *et al.* 2017; Shah *et al.* 2017; Kapwata *et al.* 2017). The province routinely reports MDR-TB numbers higher than the 200 cases per 100,000 population that the WHO bases its declaration of a public health crisis on (WHO 2016). In 2004 KwaZulu-Natal reported 583 laboratory diagnosed cases of MDR-TB, a figure that rose exponentially to 6,630 by 2012, marking the province a hotbed for MDR-TB in South Africa (Maharaj *et al.* 2016). A prospective study based on hospital admissions data published in 2017 found that MDR-TB incidence increased by 400 per cent in six years from 2011 to 2017 (O'Donnell *et al.* 2017).

Treatment outcomes for patients in KwaZulu-Natal are markedly worse than those published from MDR-TB cohorts in other provinces (Maharaj *et al.* 2016), even though MDR-TB in just this one province accounts for up to 25 per cent of South Africa's total burden of the disease (Narasimooloo and Ross 2012). Scholars justifiably argue that success in KwaZulu-Natal is critical to South Africa's efforts to turn the tide on new infections, which can only be achieved by interrupting transmission of MDR-TB and development of mutation (Shah *et al.* 2017; Narasimooloo and Ross 2012). Colloquially, practitioners in the field aver that if KwaZulu-Natal sneezes, the rest of the country contracts MDR-TB. These considerations influenced the decision to locate this study in this province.

KwaZulu-Natal is burdened by a dual TB/HIV syndemic, with researchers routinely finding 75 per cent or more of patients with all types of TB co-infected with HIV (Loveday *et al.* 2018; O'Donnell *et al.* 2018; Shah *et al.* 2017; Mazinyo *et al.* 2016; Maharaj *et al.* 2016; Gandhi *et al.* 2012; Daftary and Padayatchi 2016; Karim *et al.* 2009). A critical consideration for MDR-TB management studies is that South Africa, and

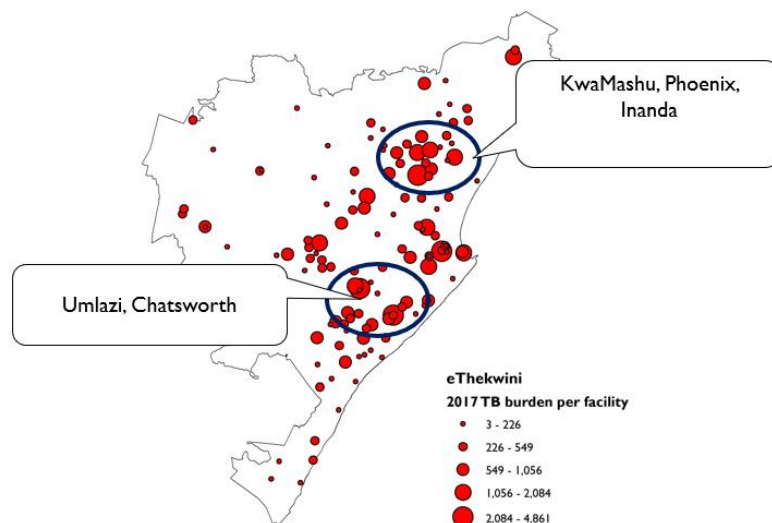
KwaZulu-Natal province specifically, host the largest dual HIV/TB co-infection syndemic globally (Shah *et al.* 2017; Karim *et al.* 2009). Associations between HIV and TB in South Africa are so well documented that studies note that TB management deficiencies could be addressed by using strategies that 'have been successfully implemented in the HIV programme' (Padayatchi and Friedland 2008:978), a finding which this study aims to implement, including by referencing HIV studies where literature on TB/DR-TB may be lacking. The HIV and MDR-TB links are highlighted here because HIV-associated TB complicates TB management efforts. The burden on patients of biomedical treatment for two serious diseases must be considered in establishing why individuals and groups may fail to adhere to treatment for MDR-TB, which this study attempts to do in Chapter Four, by focusing on young women from low socioeconomic contexts.

It is important to establish at the onset that HIV and MDR-TB co-infection is correlated with high mortality rates, even for people who receive appropriate treatment (Bionghi *et al.* 2018; Gandhi *et al.* 2012). Reducing immunosuppression in PLHIV through treatment is therefore considered good practice in improving TB programme outcomes and reducing mortality (Mazinyo *et al.* 2016; Daftary *et al.* 2015; Gandhi *et al.* 2012; Padayatchi and Friedland 2008). Towards this end, in September 2016, the South African government launched a universal 'test and treat' initiative, which initiates people on antiretroviral therapy (ART) to treat HIV as soon as they test positive, regardless of CD4 count. This development has implications for MDR-TB treatment, as ART strengthens immune systems of PLHIV and reduces their risks of contracting opportunistic infections like TB (Maharaj *et al.* 2016; O'Donnell 2014). Discussions in Chapter Four include reviews of studies that demonstrate that being on ART is protective of people with MDR-TB, who are consequently more likely to adhere to treatment (Kigozi *et al.* 2017; Terra and Bertolozzi 2008).

To further contextualise the study, KwaZulu-Natal province comprises eleven districts, among them eThekweni Metro (including the city of Durban and surrounding areas), which is a largely densely populated urbanised metropolitan municipality, albeit with some rural communities on its borders to the west, south and north (Department of Health 2017). The outlying areas are mostly underserved in terms of access to health infrastructure (Department of Health 2017). The metro is experiencing rapid development. It hosts the busiest port in Africa, which is linked by a good railway network to other southern African countries.

Approximately 3.6 million people reside in eThekweni Metro, the largest proportion of the population (32 per cent) resides in the North, although the highest population density is recorded in South Central (Department of Health 2017). The metro is serviced by 17 hospitals (including two specialised TB hospitals and six DR-TB centres), eight community health centres and 103 primary healthcare clinics (see Figure 7) (Department of Health 2017). While the North Service Area records the highest population density and TB incidence, higher DR-TB incidences are recorded in the South Central and Lower South service areas, in townships like Umlazi and Chatsworth, where many respondents to this study resided as discussed in Chapter Six. King Dinuzulu Hospital, the recruitment site for this study, is in the South Central Service Area as discussed in more detail later in this section. Figure 3 illustrates the higher concentration of TB in more densely populated areas of the metro, which are also those along the coastline.

Figure 3: Burden of TB (2017) in eThekweni Metro

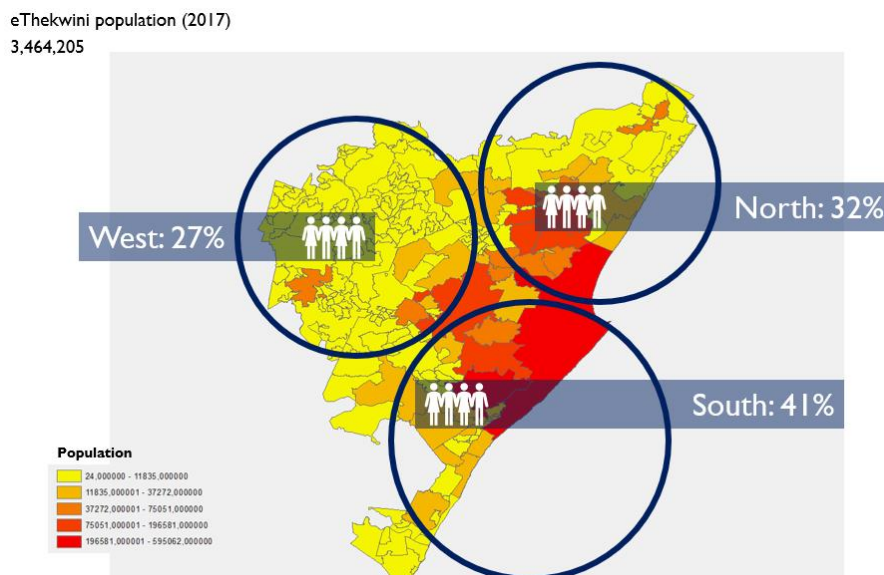


Source: Department of Health, Province of KwaZulu-Natal (2017) in USAID Tuberculosis South Africa Project (2017)

eThekweni Metro boasts a diverse society with various social, economic, environmental and governance challenges. It is ethnically varied; about 68 per cent of the population is Black, 20 per cent Indian, nine per cent White and three per cent Coloured (Statistics South Africa 2015). Fifty-two per cent of the population in 2015 was female (Statistics South Africa 2015), a figure that dropped slightly to 51 per cent in 2016 as reflected in Figure 5. Approximately 19 per cent of adults able to work are

unemployed, and the average annual income of households is a low ZAR 44,391<sup>6</sup> (Statistics South Africa 2015).

Figure 4: Population of eThekweni Metro (2017)

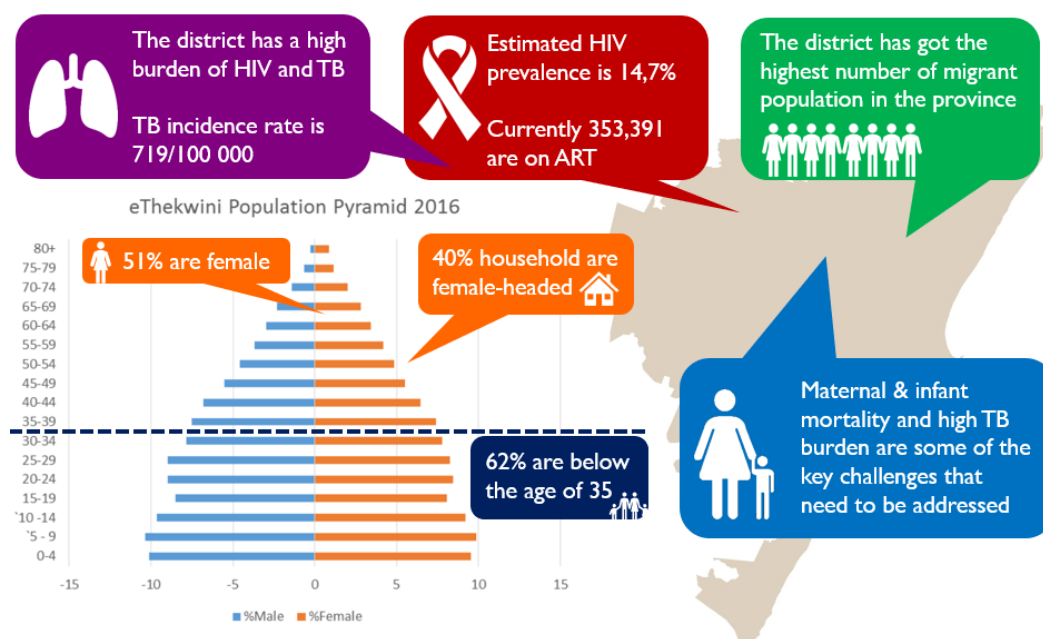


Source: Department of Health, Province of KwaZulu-Natal (2017) and Statistics South Africa (2017), in USAID Tuberculosis South Africa Project (2017)

By far the leading cause of mortality (eThekweni Municipality 2018), TB accounts for 21 per cent of deaths, followed by diarrhoeal diseases (8.7 per cent) and HIV (8.7 per cent) (Province of KwaZulu-Natal 2015). Tuberculosis is unevenly distributed in the metro, accounting for why the disease is not accorded the attention and multi-sectoral response it deserves. Tuberculosis has been termed ‘the disease of the poor’ and in South Africa this description is accurate as it disproportionately affects the poor, young people and Black Africans (South African National Tuberculosis Association 2013). A study in KwaZulu-Natal found that 98 per cent of patients receiving treatment for MDR-TB at a hospital were Black; only three Indian and two Caucasian patients were available to participate (Narasimooloo and Ross 2012). It may also be that wealthier (often non-black) patients can afford to access TB treatment through private medical facilities.

<sup>6</sup> Approximately US\$3,282.88 using a rate of 1US\$/ZAR13.50

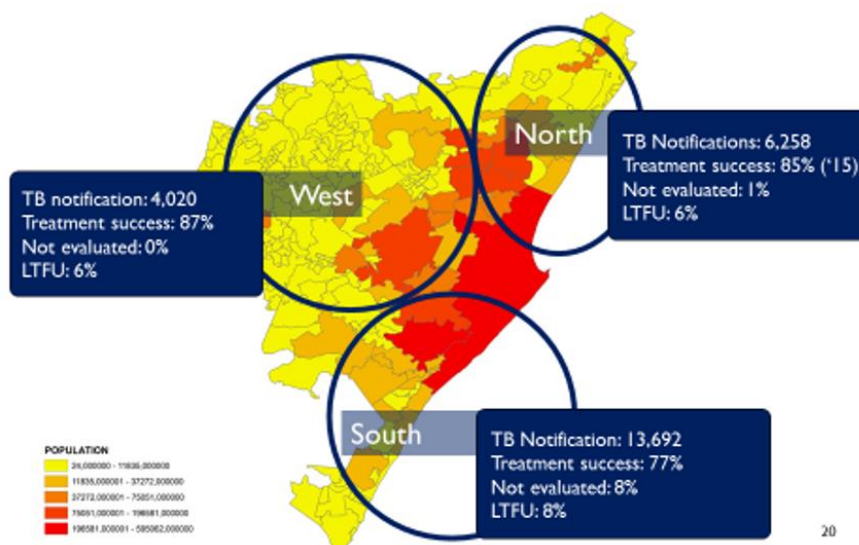
Figure 5: eThekweni demographics (2016)



Source: Department of Health, Province of KwaZulu-Natal (2017) and Statistics South Africa (2015), in USAID Tuberculosis South Africa Project (2017)

Approximately 9.3 million inhabitants of KwaZulu-Natal are uninsured and dependent on public healthcare services (Department of Health 2016). The highest proportion (26.7 per cent) reside in eThekweni Metro (Department of Health 2016). The already heavy burden on provincial, district and municipal health systems is exacerbated by the substantial MDR-TB challenge, not to mention TB, HIV and XDR-TB. All these diseases fall almost squarely on the Provincial Department of Health and municipal authorities to manage (Department of Health 2017).

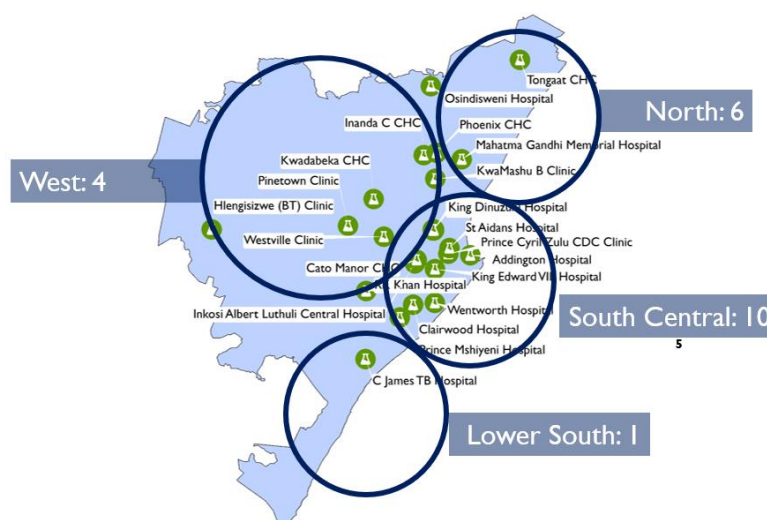
Figure 6: eThekweni Metro TB epidemiology (2016)



Source: Department: Health, Province of KwaZulu-Natal (2017), in USAID Tuberculosis South Africa Project (2017)

King Dinuzulu Hospital, in eThekweni South Central (see Figure 7) is the recruitment site for this research. The hospital was selected because it houses the largest specialised DR-TB unit in KwaZulu-Natal province. An average of 250 new MDR-TB patients are initiated on treatment each month, and healthcare workers see an estimated 2,500 patients (Maharaj *et al.* 2016). Additionally, patients receiving treatment at decentralised DR-TB sites in KwaZulu-Natal are periodically reviewed at King Dinuzulu Hospital.

Figure 7: Spread of health facilities in eThekweni Metro



Source: Department of Health, Province of KwaZulu-Natal (2017) in USAID Tuberculosis South Africa Project (2017)

The sheer number of people with MDR-TB accessing services at King Dinuzulu Hospital positions this centre as a particularly rich site to identify and recruit the total number of young women with MDR-TB anticipated to be adequate to contribute to this study. The hospital is the site of numerous TB studies, notably by The Centre for the AIDS Programme of Research in South Africa (CAPRISA 2019), which has a research clinic hosted there. In February 2019, of 16 ongoing studies at the site, five had a focus on TB, four of which were specific to DR-TB. The heavy presence of researchers at King Dinuzulu Hospital impacted this study's recruitment strategy, as explained in discussions of this study's methodological approach in Chapter Six.

## **Summary**

This chapter demonstrated that growing numbers of people diagnosed with MDR-TB as the first instance of having TB in KwaZulu-Natal, and South Africa urge for rethinking the country's responses. There is growing acknowledgement of the need to address social determinants of MDR-TB infection, which challenges privileging of biomedical responses to the disease almost to the exclusion of all other interventions. The chapter established that rising incidence of MDR-TB is an indicator of poor TB programme performance and reflective of poorly targeted and implemented responses spanning an extended period (Karim *et al.* 2009). This urges for rapid and urgent development of strategies to reduce primary MDR-TB infections, including ones focused on improving patients' adherence to treatment as an infection prevention strategy (Shah *et al.* 2017). Literature presented suggests that improving socioeconomic status, enhancing patients' knowledge and changing attitudes contribute to strengthening TB control efforts (Maharaj *et al.* 2016; Mohr *et al.* 2015; O'Donnell *et al.* 2014). This is the pith of this study, which explores how public health communication can be better employed and targeted to achieve improvements in treatment adherence among young women from low socioeconomic contexts in eThekweni Metro, which was described in detail in this chapter.

The next chapter probes how communication, within the context of the myriad issues that people with MDR-TB must contend with, can be practicably developed to achieve improvements in young women's adherence to MDR-TB treatment. Literature indicates that with the necessary support, women are more likely to adhere to treatment long-term (O'Donnell *et al.* 2014). Whether a patient is successfully treated and cured of TB, it is argued, is directly related to the quality of care they receive, and how adequately the complex interactions among personal, socioeconomic and infrastructural factors that determine patients' behaviours are understood prior to



implementation of responses (Matebesi and Timmerman 2012 no date). Ensuring complete adherence to TB treatment among patients in eThekweni is an urgent issue for KwaZulu-Natal province, and South Africa as whole, because of how infectious this disease is, and how rapidly its drug-resistant forms are spreading (Munro 2007) as established in this chapter.

## **CHAPTER THREE**

### **CONTEMPORARY COMMUNICATION RESPONSES TO THE MDR-TB CHALLENGE**

#### **Introduction**

For over a decade, scholars have noted lack of urgency in advancing ideas and strategies, including communication methods, to support TB/MDR-TB treatment adherence and contribute to averting new infections (Sarkar and Scalway 2005). This is notwithstanding excited predictions by scholars in the 1990s that in the future, ‘communication scholars will work to end the prejudicial treatment of marginalised cultural groups within the modern health care system, such as prejudicial treatment of people with AIDS, the poor, minorities, women, and the elderly. Future research will examine the health communication needs of marginalized cultural groups and identify strategies for enhancing health communication with members of these groups’ (Kreps 1996). It is significant that this research aims to contribute to achieving this aspiration, with focus on young women with MDR-TB resident in resource-limited settings.

South Africa’s growing TB and MDR-TB epidemics have been attributed to sub-standard patient counselling and low TB health education (Matebesi and Timmerman 2012). While researchers agree on the centrality of communication in supporting MDR-TB patients to adhere to treatment (Fagundez *et al.* 2016; Maharaj *et al.* 2016; Ndjeka *et al.* 2008), there is little evidential literature about *how* to effectively implement this in-context. Indeed, as discussed in this chapter, while academic research on whether and how communication has been used to improve treatment for HIV and other public health challenges show that this has been attempted, communication is seldom applied explicitly, or as the main component of interventions (Maharaj *et al.* 2016; Munro *et al.* 2007) in TB management in South Africa.

This chapter reviews extant literature to establish the potential of health communication to contribute to improving MDR-TB treatment literacy and attitudes to treatment as the first step to influencing changes in treatment behaviours within the specific context of eThekweni Metro, South Africa. It is important to signpost here that where TB/MDR-TB communication literature is lacking (Nglazi *et al.* 2014; Sarkar and Scalway 2005) this study borrows from HIV research and other health communication studies. Although HIV is more recent than TB, some insist that the enormity of the HIV epidemic re-directed resources, research and implementation

attention from the antiquated TB problem in developing countries (Khan *et al.* 2017; Sarkar and Scalway 2005). Priorities of external funding agencies, and competition among international and local NGOs for shrinking resources also impact prioritisation of TB (Khan *et al.* 2017).

It could be supposed that some attention would have shifted back to the TB epidemic ever since TB and HIV assumed 'twin' status. Lack of synergies in implementing TB and HIV programmes, however, mean that the problem persists, and TB responses continue to lag behind HIV ones (Daftary *et al.* 2015; Karim *et al.* 2009). Specific to South Africa, since 2012 national policies emphasise strategies to address HIV, to the detriment of advances in eradicating TB. This trend is mirrored in broader global and local public health communication studies discussed in this chapter. Extant literature, however, does not sufficiently discuss use of health communication in responding to the TB epidemic. Thus, given evident shortcomings in TB research and considering the convergence of HIV and TB, it is deemed appropriate to borrow from literature on HIV communication to make sense not only of the potential contribution of MDR-TB communication to enhanced treatment adherence, but other arguments raised in this thesis.

The review in this chapter further delves into literature on the impacts (or not) of other public health communication campaigns in increasing target audiences' knowledge and impacting their attitudes, intentions and behaviours. These include studies on topics as varied as heart disease and cancer prevention, paediatric health, smoking cessation, vaccination uptake and others (Corace and Garber 2014; Bekalu and Eggermont 2014; Parashar *et al.* 2013). In particular, results of 1970s heart disease prevention communication which demonstrated effectiveness of well-designed, targeted and sustained communication campaigns in positively impacting public health practices informed this study, as discussed later (Maccoby 1976).

Some of the literature presented insists that patients' abilities to adhere to prescribed treatment for medical conditions are directly related to how they understand the disease in-context (Terra and Bertolozzi 2008; Kleinman 1980; Zola 1966). These findings give impetus to this study, as they substantiate the importance of augmenting MDR-TB communication efforts in defined contexts. Indeed, the centrality of health communication and education to increasing treatment literacy is included in the WHO's (2010) TB control priorities and emphasised in national and global TB eradication strategies and plans on the same topic which are discussed below. The

international body urges for more research on patient knowledge about and attitudes towards TB because this is the key that will unlock appreciation of how treatment adherence can be enhanced in specific contexts (WHO 2013). Responses have however been lacklustre, particularly in relation to investigating ways of using communication strategies to increase knowledge about MDR-TB in order to impact disparities in vulnerable groups' health services access (Maharaj *et al.* 2016). This is the area to which this study aims to contribute knowledge.

## **Global and national tuberculosis management policy frameworks**

Enabling policies that emphasise the importance of health communication in TB/DR-TB biomedical treatment exist at global and national level. It is thus surprising that practice and implementation in South Africa is so low. Globally, stakeholders set the goal of ending TB by 2030 in United Nations (UN) Sustainable Development Goal (SDG) 3 (Lönnroth and Raviglione 2016); WHO aims to have eradicated TB by 2035, while South Africa's ambition is to accelerate TB prevention to considerably reduce the burden of the disease by 2022. These targets and deadlines urge for stakeholders to implement programmes to halt transmission of both DS-TB and DR-TB (Shah 2017:252). Although the robust policies in place provide an enabling policy environment for studies such as this one, in practice they are not always responsive to needs of communities. Indeed, the most significant of them fail to articulate the importance of improving health literacy and public health communication in their suggested responses. Framing communication in the context of this study and explanations of the use of the terms health literacy and health communication and how they fit into discussions about MDR-TB biomedical treatment is explained in the next sub-section.

The UN set 17 SGDs to extend the lifespan of the unmet Millennium Development Goals (MDGs) (2000-2015). Achievement of Health Goal 3 (Goal 3) aims to 'ensure healthy lives and promote well-being for all at all ages'. Target 3.3 aims to 'End the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases'. Interventions to achieve this goal focus on reducing TB incidence and death rates by 80 per cent and 90 per cent respectively over 15 years (2016-2030) (Lönnroth and Raviglione 2016). This thesis argues that improving treatment adherence and stopping onward transmission of MDR-TB in communities like eThekweni Metro can significantly contribute to achievement of these objectives (Kigozi *et al.* 2017; Shah *et al.* 2017) and

that communication has a role in the multisectoral approach that is necessary if the varied goals discussed are to be achieved.

Concurrently, in 2014 the 67<sup>th</sup> World Health Assembly adopted the WHO End TB Strategy, which was developed in parallel with the SGDs but has a longer timeline (Lönnroth and Raviglione 2016; Cazabon *et al.* 2016; Wingfield *et al.* 2014). This study focuses on goals of the End TB Strategy, which considers good health as both a contributor to and beneficiary of development, because of the alignment of targets and priorities in the SGDs and End TB Strategy and because the latter is specific to the global TB epidemic (Lönnroth and Raviglione 2016). The strategy launches by acknowledging that TB is most severe among the poorest and most vulnerable, and that it worsens existing inequalities. It positions TB as a development, social and human rights issue, while foregrounding the critical role of public health and biomedical responses in addressing the epidemic worldwide (Lönnroth and Raviglione 2016). The End TB Strategy provides a coherent policy and implementation framework to end TB through reducing TB deaths by 95 per cent and cutting the number of new TB patients by 90 per cent between 2015 and 2035 (Kigozi *et al.* 2017; Cazabon *et al.* 2016). Improving treatment adherence and halting transmission thus becomes an emergency in low socioeconomic communities, such as those in eThekweni Metro, which are among some of the most overburdened in the world (Kigozi *et al.* 2017; Shah *et al.* 2017).

The End TB Strategy acknowledges that effective treatment prevents new infections and aims to contribute to improving reach and quality of medical treatment and associated responses towards eradicating TB globally (WHO 2017). Priority Action 2 emphasises addressing needs of vulnerable and hard-to-reach groups, while Priority Action 5 calls on nations to ‘optimize prevention and care of drug-resistant TB’ patients and acknowledges MDR-TB as a global crisis threatening public health (WHO 2017). This study’s focus on young women in low socioeconomic communities as a group needing targeted MDR-TB treatment adherence support is in part substantiated by prescriptions of this policy.

Locally, South Africa’s National Strategic Plan on HIV, Tuberculosis and Sexually Transmitted Infections (NSP) (2017-2022) outlines the national response to the three health challenges (SANAC 2011). The document was launched during national World TB Day commemorations in Bloemfontein, Free State province on 31 March 2017. This NSP, the fourth since 2000, takes up where the 2012-2016 version left off. The

plan is aligned to South Africa's National Development Plan and locates the country's responses to HIV, TB and STIs 'within the broader struggle for economic and social development' (SANAC 2017:x).

The current NSP calls for 'a robust prevention agenda', as it foregrounds the importance of effective TB treatment (SANAC 2017:xii), unlike the NSP (2012-2016). Goal 1 pronounces plans to 'Accelerate prevention to reduce new HIV and TB infections and STIs' and highlights that 'treatment as prevention', achieved through extensive uptake of TB treatment, is key to South Africa's efforts to eradicate TB (SANAC 2017:14). The strategy urges stakeholders to prioritise 'prevention in all its facets to ensure that the "tap" of new infections is turned off' and sets the target of reducing TB infections by more than 30 per cent, from 450,000 to 315,000 patients by 2022 (SANAC 2017). The plan emphasises finding missing TB patients, initiating them on treatment and promoting TB infection control measures to prevent community transmission of TB and, by extension, the large number of new DS-TB and DR-TB infections recorded each year (SANAC 2017:4). Given that low adherence to treatment and MDR-TB transmission rates in South Africa are exacerbated by ineffective communication as discussed earlier, a strategic and targeted communication model that is context and population-specific has potential to contribute to achievement of this objective.

Goal 3, Sub-objective 3.2.2 of the NSP is clear that health information and behaviour change communication are important for reaching vulnerable populations with targeted interventions to impact risky behaviours and increase demand for health services (SANAC 2017). Goal 4, Sub-objective 4.6.2 elucidates the need to 'Develop advocacy campaigns for health promotion specific to TB control' (SANAC 2017:xviii). Indeed, while the NSP (2012-2016) focused on identifying people with TB, and diagnosing and initiating them on treatment, one of its weakness is that it underemphasised providing and strengthening resources to encourage TB patients to remain on and complete treatment. The 2017-2022 plan, however, is clear about the importance of scaling up and strengthening treatment adherence strategies for TB through 'community education and awareness initiatives ... [and] routine patient counselling' (SANAC 2017:21). So strong is the role of communication in the current NSP that 'Enabler 1' is 'social and behaviour change communication (SBCC) to ensure social mobilisation and increasing awareness' about TB, HIV and STIs (SANAC 2017:52), and supporting patients to access health services, remain in care and adhere to treatment (SANAC 2017). It is in the context of this enabling policy framework

that this study explores how public health communication can be better applied and targeted to support improvements in treatment adherence among vulnerable populations from low socioeconomic contexts.

Finally, the South African National Tuberculosis Guidelines (2014) are the blueprint ostensibly used by healthcare professionals when providing services to patients. It highlights that 'Inadequate counselling of patients resulting in low knowledge levels, poor understanding of what is expected of them and of the importance of completing treatment and monitoring the response to treatment' is a key factor in low treatment adherence among patients (South Africa National Department of Health 2014:74). The document outlines procedures healthcare workers must follow when providing TB services to clients in facilities nationally (Naidoo *et al.* 2013). They are required to spend a significant amount of time counselling patients, so they understand the importance of adhering to prescribed biomedical treatment (South Africa National Department of Health 2014:74; Naidoo *et al.* 2013). In practice, however, the guidelines are not always referred to or followed, as discussed as part of findings presented in Chapters Eight and Nine.

### **Then and now: The historical emergence of health communication research and reviewing contemporary applications**

Enhancing health literacy about MDR-TB treatment is integral to this study's aim to contribute to improving vulnerable populations' attitudes towards and intentions to adhere to treatment in resource-constrained communities in eThekweni Metro. It is important to define the terms 'health literacy', 'health education' and 'health communication' as they are used in this thesis and explain how they are linked. Health literacy is the 'capacity to obtain, process, and understand basic health information and services to make appropriate decisions about health' (Cooper 2011:1). It is an outcome of health education provided to patients by healthcare workers through interpersonal communication in face-to-face interactions in groups or one-on-one. Health education aims to close gaps between 'what is known about optimum health practice and that which is actually practiced' (Griffiths 1972:7). It is a discrete area with its own experts that emerged between the 1930s and 70s, after scholars and practitioners realised that health education needed support of the public (Griffiths 1972) if it was to take its rightful place as the 'central social process in the provision of health care delivery' (Kreps *et al.* 1998:1). Health education is integral to health promotion (Cross *et al.* 2017), as explained below.

Finally, health communication emerged fully as a distinct area in the 1970s (Kreps *et al.* 1998) and is firmly situated at the core of public health practice. Health communication is ‘the art and technique of informing, influencing, and motivating individual, institutional, and public audiences about important health issues’ (Bernhardt 2004: 2051). Health communication research seeks to understand how people, groups and societies communicate about health issues like MDR-TB, with focus on ‘the diverse processes and effects, including how different channels and types of information can be mobilised instrumentally and strategically in domains such as public health’ (Storey *et al.* 2014:2). Research in this area is occurs at (i) intrapersonal, (ii) interpersonal, (iii) group, (iv) organisational and (v) societal levels (Storey *et al.* 2014; Bernhardt 2004; Corcoran 2007; Kreps *et al.* 1998) and must be designed and understood in the situated social, economic and demographic contexts in which it occurs (Sumartojo 1993). In line with encouragements of scholars, health communication in this study is situated within the wider concept of health promotion, as expounded below. In this conceptualisation, health promotion’s concern with accounting for the ‘social, political and environmental factors which influence behavioural choices’ (Cross *et al.* 2017:6) locates it a step ahead health communication.

Research such as this, which aims to contribute to strengthening health communication at all levels as outlined above, but with a focus on ultimately impacting the societal level most (Cross *et al.* 2017), generally examines how the development, dissemination and use of targeted health education and communication can increase knowledge, promote shifts in attitude and intentions, and improve health practices (Kreps *et al.* 1998). This understanding is integral to this study’s aim to propose how mass media, social media and interpersonal communication can be optimally used for MDR-TB treatment education. The study is supported by relatively recent advances in the field, from a time when communication was equated with the dissemination of leaflets and pamphlets and passive mass communication decades ago (Storey *et al.* 2014) to current times where there is appreciation that ‘promoting health and protecting the public require both sound science and effective public health communication’ (Bernhardt 2004:2052).

Early TB communication research was hampered by disappointing results. For instance, a study which aimed to increase TB screening rates among men in the automotive industry was unsuccessful at impacting intentions and behaviours. The 1959 TB Screening Study documented disappointing findings in terms of increasing TB



screening among men in a workplace, even when free services were available, and a health education campaign included to teach people about the gravity of TB (Kar *et al.* 2001). This study has relevance for this doctoral research, as it demonstrates difficulties of achieving behaviour change through communication campaigns that uses one channel or medium. It highlights for consideration the futility of attempting to achieve significant shifts in health practices in contexts where little or no comprehensive health communication has been provided before and where public awareness is low. The 1959 study did, however, contribute the psychology-influenced Health Belief Model (Hochbaum 1958; subsequently modified by other authors) to the public health communication research arsenal (Kar *et al.* 2001, Rosenstock 1974). It is worth mentioning that the suitability of the Health Belief Model to advancing the objectives of this study was considered during development of the research proposal. Ultimately, the model was rejected in favour of the VPCM (Flaskerud and Winslow 1998) because of the latter's suitability for studying marginalised groups and appreciating their health practices and external influences on these within distinct cultural contexts. There were other considerations, chief among them that the VPCM is better suited to studies that explore the proposed relationship among 'access to healthcare, use of health promotion services and disease states in susceptible populations' (Rawlett 2011:15).

Digressing briefly, it benefits this thesis to signpost here that application of the VPCM (Flaskerud and Winslow 1998) helps to abet use of the Knowledge Gap Theory (Tichenor, Donohue and Olien 1970) and Two-Step Flow Theory (Lazarsfeld and Katz 1955) in this study (together with its later revisions as the Multi-Step Flow and One-Step Flow theories), although this does not suggest a belief that they are unsteady on their own. Both models are derived from research in the United States of America some 49 and 64 years ago respectively. This study is aware that this may lead to criticisms that their applicability to research in African contexts is questionable and that they are outdated. Motivation to use these two theories was partly influenced by the fact that they were postulated in parallel mass media reception inquiries during the 'golden age' when health communication emerged strongly, as discussed below, and substantiated by scholars' insistence that they are still relevant (Hughes and Osman 2014; Gleave and Smith 2009). It was, however, deemed prudent to pair the older models with the more recent VPCM to buttress their suitability for research on the MDR-TB problem in contemporary eThekweni Metro, South Africa.

Scholars draw attention to two distinct branches of health communication, urging researchers to position themselves in either the healthcare delivery or health promotion research fields (Kreps *et al.* 1998). The former is concerned with understanding how communication impacts healthcare delivery, while studies in the latter camp seek to understand the persuasive use of communication messages and media to promote public health and practices (Kreps *et al.* 1998). Health promotion aims to build agency in individuals and bring about social change (Cross *et al.* 2017). Among others, scholars in this field conceptualise HIV, heart disease and cancer prevention campaigns, evaluate use of mediated communication channels for disseminating health information, and examine the portrayal of health issue in popular media (Kreps *et al.* 1998). More recently, researchers examine new media's contributions to public health communication (Cross *et al.* 2017; Kreps *et al.* 1998). This study is decidedly located in the health promotion branch of health communication research.

Between the 1960s and 1980s, researchers began documenting the importance of understanding the cultural contexts and circumstances of participants to support targeted and culturally acceptable health communication strategies for individuals and communities in specific areas. Seminal studies by Zola (1966) and Kleinman (1980) helped establish the importance of this (Kreps *et al.* 1998) and set the stage for contemporary work such as this one. Zola (1966) examined ways in which culture socially conditions what patients feel are problems significant enough to seek help for and how patients from defined ethnic groups present health problems to care providers. She demonstrated the importance of healthcare practitioners understanding patients' backgrounds and developing contextualised strategies for communicating with individual patients. Kleinman's (1980) book entitled 'Patients and healers in the context of culture', which is based on fieldwork in Taiwan, substantiated Zola's (1966) finding that culture significantly mediates interactions between doctors and patients and ought to be considered in health promotion research. The book is credited with bringing to the fore important questions about how ill-health is culturally understood and the importance of appreciating choices that individuals and families make about where and when to access biomedical healthcare where different treatment options are available. These invaluable considerations are applied in assessing findings of this research which are presented in Chapter Eight.

Developments in health communication research were so important that scholars interested in both the healthcare and health promotion branches came together and

formed the Therapeutic Communication interest group of the International Communication Association (ICA) in 1972 (Kreps *et al.* 1998). This significant move provided an 'academic home for an eclectic group of scholars, communicated to the rest of the communication discipline that health was a legitimate topic for communication research and encouraged scholars in the discipline to consider health-related applications of their work' (Kreps *et al.* 1998:6). It also indicated that while healthcare and health promotion communication research were distinct, they were not at odds with each other. The first books about health communication were published in the 1980s, followed by many more books and numerous edited volumes and journal articles (Kreps *et al.* 1998). Outputs of these studies established the validity of health communication scholarship focusing on significant social issues, including the stubborn challenge of how health promotion can contribute to reducing patient mortality and preventing the spread of MRD-TB that this study tackles.

As intimated in the introduction to this chapter, the Stanford Heart Disease Prevention Program (1972-1974) (Maccoby 1976) was a significant longitudinal research that established the power and influence of health communication campaigns on public health outcomes and contributed to cementing health communication as a discrete scholarly discipline (Kreps *et al.* 1998). There was evidence that environmental and cultural factors contributed to high incidence of heart disease among Americans. In response, researchers implemented a communication strategy targeting large numbers of people in three cities with risk reduction information (Kar *et al.* 2001; Maccoby *et al.* 1985; Maccoby 1976;). Health communication was provided using a combination of mass media alone (film, television, radio and print) or mass media and face-to-face campaigns. The exercise aimed to increase audiences' knowledge and impact their attitudes and motivations around increasing exercise, eliminating smoking and reducing blood cholesterol and pressure levels through changes in diet (Maccoby 1976).

What is interesting to this study is that combined mass media and face-to-face campaigns were utilised and specifically 'designed to overcome deficiencies in previous unsuccessful campaigns to change behavior' (Maccoby 1976:37), like the 1959 TB Screening Study. This study replicates the approach of probing the utility of more than one medium to communicate treatment education to members of a vulnerable population to hopefully contribute to reducing incidences of a communicable disease that has reached epidemic levels in South Africa. A comprehensive literature search did not yield any other published studies that apply findings of the Stanford study to

TB/MDR-TB academic research, nor HIV ones. This study may well be the first to apply insights from this research to develop a practicable MDR-TB health communication model for a resource-poor setting in an African country.

The Stanford Heart Disease Prevention Program established that face-to-face communication is effective for changing behaviour, and that mass media is useful for increasing knowledge and stimulating interpersonal discussions about health issues in communities (Maccoby 1976). This research incorporates these insights by including interpersonal communication among the strategies considered for increasing vulnerable patient's MDR-TB treatment literacy and impacting their attitudes and behaviour change intentions as expatiated in Chapter Five. The Stanford Five-City Project (1985-1990) replicated the 1972 research process, but on a larger scale over six years, with similarly good results. A review of the project three years after results were published found that residents of cities where communication campaigns had been implemented continued to implement heart disease risk reduction strategies, with continued positive impacts on their health (Winkleby *et al.* 1996)

Scholars aver that health promotion privileges participation of affected communities in designing communication strategies to ensure that lay perspectives emerge (Cross *et al.* 2017). This is important for this study, considering researchers' complaints that theory-based health promotion research which establishes how to translate what is known about the effectiveness of health communication for supporting people on TB/MDR-TB treatment to fully adhere is generally lacking (Tsodzo 2011; Munro *et al.* 2007a). This is notwithstanding quick and significant developments in health communications research since the 1970s, and the burgeoning threat to public health posed by TB from the 1950s, when SBCC rose to augment health communication approaches as discussed in the next section. Even the rise of DR-TB in high TB, DR-TB and HIV syndemic countries like South Africa in the 1990s seems to have failed to spark a resurgence in research on health topics among the marginalised as hoped by scholars in the 1980s (Kreps *et al.* 1998).

### **Social and behaviour change communication for MDR-TB treatment adherence**

Although MDR-TB is a medical condition, evidential sluggish advances in new medicines research and development of a vaccine *vis-à-vis* exponential spread of DR-TB led scholars to argue that 'behaviour change remains the current viable means of improving treatment compliance and limiting the further spread of TB infection'

(Matebesi and Timmerman (2012:15). Social and behaviour change communication (SBCC) research emerged from the need to re-think 1960s Western-centric knowledge attitudes and practices (KAP) research, which supported beliefs in the effectiveness of linear models of behaviour change communication (BCC). In this earlier conceptualisation, knowledge was believed to influence shifts in attitude, which result in desired changes in practice (Durden and Govender 2012). Conversely, SBCC approaches propose that mass media cannot *directly* achieve changes in behaviour; it can, however, increase knowledge and influence planned behaviour, which can be measured (Onyeonoro *et al.* 2013). Interpersonal communication and social media are incorporated into this study and considered for their potential to influence use of mass mediated health communication (Ngigi and Busolo 2018) to achieve sustainable changes in community perspectives, normative beliefs, standards and intentions in relation to MDR-TB treatment health-seeking behaviour (Moran *et al.* 2013).

Some studies from the 1950s and 60s established that communication alone does not result in behaviour change. In contemporary times, scholars have found that increased knowledge and favourable attitudes alone cannot influence individuals to act in relation to vaccinations uptake, HIV prevention, and delivery and new-born care health practices (Corace and Garber 2014; Bekalu and Eggermont 2014; Parashar *et al.* 2013). On the other hand, some studies on behavioural intention to adhere to ART demonstrate that knowledge and intention, and not measured behaviour change, are associated with viral suppression in PLHIV (Naidoo and Taylor 2013). This suggests that increasing MDR-TB treatment adherence knowledge and simultaneously impacting patients' intentions to practice good behaviours has potential to translate communication into positive treatment adherence practices (Naidoo and Taylor 2013).

Some studies strongly link TB knowledge levels and the extent to which patients are able or willing to adhere to treatment. Maswangayi *et al.* (2014) maintain that 'Most patients do not comply [with TB treatment] because they do not see the importance of doing so, which is usually influenced by lack of knowledge'. In this conception, low knowledge about TB frustrates patients who cannot make informed decisions about their health and may choose to abandon treatment altogether (Maswangayi *et al.* 2014; Matebesi and Timmerman 2012). There is another school of thought that adherence to TB treatment does not require behaviour change because treatment is temporary

(Arnadottir 2009). While this argument may be shaky for longer-term MDR-TB treatment, it can still be argued that there are merits in the view that it is more important to increase treatment knowledge levels and impact patients' intentions to adhere to treatment through sustained communication (Onyeonoro *et al.* 2013; Dewie *et al.* 2016) than to exert energy attempting to achieve changes in behaviour, which is difficult to do through communication alone. And even more difficult to measure.

It is important to clarify that this study does not seek to measure changes in attitude or the impact of health communication and promotion on planned behaviour. It aims to propose practicable strategies for communicating MDR-TB in eThekweni Metro, which will have the most impact among vulnerable populations in low socioeconomic areas with high MDR-TB burdens. A potential area for further research could be assessing or measuring effectiveness of the communication model proffered in Chapter Ten in positively impacting populations' attitudes towards MDR-TB treatment and consequent adherence behaviour.

This study adopts social constructivism as the research epistemology as discussed in Chapter Five. The epistemology influences this study's position that it is less important to achieve behaviour change at individual level, which some argue is 'a perspective of human behaviour that is incongruent with the African context' at any rate (Geldenhuys 2015:1). Also, Naidoo and Taylor (2013) insist that if health communication interventions transcend the individual focus to include social networks and communities around TB patients, they can influence social change. This research aims to suggest context-sensitive strategies to impact families and communities through leveraging social interactions around mass mediated MDR-TB prevention and treatment adherence communication via interpersonal communication and social media and *vice versa* (Wakefield *et al.* 2014; Mishra *et al.* 2014; Ramsay and Minozzi 2002). This aspiration finds support in understanding that personal motivations to adhere to treatment which are influenced by mass media are affected by multidimensional issues that plague people with MDR-TB, as discussed in the literature reviewed in Chapter Four.

### **Mediums of communication**

Discussions in this chapter are informed by WHO (2007) recommendations that health communication initiatives are most effective when two or more strategies are used in combination, as well as insights from the 1959 TB Screening Study and Stanford

studies. Literature demonstrates that one-on-one interactions using interpersonal communication increase patients' knowledge levels about treatment and are important for motivating them to adhere. Communicating MDR-TB information via television and radio has potential to contribute to increasing reach of health communication to others in communities where MDR-TB patients live and achieving more impactful public health messaging through repetition (Wakefield *et al.* 2014; Mishra *et al.* 2014; Ramsay and Minozzi 2002). These and other issues are investigated in the sections below.

### **Interpersonal communication and counselling: Patient-centred approach to sub-optimal adherence to treatment**

It is not contested that where patients better understand the illness and treatment, TB programmes achieve better results (Maharaj *et al.* 2016; Mohr 2015; Padayatchi and Friedland 2008), which indicates the importance of treatment education and literacy in addressing MDR-TB in low socioeconomic contexts. Some scholars assert that empowering patients is integral to increasing TB and MDR-TB treatment completion and success rates (de Oliveira and Lefèvre 2017; Fagundes *et al.* 2016; Khachadourian *et al.* 2015; Maswangayi *et al.* 2014) and complain that patient-centred solutions are not prioritised in global and local responses to the epidemic (Brumwell *et al.* 2018; O'Donnell *et al.* 2016; Khachadourian *et al.* 2015; Atkins *et al.* 2012). In this understanding, patient-centred care is pivotal to MDR-TB treatment adherence because how health workers communicate with patients can increase or reduce odds that they will adhere to treatment (Martins *et al.* 2018; de Oliveira and Lefèvre 2017; Maswangayi *et al.* 2014). Indeed, some argue that patients who have their diagnosis and prognosis disclosed to them in compassionate and empathetic ways, and who are simultaneously provided with comprehensive information about TB transmission, prevention and treatment, are more likely to be motivated to complete treatment (de Oliveira and Lefèvre 2017; Maswangayi *et al.* 2014). In practice, however, some healthcare professionals insist that improving patients' adherence is best achieved by making them accountable for their own treatment outcomes, provoking fear in them or offering them material incentives to secure their commitment to taking all treatment as prescribed (de Oliveira and Lefèvre 2017), in opposition to prescripts of the South African National Tuberculosis Guidelines (2014).

Studies establish that healthcare professionals in South Africa are generally adequately knowledgeable about MDR-TB and its management (Maharaj *et al.* 2016), but scholars note that their (very real) fears of contracting TB may negatively impact their attitudes

towards patients and, by extension, their ability to offer empathetic services and effectively share information to position patients at the centre of healthcare processes (Fagundez *et al.* 2016; Naidoo *et al.* 2013; Tudor *et al.* 2013). The premise of this study, which is informed by insights from the Stanford studies and shortcomings of the 1959 TB Screening Study, is that one-on-one or one-to-many interpersonal communication can increase impacts of mass mediated MDR-TB prevention and treatment communication. In this conceptualisation, making meanings from health communication is a shared pursuit between the healthcare provider as 'expert', patients, and others in their communities in a participatory mediated process, which takes place in and is necessarily swayed by sociocultural contexts (Cross 2017).

Health communication theory as discussed in the seminal work by Cross *et al.* (2017), which informs the conceptual framework of this study discussed in Chapter Five, urges for health promotion research to transcend reciting information to inactive audiences to lively engagement and dialogue. Therefore, this study aims to augment mass media's transmitter-receiver approach with considerations of how interpersonal communication can incorporate social and cultural norms into discussions about enhancing health communication pertaining to MDR-TB treatment. The study suggests that combining the two mediums may enhance health communication and lead to improved knowledge of consequences of MDR-TB treatment interruption among patients and the public, resulting in better support for patients at home and in their communities. Discussions in the next chapter bring to the fore the importance of family support and stigma reduction in communities for improved MDR-TB treatment completion and cure rates. They also clarify why health communication in eThekweni Metro must be targeted at (i) patients (ii) family/relatives (iii) primary groups (iv) healthcare facility staff, and (v) communities in eThekweni Metro as discussed earlier. Interpersonal communication is well suited for use with patients, family/relatives and healthcare providers at both facility and community level, the latter through capacity development (Martins *et al.* 2018).

Healthcare workers significantly influence how patients perceive their illness and health facilities. Health education about MDR-TB in South Africa is typically provided by nurses, hospital-based health educators and community caregivers (CCGs) during DOTS support. Some argue that these groups are better able to communicate with patients than physicians because of shared cultures in most cases, and fewer pressures on their time (Arnadottir 2009). Scholars insist on the importance of strengthening patient-provider relationships, with reference to the necessity of understanding how



contextual factors impact adherence behaviours (Munro *et al.* 2007b). This study attempts to do this in the review of literature presented in Chapter Four. This approach urges for building and strengthening capacities of healthcare workers to offer empathetic support to patients as a necessary step in enhancing health communication (Martins *et al.* 2018; De Oliveira and Lefèvre 2017; Maswangayi *et al.* 2014).

People being treated for MDR-TB must receive adherence counselling prior to starting treatment so they know what to expect and can persevere (Akeju *et al.* 2017). As well as the inadequate health education and mass mediated communication about MDR-TB in South Africa established later in this chapter, additional factors further diminish impacts of the limited public health communication (Munro *et al.* 2007). These include low educational attainment, lack of family support and absence or inadequacy of medical advice. For health communication via interpersonal communication to be successful, content must be tailored to individual patients in their socioeconomic context, culture, time available/moment and language (de Oliveira and Lefèvre 2017). It must be adapted to respond to treatment-specific needs of patients and precise enough to achieve pre-specified objectives (Fagundez *et al.* 2016). Scholars insist that this is only achievable if the communicator is well practiced in what they need to say and how information is best shared, and where they utilise context- and target-appropriate techniques to communicate information (de Oliveira and Lefèvre 2017). How information is received is dependent on who transmits it and their relationship with the person who receives it (de Oliveira and Lefèvre 2017; Cross *et al.* 2017). These considerations are key to later discussions in Chapter Nine about who are acceptable sources of health communication for vulnerable young women in eThekweni Metro. Understanding this in relation to specific populations and their cultures supports development of health communication and targeting it so it reaches intended audiences.

Considering this, it is unsurprising that communication about MDR-TB among lower income patients is hampered by TB terms and language that are technical, and do not lend themselves well to simplification. Medical jargon and overly technical language create difficulties for healthcare workers when speaking about TB treatment, and for patients to fully comprehend issues communicated to them (Naidoo *et al.* 2016; Tse and Soerge 2003). Failure to understand terminology extends to inability to remember or pronounce names of prescribed medications, which is a consequence of poor communication during treatment education. If healthcare providers do not ensure that

patients understand, for instance, medication measures and the importance of taking doses at specific times, patients will experience difficulties adhering to treatment because they do not know how to do so (Martins *et al.* 2018). Insufficient understanding of treatment also leads to negative feelings and low motivation in patients, caused by beliefs that they are not equal and active partners in their own treatment (Tse and Soerge 2003). This study's position is that adherence to treatment is the joint responsibility of patients and healthcare providers and explores how provisions in the policies discussed earlier can be translated into practice to increase contributions of health communication to South Africa's MDR-TB management programme.

While it is important to understand how to improve health communication to encourage and support patients to adhere to treatment long-term, this study is conscious that influence of external factors, such as food and transport costs, health services and treatment, would still need mitigating (Martins *et al.* 2018; Munro *et al.* 2007). Further, as desirable and important as interpersonal communication between clinicians and patients is, this study argues that this strategy alone is not the silver bullet strategy to the MDR-TB treatment adherence challenge. Studies from South Africa indicate that up to 80 per cent of patients forget what their doctors tell them as soon as they leave the consulting room, and that nearly half of what they remember is recalled incorrectly (Ndjeka *et al.* 2008). Therefore, while communication interventions are desirable for their potential to influence MDR-TB patients to stick to their treatment regimes, it quickly becomes evident that they work best when applied in combination with other communication strategies to support information provided during counselling (Munro *et al.* 2007). This study considers whether MDR-TB treatment communication via a second medium, in this case mass media in the form of television and radio can help ensure that health communication is more impactful in this regard (Wakefield *et al.* 2014; Mishra *et al.* 2014; Ramsay and Minozzi 2002).

### **Health communication via directly observed treatment short-course support**

There are opportunities to strengthen community MDR-TB communication using interpersonal communication in eThekweni through the patient-centred DOTS health delivery approach which, in theory, includes a strong health communication component to improve treatment adherence and completion rates. Patient-centred care (PCC) is defined as 'providing care that is respectful of, and responsive to,

individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions', in short, avoiding adopting a one-size-fits-all approach to healthcare delivery (WHO 2018). Literature and practice are clear that communicating with patients about biomedical treatment is enhanced and health care worker-patient relationships improved when healthcare approaches are patient-centred (Martins *et al.* 2018; Naidoo *et al.* 2013; Ndjeka *et al.* 2008).

South Africa utilises the DOTS strategy for the community management of TB and DR-TB patients once patients are discharged from hospital (Terra and Bertolozzi 2008). The strategy was launched globally in 1993, the same year the WHO declared TB a global public health emergency after more TB-associated deaths than in any other year were recorded (Tsodzo 2011). South Africa began implementing DOTS in 1996, two years after the end of apartheid (Ntshanga *et al.* 2009) through dedicated CCGs and volunteers (collectively called DOTS supporters in this thesis). These groups monitor patients as they ingest each dose of medication daily throughout the continuation phase of treatment (Sagbakka *et al.* 2013; Celone 2012; Ntshanga *et al.* 2009).

Following a minimum of four months as inpatients during the intensive phase of treatment, once discharged DR-TB patients go to DOTS supporters in their community five or more days a week to access medication, or supporters visit them at home to help administer drugs (Celone 2012). Every dose taken is recorded and an account kept by the DOTS supporter (Ntshanga *et al.* 2009; Celone 2012), some of whom use mHealth applications to monitor patients (Bionghi *et al.* 2018). Some scholars are persuaded that observed treatment can effectively address challenges of low adherence in developing countries (Sagbakka *et al.* 2013; Atkins *et al.* 2012; Celone 2012; Ntshanga *et al.* 2009; Terra and Bertolozzi 2008). However, systematic reviews of randomised controlled study results did not find that DOTS was superior to patient-administered treatment in low-, middle-, and high-income countries when treatment outcomes were compared (Khachadourian *et al.* 2015; Sagbakka *et al.* 2013). Indeed, Atkins *et al.* (2012:2) compliment the DOTS strategy 'staying power despite research evidence suggesting that it may not improve TB treatment outcomes'. Notwithstanding use DOTS, some studies in South Africa demonstrate that low TB treatment adherence rates primarily remain a consequence of weak follow-up and TB management systems at community level (Kigozi *et al.* 2017).

Conversely to claims that DOTS is patient-centred, critics of the two-decades-old strategy argue that it disempowers patients and denies them agency and control in their treatment, which patients resent, and may contribute to sub-optimal treatment outcomes (Getahun *et al.* 2017; Atkins *et al.* 2012; Terra and Bertolozzi 2008). People with TB report feeling policed and distrusted when receiving home-based care, which is compounded by simultaneous feelings of lack of privacy during treatment (Getahun *et al.* 2017; Tsodzo 2011; Terra and Bertolozzi 2008). For these reasons, critics insist that DOTS is ‘dehumanizing, difficult for patients, and lacking a patient-centred approach’ (Atkins *et al.* 2012:1). Usefulness of DOTS is further challenged by arguments that it is odd that in high TB and HIV syndemic contexts like South Africa, patients who must be monitored daily when taking TB medications are simultaneously trusted to routinely self-administer ART and monitor for side effects (Daftary *et al.* 2014; Atkins *et al.* 2012). The approach to the administration of ART is widely considered more empowering of PLHIV and advanced as the ideal (Mazinyo *et al.* 2016; Atkins *et al.* 2012).

Mazinyo *et al.* (2016:10) insist that ‘there is a disjuncture between the treatment supervision approach of the TB programme and the patient empowerment design of the HIV programme’. That these two approaches can exist concomitantly arguably proves that with the right support, TB patients can be taught how to take medications correctly and consistently. From this reasoning, concerns arise that there is little impetus to support TB patients to be more independent with their treatment (Daftary *et al.* 2017; O’Donnell *et al.* 2016; Atkins *et al.* 2012). This suggests that this study’s appropriation of HIV communication literature should be expanded to include strategies utilised in the biomedical treatment of PLHIV, insofar as these have relevance for enhancing MDR-TB treatment adherence towards improving the effectiveness of treatment for this communicable disease.

Patients are more likely to adhere to TB treatment when they are satisfied with how they are supported by DOTS supporters and healthcare workers, while less satisfied patients are apt to opt out of treatment (Getahun *et al.* 2017). Some argue that DOTS – with its insistence on patients taking each dose of treatment at all costs – reduces patients’ health needs to clinical and biological aspects, without considering and adjusting for the personal, environmental, socioeconomic or structural factors that may hinder adherence (Daftary *et al.* 2016; Terra and Bertolozzi 2008). With the background of acknowledged patient-centred care and empowerment shortcomings in TB treatment management, it is unsurprising that the effectiveness of DOTS is

increasingly being questioned. It is significant for this study, however, that earlier research found that districts in KwaZulu-Natal with high DOTS coverage and low DOTS-support-to-patients ratio of one to five reported higher cure rates than areas without (Ntshanga *et al.* 2009). In light of these discussions, whether DOTS supporters can be co-opted to implement a communication model aimed at expanding MDR-TB treatment education beyond healthcare facilities and mass media to communities within the frame of DOTS support is considered.

It is noteworthy that unlike other provinces of South Africa, DOTS for DS-TB patients is unpopular in KwaZulu-Natal. Unpopularity of the strategy emanates from patients' reluctance to allow supporters into their homes. Isolation of patients and their families by neighbours and community members, and stigma attached to supporters' visits to specific homes daily (in marked recognisable vehicles) may explain this trend in eThekweni Metro (Daftary *et al.* 2014; Celone 2012). Instead, family members or friends of DS-TB patients often assist in this regard (Celone 2012).

National Department of Health policy, however, discourages nomination of relatives or friends to provide DOTS support, because of fears that they may be less objective and firm while observing treatment than professional healthcare providers would be (Celone 2012). Directly observed treatment short course support is enforced for DR-TB care however, as TB tracer teams, injection nurses, home assessors and CCGs work together to support patients to take treatment daily at home (Celone 2012). Significantly, DOTS support by family or friends has positive results in some cases, because loved ones tend to be more invested in ensuring that patients are cured (Atkins *et al.* 2012). Loved ones also influence patients' perceptions about treatment and their behaviour than healthcare providers in KwaZulu-Natal do, which recommends them as a distinct group to be targeted with MDR-TB treatment adherence communication.

### **Mass media (television and radio)**

The NSP (2012-2016) recommends utilising mass media to disseminate information and elucidates that the national broadcaster, the South African Broadcasting Corporation (SABC) has a responsibility to provide 'the space and resources free of charge as part of its contribution to mitigating these epidemics' (SANAC 2012:49). The SABC operates three television channels and 18 radio stations that broadcast nationally in the country's official languages through which it can fulfil its public health communication mandate (SABC 2014). The broadcaster however relies on external

stakeholders for health content. Thus, if those working in the TB management space in South Africa do not develop and submit content, TB and MDR-TB information will continue to be missing from the airwaves.

Mass media is critical to public health management, through its contribution to setting the MDR-TB policy and practice agenda, drawing and sustaining public attention to and stimulating discussions about the MDR-TB epidemic and its impact at individual, household, community and national levels. Mass media or traditional media denotes forms of communication that reach large numbers of heterogeneous people, called audiences, using technology such as radio, television, print (newspapers, magazines, books, posters and pamphlets), films, documentaries and out of home media, or any of these in combination (Nglazi 2014; Wakefield *et al.* 2010). Television and radio are of interest to this study, and these mediums are discussed to ascertain how they can be used to complement health education provided in healthcare settings and to re-emphasise information that patients need to successfully adhere to treatment and which the public requires to protect themselves from acquiring MDR-TB infection. The scant TB/MDR-TB information broadcast on television and radio channels in South Africa is often part of broader health communication efforts, as discussed in the audit of TB content broadcast from 2015 to 2018 later in this chapter. Mass media in South Africa has high penetration as follows: television (83.4 per cent) and radio (67.9 per cent) (Treffry-Goatley 2017) and is thus a viable medium for wide dissemination of health communication. Discussions about television and radio content about TB/MDR-TB in South Africa in the sections below demonstrate that mass media is already a key, albeit underutilised, source of health communication. Establishing this informs later discussions in Chapters Eight and Nine about how targeting and dissemination of MDR-TB health communication can be enhanced to better respond to the treatment adherence support needs of vulnerable populations in eThekweni Metro.

Extant studies establish that effective health communication complements the biomedical continuum of care from prevention to treatment adherence (Lopes *et al.* 2018; Kreps *et al.* 1998). They demonstrate that for ART specifically and other disease in general, health communication contributes significantly to patients' better adherence (Storey *et al.* 2014). Some scholars insist that mass media in isolation can significantly contribute to improving attitudes, health-seeking behaviour and uptake of disease screening services, which should not be underestimated (Mishra *et al.* 2014; Ramsay and Minozzi 2002). While mass media demonstrates modest results, a study

in Tanzania concluded that adding empathetic interpersonal communication from community healthcare workers and people living with HIV is effective at encouraging people to test for HIV in areas with high prevalence (Joram 2010). Further, TB/DR-TB treatment studies demonstrate that the quantity and quality of health communication is strongly associated with the extent to which patients can or are willing to adhere to treatment. Some aver that inadequate or ineffectual treatment education and communication efforts like those in South Africa, which are discussed later, contribute to patients' poor attitudes to their disease and treatment (Matebesi and Timmerman 2012).

Although a few published reviews of research on topics such as the effectiveness of mass media in encouraging HIV testing, termination of smoking, uptake and use of health services, and reducing mental health-related stigma exist, it is more difficult to find investigations into the impact of mass media in TB management (Nglazi *et al.* 2014; Wakefield *et al.* 2010; Donovan and Carter 2003). A recent study in Portugal found that 'tumours, HIV, influenza, transplants, hepatitis, obesity, dengue, mental disorders and heart diseases were the most media covered pathologies, ahead of tuberculosis... tuberculosis only represented 1.9 per cent' of public health issues (Lopes *et al.* 2018:69). These findings corroborate claims of pervasive low TB communication in mass media. Correspondingly, there is little content about TB/DR-TB broadcast on radio and television in South Africa. Indeed, research in eThekweni Metro found that whereas 90 per cent of patients on MDR-TB treatment report receiving information directly from healthcare providers, only five per cent receive information via television and in print (Maharaj *et al.* 2016).

Mass media's relevance as a resource that both reflects and shapes public discourse is well documented and informs assumptions of this study (Daku and Gibbs 2012). Its influence on health intentions is gauged by ability to increase knowledge about a subject, promote beliefs that the issue is important, grow audience discussion of the topic (thereby increasing exposure and understanding) and encourage views that championed changes in behaviour are socially acceptable and expected (Mishra *et al.* 2014; Donovan and Carter 2003). A study in Colombia found that providing basic information about early symptoms of TB and diagnosis methods via mass media led to increased numbers of people accessing TB services (Jaramillo 2001), results which can be assumed to be similar where TB treatment adherence communication is broadcast. Scholars, however, complain that TB and MDR-TB content on South African mass media is problematic because at best it is weak and ineffectual, and at worst,

stigmatising and alienating to patients and their families (Nglazi *et al.* 2014; Daku and Gibbs 2012). Assertions are that TB/MDR-TB communication often fails to reflect realities of ordinary South Africans who are most at risk of infection and that at times content is broadcast on stations that are not easily accessible to target audiences.

Notwithstanding these challenges, mass media is useful for informing and/or educating large numbers of people from at-risk populations about public health challenges because of its enormous potential, reach and cost-effectiveness (Wakefield 2010; Hogan *et al.* 2005; Hutton *et al.* 2003). To be effective, however, it is a precondition of disease prevention and mitigation that audiences must actively apply acquired knowledge to change harmful behaviours or maintain protective ones (Nutbeam 2006). This is not always acknowledged in public health communication strategies, which are accused of not only failing to consider implicit values and attitudes of individuals, but also of relying on outdated models 'which assume that the public are "empty vessels" to be filled with useful information, on which they will then rationally act' (Ockwell *et al.* 2009:321). This study's conceptual framework, which is discussed in Chapter Five, takes cognisance of these critiques, and incorporates health belief theories to augment the conceptual approach and guard against these pitfalls. This is also done to respond to assertions in literature that communication alone cannot result in improved treatment adherence (Ockwell *et al.* 2009; Baldwin *et al.* 1990) but that full public engagement with an issue is a precondition of behaviour change. In this argument, engagement comprises knowledge; emotion, including interest and concern; and behaviour or action (Ockwell *et al.* 2009). This study furthers discussions about the potential inherent in combining mass mediated health education and patient-centred interpersonal communication strategies to attract public engagement around MDR-TB treatment information communicated via either medium, by emphasising it through the other, to hopefully impact knowledge and health behaviours (Jaramillo 2001).

Aside from inadequacies in practical use of mass media to disseminate TB information, there is a generalised dearth of systematic reviews of the impact of this medium in TB management efforts which can help us understand how implementation in South Africa can be improved (Nglazi *et al.* 2014; Sarkar and Scalway 2005). This shortage is partly explained by the contention that even though it is as contagious, TB failed to raise the same panic among stakeholders as other communicable diseases, such as HIV (Metcalf (1991). While this is a challenge, flipped on its head it presents opportunities to foray



into other disciplines for insight. The enormous effort variably mobilised to address the sister epidemic, HIV, can be enlightening in this endeavour (Daftary *et al.* 2017).

Contrary to the scarcity of research on TB management, HIV BCC research is available, and illustrative of mixed outcomes of mass media interventions in low-income countries (LaCroix *et al.* 2014; Wakefield *et al.* 2010; Bertrand *et al.* 2006). While some achieved no change at all, a few studies generated small to moderate impacts (Bertrand *et al.* 2006; Peltzer and Philip 2004; Peltzer and Promtussananon 2003; Kim *et al.* 2001). Other readings, however, demonstrate that health education via mass media can positively impact high-risk behaviour at low cost (Nglazi *et al.* 2014; Wakefield *et al.* 2010; Matebesi and Timmerman 2012). Some, however, argue that effectiveness of mass mediated communication in directly improving public health is countered by entrenched personal or community habits or addictions that result in and perpetuate ill-health (Wakefield *et al.* 2010). This assertion further urges for this study's assessment of the impact that application of health beliefs theories can have on understanding the extent to which communication can contribute to improving MDR-TB patient's adherence to treatment. Another promising area in relation to assessing the impact of mass mediated health communication on target audiences is considering the contribution that new media; social media and networking sites in particular can make to improving patient-centred care and treatment adherence and outcomes among young people in low socioeconomic contexts.

## **Social media**

About a decade ago, the role of social media and social networking in healthcare and public health communication was first mooted, with focus on their ability to facilitate communication between patients and healthcare providers on-the-go and in real-time (Giustini *et al.* 2018; Habib *et al.* 2017). Studies show that when merged with other communication strategies (Fayoyin 2016), social media can be an important contributor to enhanced treatment adherence, particularly as it allows for collaborative and mediated interactions between people located in different settings, with strong effects on daily health coping mechanisms and (Giustini *et al.* 2018). According to the survey of Digital News Report 2017 covering 36 countries, 54 percent of the population uses social media weekly as a source of news (Digital News Report 2017). Many of these people also use social media to discuss symptoms of disease and to speak to others, who enjoy helping and discussing, about possible solutions to their health challenges (Giustini *et al.* 2018; Grosberg *et al.* 2016).

Social media and networking provide patients with opportunities to expand their knowledge and increase their involvement in healthcare, impacting health intentions and practices (Grosberg *et al.* 2016). Crucially for this study, patients with similar characteristics can form groups online to discuss their conditions as a way of reducing stress caused by dealing with chronic disease and treatment (Habib *et al.* 2017). Still other studies demonstrate that social media has been successfully utilised in Africa to support massive public health education drives. Scholars contend that targeted social media campaigns on Twitter and Facebook helped Nigeria to contain Ebola in 2014, by disseminating accurate information about the disease and correcting hoax messages as they were circulated (Fayoyin 2016). These campaigns were especially effective because international NGOs, influencers, celebrities and bloggers used their broad platforms to share information and opinions on the health communication disseminated.

Another campaign to reach men who have sex with men in Ghana with HIV information found that social media was useful for building trust between healthcare providers and patients around health issues characterised by stigma and discrimination (Fayoyin 2016), like MDR-TB as discussed in Chapter Four. However, interpersonal communication was still important for providing customised education after trust had been built and target audiences were more predisposed to seek healthcare services (Fayoyin 2016). This is important to the communication model developed and proffered in Chapter Ten.

### **Mass mediated TB/MDR-TB health communication: Audit of implementation in South Africa (2015-2018)**

While the section above discussed mediums of communication, this section assesses formats in which MDR-TB information in South Africa is disseminated. It presents an audit of TB content on television and radio from 2015 to 2018, to ascertain the quantity, relevance and reach of MDR-TB communication accessible to South Africans. This discussion lays foundations for later discussions about how identified gaps in treatment literacy among vulnerable young women can be redressed. The audit includes mass mediated communication disseminated during the last two years of the third NSP (2012-2016) and the first two years of the fourth NSP (2017-2021).

Focusing the inventory of mass mediated TB communication over four years was done to account for the event that the latter NSP's emphasis on public health communication discussed earlier occasioned notable increases in the volume of mass

mediated TB/MDR-TB communication after 2017. As discussed below, it did not. Also, because the volume of TB communication broadcast was unclear before commencing the research, cataloguing four years of programming was considered manageable without the discussion becoming clumsy. The final consideration was to cover content that patients receiving treatment for MDR-TB could recall when asked, because it had been broadcast relatively recently in relation to when data collection took place.

### **Public service announcements on radio or television**

Mass mediated TB/MDR-TB content assumes many formats and is broadcast via various channels to reach at times defined and other times undefined audiences. Public service announcements (PSAs) are one format. They are short non-commercial messages disseminated in the civic interest to raise awareness of social issues to change public attitudes and behaviours in relation to them (Martiniuk *et al.* 2010). The format can be impactful as evidenced by findings, albeit from North America, that by the time someone graduates from high school, they will have devoted more time watching TV PSAs than hours spent in school (Martiniuk *et al.* 2010). To capitalise on the utility of this strategy to reach many people in a short space of time, three TB campaigns were broadcast on national public television and radio. These include the We Beat TB animated television and radio PSAs campaign (USAID Tuberculosis South Africa Project 2018; TB CARE II 2013) and National Department of Health How Will I Know campaign.

The We Beat TB campaign comprises five PSAs of between two and four minutes each. The design comprises distinctive animated white stick figures on a black background acting out information about: (i) TB infection control (ii) children can get TB (iii) TB/HIV co-infection (iv) TB/diabetes co-infection and (v) TB treatment adherence. The campaign was developed and launched in 2013, but between 2015 and 2018, the five PSAs were broadcast on the privately owned free-to-air eTV channel, and SABC 1 and 2 between 5 and 18 November 2017 and on five African language radio stations: *Lesedi FM*, *Motsweding FM*, *Thobela FM*, *Ukhozi FM* and *Umhlobo Wenene FM* from 26 November to 9 December 2017 (USAID Tuberculosis South Africa Project 2017).

South Africa's How Will I Know campaign, identified by its green and white lung design, was conceptualised by the National Department of Health. The campaign aimed to encourage South Africans, especially residents of mining and peri-mining communities, inmates and children in early childhood development centres, to be

screened and tested for TB in a massive drive between 2014 and 2015 (ENCA 2015b). The campaign, which acknowledged the historical and contemporary association between the TB epidemic and mines in South Africa discussed in Chapter Two, was launched by then Deputy President Cyril Ramaphosa and Minister of Health Aaron Motsoaledi on 24 March 2015. Broadcasts involved taped audio-visual clips of the minister reading a prepared speech and presenting statistics on the burden of TB in South Africa. He also emphasised the importance of getting screened for TB as the first step to either getting treated or implementing personal or household infection prevention practices.

The National Department of Health Phila<sup>7</sup> Campaign was implemented on television and radio with the tagline 'Inspired to live' in 2017 and 2018. This Government of South Africa campaign profiles the country's quadruple health challenges: HIV, TB, non-communicable diseases and mother, child and women's health (Mkhize 2017). It communicates public health information to increase knowledge and inspire behaviour change towards better health and improved quality of life. Messages specific to TB disseminated through this campaign encourage (i) screening and prevention, (ii) early diagnosis, and (iii) adhering to complete treatment (Mkhize 2017). As this was a comprehensive health campaign, a concern of this study is that the TB messages broadcast may have been diluted by being broadcast together with other health-related messages, particularly HIV messages which have been shown to overshadow TB communication. Published reports and reviews of the two Department of Health campaigns are scarce.

### ***Public service announcements: Broadcasts into healthcare facilities***

The Mindset Network broadcasts on channel 319 on the subscription only DSTv platform, as well as StarSat, OpenviewHD and Freevision. Content is also transmitted directly into the waiting areas of 962 public health facilities through partnership with the state-owned company Sentech (Mindset no date). Additionally, the network could reach 3.5 million homes with public health content, were it not for the structural challenges discussed below. It is worth noting that content on Mindset is aligned to National Department of Health policies, to ensure that information is relevant to the South African context (Mindset no date). Notwithstanding this, however, Mindset relies on private and public sector clients buying airtime on the channel, which necessarily affects content broadcast as those able to pay determine the regularity of

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<sup>7</sup> Phila is the isiZulu word for 'to live' or 'to have life'.

content dissemination. High broadcast fees coupled with low emphasis on public health communication about TB/MDR-TB in South Africa mean that content is not broadcast often on the channel.

From 15 January to 13 April 2017, five short documentary videos of between three and five minutes each on the themes of: TB stigma, TB in children, TB treatment adherence, TB prevention and MDR-TB treatment side effects were broadcast on Mindset. Each video was broadcast once a day (at 9am and noon) and shown 70 times during the four months. Additionally, four We Beat TB public service announcements (PSAs) on the topics of: TB symptoms, TB treatment, infection control and TB and HIV were screened daily, Monday to Friday, from 29 March to 17 May 2017.

Although Mindset ostensibly airs in hospital waiting areas to reach personnel, patients and visitors with health information, in reality many hospitals do not have working television sets due to theft, vandalism and attrition. Where they are operational, televisions are reportedly often switched off, or tuned to a different station, to a soap opera or local drama, formats which are popular among young women as discussed in Chapter Nine. It is not possible to monitor number of people reached with information in health facilities via Mindset, which compromises efforts to calculate reach, impact of disseminated information and its potential to influence audiences (Saunders and Goddard 2002). Thus, even though MDR-TB content might be broadcast, there are no guarantees that patients in healthcare facilities will watch it.

This gap helps to substantiate the validity of this study, which argues that the 'how' of MDR-TB communication in relation to targeting and dissemination needs strengthening, to increase chances that people with MDR-TB and others in low socioeconomic contexts will be reached with information. The challenge outlined above also illustrates that no matter how well-focused mass media campaigns or educational programmes are, their success is only guaranteed by the extent to which they are backed by structural considerations, including target audiences' access to technology like televisions, radio sets and internet-capable devices (Saunders and Goddard 2002) and their active consumption of content on stations that run campaigns. This urges for understanding the media consumption habits and access to technology of select audiences before recommending strategies for implementation (Onyeonoro *et al.* 2013), as this study attempts to do in Chapters Eight and Nine respectively.

### **Mass mediated news programmes**

Health journalists have a role to play in influencing public perceptions and healthcare practices by using the influential medium of news programmes to frame public health problems as socially significant and deserving of attention. Health journalism is a subpart of science journalism. Science news is often approached as (i) news that popularises scientific findings and (ii) news that discusses scientific issues within a broader societal context (Summ and Volpers 2016). Typically, health journalists firstly cover new research findings and secondly, broader public health or 'wellbeing' issues, such as antibiotic resistance or TB (Maksimainen 2017). While the first is important for providing factual information, the second is crucial for helping audiences to evaluate information and make decisions about whether to apply it or not to their own lives (Maksimainen 2017). The challenge is communities like South Africa with media plurality (but, it is argued, with little diversity) and competition among media institutions (Duncan 2015) is that where TB and MDR-TB content is included in news programmes, focus is often on sharing scientific findings and presenting factual information. This approach, however, fails to factor in that different people interpret information differently, at times in ways opposite to what was intended (Maksimainen 2017).

Scholars contend that TB receives little coverage in the news, unless topics are sensationalist and/or focus on emerging outbreaks of infection in large congregate settings. Examples of this include wide coverage given to the Tugela Ferry XDR-TB outbreak in South Africa discussed in Chapter Two, 11 patients identified with XDR-TB in Germany, and the 2007 case of an American lawyer with XDR-TB who travelled to multiple countries in Europe and North America, exposing countless people to infection, before eventually being quarantined (Migliori *et al.* 2007). A review of popular evening television broadcasts in Italy found that coverage of TB in the news was subpar, while information on issues like HIV (without linking it to TB) avian flu and acute respiratory syndrome received more airtime (Migliori *et al.* 2017). Scholars urge for thoughtful reporting to connect with audiences and increase knowledge among the public. They, however, acknowledge that hard news formats for public health communication are not always appealing for audiences because 'highly technical information puts most people to sleep. However, such information is vital to understanding risk' (LaFountain 2004:50).

As well as the low quantity of mass-mediated TB communication discussed earlier, some research suggests that the quality of representation of MDR-TB on mass media

is questionable, as it is generally at odds with WHO-articulated best practice. Journalists are accused of ignoring the systematic and social drivers of TB and overly focusing on individual behaviour and patients' responsibility for having TB in the first place (Tudor *et al.* 2013; Daku and Gibbs 2012), which alienates people with MDR-TB from the information shared and increase experiences of stigma. Mass mediated news is accused of reporting a range of causes of MDR-TB, while only emphasising the effectiveness of biomedical treatment Daku and Gibbs (2012), to the exclusion of other infection prevention interventions.

Studies draw attention to limited voices of people living with MDR-TB in the media, which suppresses their experiences and positions doctors and other healthcare providers as experts with the only solutions (Lopes *et al.* 2018; Daku and Gibbs 2012). This reduces participation and agency of patients and their support systems as equal partners in MDR-TB treatment, diluting the patient-centred aspect of mass mediated health communication. This study considers urgings of scholars for research to understand how communication can increase MDR-TB knowledge and treatment literacy, and which probes the potential of PCC approaches for improving attitudes and perceptions of treatment by those infected and affected (Maharaj *et al.* 2016; Naidoo *et al.* 2016; Dias *et al.* 2013; Cramm *et al.* 2010). To understand how communication can be practicably applied in support of this aim, it is critical to understand population-specific reasons for sub-optimal adherence among the case study of vulnerable young women that is the focus of this research, as this chapter attempts to do in Chapter Four.

Scholars assert that 'health journalism matters. It does impact on people's behaviour and it does impact on people's health. In the worst cases, health journalism is a matter of life and death' (Maksimainen 2017:6). This assertion is well-illustrated by published studies which demonstrate positive correlations between broadcast news that statins were dangerous and changes in health practices in the United Kingdom. For months, sustained news programming carried debates and discussions about the harms or benefits of statins for treatment of high cholesterol. This focus was initiated by published research that found evidence of more harm than good from taking statins. After the debates had waned, statistical analyses revealed that approximately 200,000 more people stopped taking statins during a six-month period in 2013/2014 than in the six months before the news programmes (Matthews *et al.* 2016).

Recent insights into the importance of health reporting that are relevant for this thesis are from the 'Angelina Jolie effect', which is a term coined to indicate increased Internet searches about breast cancer genetics and testing for several years after 2013 (Liede *et al.* 2018). Actress Angelina Jolie's much-reported decision to undergo a preventative double mastectomy in 2013 because her genes significantly increased her breast cancer risk is correlated to peaks in breast cancer gene tests (Kmietowicz 2016). Some studies found that even though testing numbers increased, numbers of mastectomies did not increase in the United States of America, Austria, Australia, Canada and the United Kingdom (Troiano *et al.* 2017; Desai *et al.* 2016). Discussions about the ethics of whether media publicity around Ms Jolie's operation raised awareness and helped women at similar risk, or only benefited companies offering gene tests are also debated (Kmietowicz 2016). This finding suggests that whereas celebrity endorsements can influence uptake and use of healthcare services, without effective targeting, mass mediated health communication may fail to reach and benefit populations who need services most (Maksimainen 2017).

Other research, however, demonstrated increases in mastectomies among United States and Canadian populations over a number of years after 2013 (Liede *et al.* 2018). A search for literature about the 'Angelina Jolie effect' on women in Asian or African countries yielded no results. It may be that Ms Jolie's location in the Global North means that women from different cultures in the Global South may identify less with her. Thus, the announcement likely had less influence on the health intentions and practices of women from other races and cultures, who may have felt that they were not as at high a risk for breast cancer as women from similar cultures as Ms Jolie.

### ***'Edutainment' for behaviour change and dissemination***

Another format, perhaps the most efficacious one, for public health communication is edutainment (also known as entertainment education or educate-entertain). The terms describe the tactical and theoretically supported process of developing educational messages through application of a range of mediums, including mass media, to achieve desired behavioural or social change (Soul City Institute 2013). The popular concept in African public health programmes (Govender 2013; Obregon and Tufte 2013) was first advanced by Arvind Singhal and Everette Rogers in the 1990s, although in practice it had been in existence long before then (Govender 2013). It is a particularly good format for incorporating cultural appropriateness into process of developing health education programs that aim to influence behaviour change (Airhihenbuwa 1990; Airhihenbuwa 1993). Some scholars insist that contemporary



edutainment is narrow in its application and objectives because it seeks to impact changes in behaviour only at the level of the individual (Obregon and Tufte 2013). There is, however, evidence that the original aim of theory-based edutainment programming was to ‘achieve desired individual, community, institutional, and societal changes among the intended media user populations’ (Wang and Singhal 2009:273). To be effective, edutainment must stimulate discussion and debate among audiences as the first step to encouraging individual and collective changes and adoption of desired protective behaviours (Treffry-Goatley 2017), which is central to aims of educating communities about risks of specific diseases.

An extensive review of literature uncovered one example of mass mediated TB or MDR-TB edutainment content disseminated in South Africa. *The Lucky Specials* is a feature-length scripted film developed in 2016 and targeted at young people. It is described as combining ‘the best of fiction and non-fiction storytelling to demystify tuberculosis’ (luckyspecials.com 2017; Health24 2016; Lephale Express Online News 2017). The film aims to challenge misconceptions about TB, MDR-TB and TB/HIV co-infection with fact and, makes for engaging and educational viewing. It is set in a small mining town and features a cast of relatable young actors; the male lead who has TB is a miner by day and the lead guitarist for a band called The Lucky Specials by night. Animations are employed to communicate the biomedical aspects of TB infection and show how treatment interacts with bacilli in the body (luckyspecials.com 2017; Health24 2016). When he fails to take all his TB medications as prescribed, the lead actor develops MDR-TB, for which he undergoes treatment with the support of friends and healthcare workers. A strong theme in the movie is that TB and MDR-TB are curable and preventable, even in people with HIV, if people with the disease stick to their treatment until completion (Kapitako 2017).

Although it was produced in early 2016, broadcasting of *The Lucky Specials* on television only began in late 2017. Delays in bringing the film to audiences in South Africa resulted from a decision to launch it in private viewings in cities around the world in February and March 2017. Indeed, before it was available on television in South Africa, *The Lucky Specials* ‘travelled to film festivals around the world, winning awards and acclaim, and showcasing why this film can have such a strong impact in helping communities respond to tuberculosis’ (Global Giving 2017:1). For more than a year after the release of this significant motion picture, the only specialised one on the important topic of MDR-TB infection and treatment in South Africa, and perhaps Africa as a whole, it was embargoed in-country, and not available to educate and

entertain the people who needed it most – MDR-TB patients and their support structures. The irony of the film’s cast proclaiming their belief that the film ‘will help save people’s lives’ (Kekana 2017) is not unnoticed, as the content was unavailable for public viewing for over a year while lives were arguably being lost.

Even after it was cleared for public broadcast, distribution modalities of the film ensured that it remained inaccessible to audiences who needed MDR-TB information the most for a while longer. Considering its aim of educating audiences about the importance of adherence to TB and MDR-TB treatment in a country with epidemic proportions of the diseases that mainly affect people of low socioeconomic status, the decision to broadcast *The Lucky Specials* on Channel 135 on the subscription only paid DSTv platform first on 16 August, and again on 19 August 2017 (TV SA 2017) seems odd. The film was only ‘exclusively’ aired on the free-to air SABC 1 station of the national broadcaster over two months later, on 3 December 2017, albeit potentially reaching millions of viewers in their homes (Lephalale Express Online News 2017; People Magazine 2017).

Paradoxically, while distribution of the film in South Africa was initially concentrated to festivals, premier events and subscription television, with a brief presence on public television in late 2017 as detailed above, other countries in Africa adopted different strategies with more urgency. In Namibia the film was broadcast on televisions in clinic and hospital waiting rooms starting as early as June 2017 as part of MDR-TB treatment and prevention education efforts to reach patients and caregivers (Kapitako 2017). In Uganda, *The Lucky Specials* was screened at community movie nights accessible to the original target audiences: people with TB and others in their communities (Global Giving 2017). While public viewings were also arranged in eThekweni Metro, they only started in November 2017.

Similarly to discussions about the utility of broadcasting health communication on Mindset Television earlier, distribution of *The Lucky Specials* in South Africa and other countries further illustrates that health communication dissemination approaches in South Africa must be improved to reach people in low socioeconomic contexts, who are more likely to be affected by public health problems. Health communication matters, but only if target audiences receive it (Maksimainen 2017). This study aims to contribute knowledge about how health communication can be better targeted for the benefit of vulnerable young women with MDR-TB resident in eThekweni Metro.

## Summary

It is clear that diversity in responses to the MDR-TB epidemic that transcend biomedical ones is urgently needed (Maharaj *et al.* 2016; Tudor *et al.* 2013; Daku and Gibbs 2012), although clarity on how to implement health communication as an alternative approach is still lacking. This study is premised on scholars' insistence that health communication can meaningfully reduce high-risk behaviours in relation to TB, and that growing infection rates in South Africa signify that health education and communication initiatives are either too limited and narrowly focused to significantly impact audiences (Matebesi and Timmerman 2012). Indeed, ability to adhere to long-term TB and HIV treatment is correlated to patients' treatment knowledge, attitudes and beliefs; which are impacted by poverty, gender, education, experiencing real or perceived stigma, and other social, structural and cultural factors (O'Donnell *et al.* 2014). For this study, this necessitates understanding why young women from marginalised communities being treated for MDR-TB at a public healthcare facility may fail to fully adhere to treatment until completed. This discussion is covered in Chapter Four.

As this chapter and Chapter Two attempted to demonstrate, the historical and contemporary overemphasis on biomedical causes and solutions to the MDR-TB challenge, at the expense of alternative perspectives, hampers abilities of other discourses to have significant influence (Daku and Gibbs 2012), towards supporting achievement of global and national targets to end TB. Chapter Four demonstrates the centrality of adherence to treatment, but also varied challenges to treatment adherence experienced by young women from low socioeconomic contexts in urban settings. The availability and/or shortcomings of TB/MDR-TB communication in South Africa discussed in this chapter are insightful to how these challenges are presented and understood in the next.

## CHAPTER FOUR

### MDR-TB COMMUNICATION CHALLENGES AND REASONS FOR YOUNG WOMEN'S SUB-OPTIMAL ADHERENCE TO TREATMENT

#### Introduction

The importance of complete adherence to treatment to efforts to eradicating MDR-TB has been established in Chapters Two and Three and needs no emphasis. Patients risk relapse, progression of the disease to XDR-TB, death, and transmission of infection to others if treatment does not work, or if they do not complete it. Ensuring that TB is diagnosed early, and that patients are initiated on appropriate medication and supported to complete it is essential to interrupting transmission of MDR-TB and preventing development of drug-resistance (Shah *et al.* 2017; Arshad *et al.* 2014). Understanding some of the general and specific issues that adversely impact young female MDR-TB patients in their bid to adhere to treatment until completion is important. By doing this, it may be possible to develop a communication dissemination model adequate enough to address some of them to contribute to increasing adherence rates and reducing negative treatment outcomes among this population.

Adherence to TB treatment regimens (and ART) is linked to patients' knowledge, attitudes and beliefs; which are impacted by poverty, gender, education, perceived stigma around HIV or TB or both, and other social, structural and cultural factors (O'Donnell *et al.* 2014). Considering this, this chapter appraises the factors through which young women's MDR-TB treatment experiences are moderated, and how these contribute to sub-optimal adherence among populations from marginalised communities (Smith *et al.* 2016; Nutbeam 2006) in eThekweni Metro. The rationale to incorporate gender considerations in public health studies espoused in Chapter One informs this examination. It is hoped that doing this will support understanding of how the lived realities of young women being treated for MDR-TB at a busy public hospital may affect their willingness and ability to fully adhere to prescribed treatment. The chapter also presents literature in support of the conceptualisation of theory-based approaches to TB communication studies with vulnerable populations discussed in Chapter Five. This discussion helps to lay foundations for the (later) examination of whether, and how, health communication via radio and television, interpersonal communication and social media in healthcare and community contexts can support improvements in medication adherence among a defined vulnerable population.

## **Mechanisms of MDR-TB treatment during the continuation phase of treatment**

Literature generally associates high MDR-TB incidence with higher numbers of new infections than the health infrastructure can handle; low identification, diagnosis and retention of patients in care; poor patient outcomes; and development and spread of DR-TB (Shah *et al.* 2017; Kerantzas and Jacobs 2017). High costs of treating MDR-TB, longer hospital stays and treatment timelines (nine to 36 months), drug toxicity, serious side effects and generally poorer outcomes for patients negatively impact patient's willingness and ability to adhere to treatment until completion (Shah *et al.* 2017; Kerantzas and Jacobs 2017; Maharaj *et al.* 2016; Tudor *et al.* 2013; Daku and Gibbs 2012).

Interrupting or abandoning treatment has serious implications for patients, their families, healthcare providers and others they are in regular contact with; who may acquire MDR-TB infection as a result (Kigozi *et al.* 2017). Halting the infectiousness of MDR-TB is not very hard; South Africa's National TB Management Guidelines (2014) state that on correct treatment, patients should be less infectious within two weeks of starting treatment (Kigozi *et al.* 2017). Without correct and consistent treatment, however, each infectious person can infect as many as 10 to 15 other people (Kumar and Chaturvedi 2012) who can infect still more individuals. This information makes the case for early diagnosis, treatment initiation and supporting adherence to treatment for halting new infections. For treatment to be effective, patients must be initiated on correct medications within two days of diagnosis and sustain such treatment for the prescribed period (Celone 2012; Kigozi *et al.* 2017).

It is imperative to firstly understand reasons for sub-optimal adherence from the perspective of the patient if interventions are to contribute to improving MDR-TB treatment adherence among vulnerable populations (Matebesi and Timmerman 2012). This chapter interrogates why young women from marginalised communities may struggle to stay on prescribed MDR-TB treatment. It considers evidence that optimum adherence is achieved where strong intersections between the behaviour of the patient, attitudes of care workers, supportive health policies, and several other social determinants exist (Fagundez *et al.* 2016). Discussion in this chapter explore the context of young women's treatment in eThekweni Metro, to gain nuanced understanding of reasons for their sub-adherence to treatment.

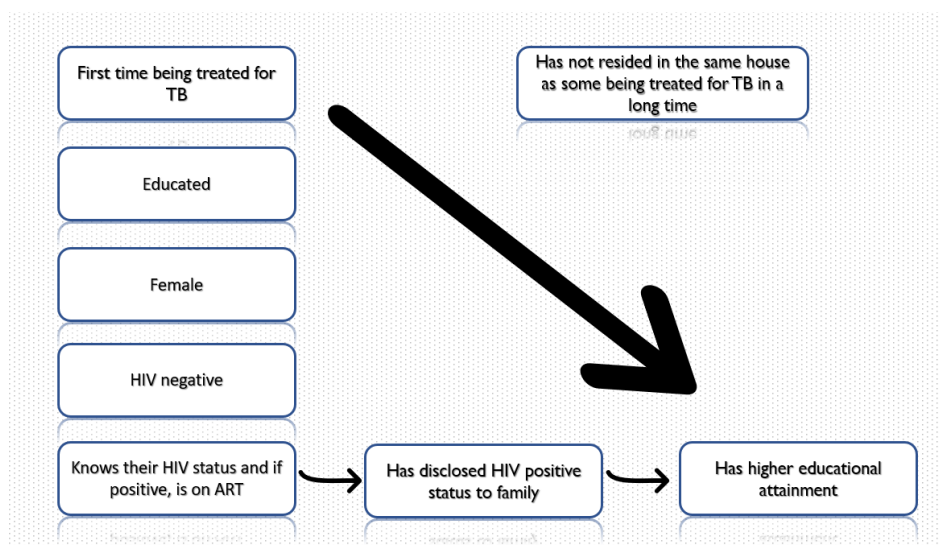
## **Causes for young women's sub-optimal adherence to treatment**

Reasons for patients' failures or refusals to adhere to treatment are complicated but can be explained as being due to 'modifiable and unmodifiable factors' (Pasma *et al.* 2014). This section discusses some modifiable factors, with reference to social and psychological drivers and determinants of MDR-TB disease and non-adherence to treatment, which are generally neglected in research and practice (Naidoo *et al.* 2016). Although they are inexorably linked and contribute to treatment adherence challenges among young women from marginalised contexts, some factors discussed below remain outside of the scope of this research to address. They are presented insofar as they are deemed important for supporting understanding of lay perceptions that impact health-seeking behaviour and sub-optimal adherence among young female MDR-TB patients (Naidoo *et al.* 2016). By understanding these factors, this study argues that it may be possible to develop a communication model adequate enough to address some of them in ways that contribute to reducing negative treatment outcomes among this population.

### **Not inherently non-adherent: Characteristics of the patient most likely to adhere to treatment**

This study seeks to explore how the KwaZulu-Natal MDR-TB programme can be supported to enhance treatment adherence rates among young women in eThekweni Metro by strategically employing and integrating communication methods specific to the characteristics and contexts of this case study in this specific environment. It is understood that TB patients are not fundamentally non-adherent, and that enhanced treatment education and support designed to complement biomedical interventions can improve treatment completion rates (Kigozi *et al.* 2017; Daftary *et al.* 2015; O'Donnell 2014; Dias *et al.* 2013). Pasma *et al.* (2014) argue that early profiling of potentially non-adherent patients being treated for chronic and serious diseases is the first step to helping struggling patients stay on treatment and monitoring to ensure that those likely to adhere to treatment do so. In line with this thinking, Figure 8 visually illustrates documented qualities that are protective of people with MDR-TB, which increase chances that they will remain on treatment.

Figure 8: A typical profile of a patient most likely to adhere to MDR-TB treatment



Characteristics included in Figure 8 were extrapolated from literature discussed in detail below. Chief among these qualities are first time receiving treatment for TB, not currently living in the same household as someone with TB, and not resident in an urban area, especially marginalised communities characterised by poverty and overcrowding. Key predictors of knowledge about TB in South Africa are linked to participants' race, sex, whether they completed high school, whether they are gainfully employed, and whether they had previously been diagnosed with and treated for TB (Naidoo *et al.* 2016; Fagundez *et al.* 2016).

### ***First time being treated for TB***

People being re-treated for TB are more likely to fail to adhere to treatment compared to those being treated for the first time (Kigozi *et al.* 2017; Fagundez *et al.* 2016; Van Den Boogaard *et al.* 2009; Terra and Bertolozzi 2008). This finding lends credence to arguments that the most important consideration in preventing drug-resistant disease is to cure patients at the first try (Variano 2013; Matebesi and Timmerman 2012). Naidoo *et al.* (2016) found that 90.9 per cent of people previously diagnosed with TB who contributed to their nationally representative study of over 5,000 participants in South Africa demonstrated significantly higher levels of knowledge about TB treatment and the fact that TB is curable than participants who had never had TB. The study demonstrates a positive correlation between high knowledge levels and participants having received information through verbal communication from a healthcare provider (Naidoo *et al.* 2016).

Other studies established that patients who had lived with someone being treated for TB for a long time, and who have been treated for TB themselves still demonstrate significant misunderstandings about modes of transmission and treatment plans, leaving them more prone to taking treatment incorrectly, or abandoning it altogether (Maharaj *et al.* 2016; Matebesi and Timmerman 2012). If the latter is the case among re-treatment patients, knowledge among people being newly treated for MDR-TB could be assumed to be too inadequate to support long-term treatment adherence. Indeed, a study with Brazilians successfully treated for TB found significant misconceptions about the disease among former patients who had regularly interacted with healthcare staff during six or more months of treatment until they were cured (Dias *et al.* 2013). Researchers insist that while communication is critical to effective TB management efforts, responsibility to disseminate appropriate communication should not be limited to healthcare professionals (Dias *et al.* 2013) and urge for more studies to address the question of 'how' TB prevention and treatment should be approached, a question this research aims to contribute to addressing.

While Naidoo *et al.*'s (2016) study discussed above is nationally representative, research by Maharaj *et al.* (2016) explained in the preceding paragraph is specific to KwaZulu-Natal province, and MDR-TB patients receiving treatment at King Dinuzulu Hospital. While national stakeholders might be more successful at communicating about MDR-TB and implementing interventions and campaigns in line with this understanding, the situation in eThekweni Metro needs more urgent and targeted attention. Discrepancies between findings by Naidoo *et al.* (2016), Maharaj *et al.* (2016) and Matebesi and Timmerman (2012) conceivably point to deficiencies in information provided to patients when they are initiated on treatment, or during subsequent follow-up visits.

This study takes these gaps into consideration as it aims to design and proffer a model to guide the (re)positioning of communication in responses to MDR-TB in resource constrained settings using eThekweni Metro in KwaZulu-Natal province as a case study. It is apt that this research seeks to understand experiences of young women with MDR-TB in eThekweni Metro, who account for 40.9 per cent of the total TB burden in the province (National Institute for Communicable Disease 2017). Women were selected as the case study of this research primarily based on findings that with the necessary support, they are more likely to adhere to and complete treatment than men are (Maharaj *et al.* 2016). A consideration of this research was to develop and proffer a communication dissemination model with potential to contribute to



enhancing MDR-TB patients' adherence to biomedical treatment. Based on the foregoing explanation, women are a good case study to achieve this objective.

### **Being female, a child or resident in a rural area**

Some studies find that women, children and inhabitants of rural areas are more likely to adhere to TB treatment (Van Den Boogaard *et al.* 2009; Wang *et al.* 2008; Munro *et al.* 2007b). The understanding is that experiencing stigma motivates women to be cured of TB, so they can stop visiting health facilities and living under the real or perceived gaze of members of their communities as they struggle with ill-health (Taylor-Abdulai 2015; Courtwright and Turner 2010). Studies also show that women's elevated feelings of responsibility to get well enough to continue caring for children, parents or other family members, and to avoid spreading MDR-TB infection to children in their households account for their better adherence (Munro *et al.* 2007b). Variano (2013) suggests that counselling patients about potential risks of MDR-TB infection to children, particularly those under five years-old, as they are discharged from inpatient treatment encourages greater adherence among women to minimise this risk. This motivation would particularly resonate with mothers, and young women with MDR-TB who reside in households with young children.

### **Older and more educated women of higher socioeconomic status**

As well as maternal instinct, age is a factor in adherence. Women 24 years and older reportedly demonstrate better adherence than younger females (Kigozi *et al.* 2017). Indeed, the 33.3 per cent reduction in TB incidence recorded in South Africa between 2004 and 2015 is reportedly attributable to NTP successes achieved among females aged 25 to 44 years (National Institute for Communicable Diseases 2017). Additionally, as higher education levels are associated with superior socioeconomic status, lower station is arguably indicative of some patients' reduced chances of successfully adhering to treatment plans (Naidoo *et al.* 2016; Fagundez *et al.* 2016). Thus, older women with more education are more likely to adhere to treatment because they are better able to access and understand treatment education and apply it. Young marginalised women aged 18 to 34 years comprise the case study of this research, for its members' potential to share nuanced and unanticipated reasons for non-adherence to MDR-TB medication that can be added to those already known about specific populations in-context.

### **Multidrug-resistant TB and HIV co-infected patients who have disclosed their diagnosis**

Insufficient understanding of transmission, prevention and treatment about a disease engenders fears, stigma and discrimination about it (Dias *et al.* 2013; Sukumani *et al.* 2012). Studies demonstrate that where family and others in a community have little knowledge about TB and HIV and their epidemiology, stigma and discrimination directed at patients is likely to be elevated (Dias *et al.* 2013; Glynn *et al.* 2001) particularly in urban areas (Gugssa *et al.* 2017). In some studies, being HIV positive is correlated with better adherence to anti-TB medications, especially among more highly educated patients (Maharaj *et al.* 2016; O'Donnell 2014). However, better adherence to TB treatment among people also taking ART is only true for patients who have disclosed their HIV status to family (Kigozi *et al.* 2017; Terra and Bertolozzi 2008). This finding substantiates assertions that family support aids internal and external stigma reduction for improved treatment adherence among patients with chronic and infectious diseases (Dias *et al.* 2013; Sukumani *et al.* 2012).

It is important to note the lack of concurrence in studies that probe patterns in adherence to both anti-TB medication and ART among co-infected patients. While some document preference for ART over TB treatment (Daftary *et al.* 2014), others find that patients are more adherent to anti-TB treatment than ART (Bionghi *et al.* 2018; Mazinyo *et al.* 2016). Still others report that living with HIV is significantly correlated to low adherence, a finding they attribute to the large quantities of medications patients must take for both diseases (Adane *et al.* 2012). It may be that patients being treated for two diseases focus on the one with the shorter-term regimen, and thus abandon ART while taking anti-TB treatment (Daftary *et al.* 2014; Terra and Bertolozzi 2008).

Other studies report converse findings; that patients being treated for DR-TB and HIV co-infection are significantly more likely to adhere to ART, compared to anti-TB medications during the first six months of DR-TB treatment (Daftary *et al.* 2015; O'Donnell *et al.* 2014). Literature in line with this argument demonstrates that uptake of and retention on ART among TB/HIV co-infected patients in South Africa is above 75 per cent (Shah *et al.* 2017; Maharaj *et al.* 2016); an earlier study put the figure at 71 per cent, indicating an increase over years (Narasimooloo and Ross 2012). It is acknowledged that the higher number of drugs taken daily by TB patients, which are more toxic and generally less tolerable than ART, contribute to low adherence to TB

treatment as opposed to that for HIV (Kigozi *et al.* 2017; Daftary *et al.* 2014; Adane *et al.* 2012).

Some advance arguments that preference for ART is a result of motivational counselling and treatment adherence interventions on the HIV side being more superior than those offered to TB patients (Kigozi *et al.* 2017; Terra and Bertolozzi 2008). Specifically, the 'empowerment approach' adopted by HIV programmes, incorporating as it does patient education, treatment literacy, adherence counselling and self-management support while taking treatment is in direct contrast to the routine monitoring of patients taking anti-TB treatment (Mazinyo *et al.* 2016:10) and reportedly results in better outcomes (Daftary *et al.* 2015; Terra and Bertolozzi 2008). While contradictory, these findings urge for researchers to consider how what is known about HIV treatment can be applied to the management of MDR-TB in eThekweni. Further, beyond collective reasons, it is also necessary to dig deeper to understand individual motivations for why people within a specific context taking long-term treatment for a serious disease like MDR-TB may succeed or fail in adhering to treatment, as this study attempts to do below.

### **Individual patient characteristics**

For research in the human sciences such as this, it is necessary to transcend prosaic considerations of when, how often, for what duration and why patients do not take prescribed MDR-TB medication, to foreground the heterogeneity of individual patients, even those situated in similar socioeconomic contexts (Bertolozzi 2008) and with characteristics such as gender, race, age and culture in common. This understanding influences how non-adherence can be addressed, as this study cannot assume that the personal narratives of all women with MDR-TB being treated at King Dinuzulu Hospital would be invariable, even though they might bear similarities. Experiences of women with MDR-TB differ, impacted as they are by divergent life experiences, and ways of responding to ill-health.

Additional factors, among them alcohol and drug abuse, mental illness, homelessness, religious convictions, personal motivations and being a migrant, all affect individuals' abilities to adhere to TB treatment (Munro *et al.* 2007b). Attitudes and personal circumstances of individual patients cannot be underestimated, as they can have more significance to treatment adherence than increased knowledge. Scholars recommend that interventions expand beyond providing MDR-TB information to convince patients to take treatment, and instead implement campaigns and programmes aimed at

increasing knowledge and sparking behaviour change among patients and communities (Maharaj *et al.* 2016; Michau *et al.* 2014). It is apposite, therefore, to contemplate how personal characters of individuals can determine adherence behaviour. These are considered together with other factors discussed in this section, chief among them participants' gender and their experiences of MDR-TB treatment within their culture, in the findings presented in Chapter Eight.

### **Gender-based experiences with MDR-TB treatment**

It would be remiss of this study not to consider gender, a dynamic and context-specific social construct as it may be, as a key mediator for women's relationships with their health, healthcare providers, and MDR-TB treatment. Morgan *et al.* (2016:1) defines gender as '... the socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for males, females and other genders and which affect how people live, work and relate to each other at all levels, including in relation to the health system'. Analysis of TB infection patterns, management and treatment makes for interesting reading. While HIV, which is linked to TB infection, affects more women than men in southern Africa, significantly more men than women aged 35+ years have TB, although data indicates greater parity between the sexes in infection rates in people aged 15 years and younger (WHO 2016).

In 2016, TB was the number three natural cause of death of women in South Africa, and the leading reason among men (WHO 2016). Men in Africa are reportedly more prone to developing TB because they are more exposed to TB bacilli in their daily lives, and more susceptible to developing TB disease due to biological makeup. On the other hand, there are suggestions that high mortality and lower reported TB incidence among women stems from under-reporting of symptoms due to fears of social isolation caused by the highly infectious nature of TB, and its associations with HIV (Smith *et al.* 2016; Vlasoff 2007). Highlighting the link between HIV and TB established in Chapter Two is important, especially considering findings that where a smear-positive TB diagnosis in women occurs, it can generally be connected back to the disproportionate burden of HIV among women, and in particular young women in South Africa (Smith *et al.* 2016).

Considering gender-determined factors in TB infection and treatment adherence is important for this study, which seeks to understand ways in which young women with MDR-TB situated in a patriarchal society with strong cultural beliefs about women's submissiveness relate with and respond to their healthcare providers and MDR-TB

treatment. Indeed, scholars such as Munro *et al.* (2007b) insist that research is needed to understand how gender, among other factors, influences and/or impacts TB patients' adherence to treatment and to inform the (re)design of support systems so they better respond to patients' needs. As argued in Chapter One, it is important to apply a gender lens to TB studies as consequences of communicable diseases are influenced by sex and gender considerations, to result in different health outcomes for males and females (Shah *et al.* 2017; Fagundez *et al.* 2016; Maharaj *et al.* 2016; Vlasoff 2007).

For instance, poor women in developing countries reportedly delay seeking treatment from a healthcare facility until they experience severe symptoms, while visiting traditional healers or local pharmacies for care (Variano 2013; Vlasoff 2007). Studies in the Gambia, India and Viet Nam found that women prefer consulting traditional health practitioners, pharmacies and private providers because of their greater convenience, proximity and privacy (Smith *et al.* 2016). The flexible payment methods and timelines of traditional health practitioners, and the ease with which ailments and treatments are explained, compared to the scientific explanations given in healthcare facilities, are significant pull-factors to alternative sources of care (Vlasoff 2007). Reliance on other care institutions is also linked to poor socioeconomic status as women, more than men, often cannot afford to access modern medical services as soon as they experience symptoms.

Highlighting sex differences in TB health-seeking behaviour and diagnosis in primary healthcare facilities in South Africa, some researchers found that although women are more likely to seek care for a cough of less than two weeks when compared to men, they are less likely to be asked for a sputum sample, and less likely to have a positive sputum sample when tested (Smith *et al.* 2016). Women are more likely to deliver poor samples, because of their more genteel approach to coughing and sputum generation (Smith *et al.* 2016). These concerns are compounded by systematic socioeconomic and cultural biases which may undermine efforts to correctly diagnosis TB in women. For instance, stereotypes held by healthcare workers about the 'typical' TB patient being male may reduce correct diagnoses of TB in women who visit healthcare facilities (Smith *et al.* 2016). It is not uncommon for women to be treated in ways that make them feel inferior and without agency when they do visit health facilities, creating situations where a population with the greatest need for health services receives the least support (Vlasoff 2007).

Because of these varied factors, women with MDR-TB from low income backgrounds may delay seeking care (Naidoo and Taylor 2013), even when they have symptoms, and experience late diagnoses and initiation on appropriate treatment, which may discourage them from utilising healthcare services. Because of these complications, women may also take longer to recover, and because of family and societal expectations, they often return to their normal duties before they are completely healed, further compromising their recovery (Vlasoff 2007). It is significant that women may be disproportionately susceptible to infection with primary MDR-TB from participating in gender-determined caregiving roles (Smith *et al.* 2016). Indeed, women in Equatorial Guinea were more likely than men to indicate previous or ongoing contact with a TB patient as a possible source of their TB; 41 per cent of participants reported having contact with a family member currently or previously diagnosed with TB (Fagundez *et al.* 2016). Requirements for women to care for ill family members are based on tradition, as well as concerns about household finances, with poorer families less able to afford costs associated with MDR-TB treatment, which some household members must cushion. Lower socioeconomic status also impacts adherence to treatment, as discussed below.

### **Financial insecurity and poor socioeconomic conditions**

Treating MDR-TB requires hospitalisation for long periods in some instances and involves numerous visits to health facilities in all. The lengthy treatment timelines are financially taxing for patients, many of whom do not have money for transport to go to a hospital when required to do so. Prolonged MDR-TB treatment can easily exhaust the financial resources of poor families as they support their family member on treatment (Maswangayi *et al.* 2014). Subordinate incomes resulting from women's lower participation in formal employment and subsequent diminished autonomy in decision-making also contribute to lower health-seeking behaviour and poorer outcomes for serious diseases among women, who are not always able to afford to pay for services (Vlasoff 2007).

While it can be argued that since TB treatment in South Africa is free of charge costs should not present a barrier to accessing timely healthcare services, for many women in marginalised communities, meeting hidden costs of MDR-TB treatment (i.e. for transportation, or to pay for childcare while they visit a health facility), is beyond their capability (Tang and Squire 2005 in Maswangayi *et al.* 2014). In some patriarchal families like those of the Zulu, gender norms and power relations between men and women result in women's restricted freedom of movement and association and curtail their

ability to visit health facilities when ill. Where women are employed, taking time off work is also hard as absenteeism can threaten employment and livelihoods (Dias *et al.* 2013).

Discussions about the development of TB in the Global North in Chapter Two established a direct link between poverty and TB. Many people with MDR-TB in eThekweni Metro, and indeed South Africa, are from marginalised communities, with attendant poor employment opportunities, income levels and food and financial security (Tola *et al.* 2015; Maswangayi *et al.* 2014). Patients from these communities are consequently less able to access healthcare services and take up treatment. Encouragingly, community-based interventions for treating patients with MDR-TB, like the DOTS strategy discussed earlier, demonstrate some improvements in treatment success rates, while evidence from a single study suggested that similar initiatives show promise in achieving significant decreases in relapse rates (Arshad *et al.* 2014). Achievements in this area rely on both family and community support for patients and increased public knowledge about MDR-TB, if patients are to get the help they need.

### **Poor support structures around TB patients and experiences of stigma**

Public awareness of the infectious nature of MDR-TB in the context of deeply entrenched misconceptions about how infection occurs results in some patients experiencing intense stigma, especially from close contacts (Maswangayi *et al.* 2014; Dias *et al.* 2013; Sukumani *et al.* 2012). This is partly attributable to longstanding negative representations of the disease in the media and resultant shared narratives (Lopes *et al.* 2018). People with MDR-TB self-stigmatize and self-isolate, viewing themselves as disease vectors or contagions, with negative impacts on their treatment (Dias *et al.* 2013). Research findings that although external stigma from workmates, extended family and community members is high, family members living in the same households as patients are less likely to be sources of stigma are interesting (Dias *et al.* 2013).

Links between TB and HIV results in assumptions that anyone with TB is also living with HIV, and *vice versa*, which partly accounts for significant stigma directed at people with TB (Variano 2013; Sukumani *et al.* 2012). HIV is not the only blot that accompanies a TB diagnosis as infection with TB in many cultures is associated with pollution, weakness, or being cursed (Dias *et al.* 2013; Munro *et al.* 2007b), as discussed further in findings presented in Chapter Eight. Consequently, people with TB may be reluctant to disclose that they have TB to even close friends and relatives, with

implications for infection prevention efforts and abilities to recruit support during treatment (Variano 2013; Dias *et al.* 2012). Failure to disclose an MDR-TB diagnosis hampers patients' ability to access the health services they need for the time necessary to be cured.

Families need to be supportive of people with MDR-TB during treatment (Maswangayi *et al.* 2014; Sukumani *et al.* 2012). They can only do this, however, when they are sufficiently educated about MDR-TB, its treatment, and how to practically support their loved ones (Dias *et al.* 2013; Sukumani *et al.* 2012; Padayatchi and Friedland 2008) because when patients take treatment secretly, they may skip or forget to take doses (Maswangayi *et al.* 2014). Further, visits to health facilities for treatment and check-ups become causes of anxiety and may be impossible to achieve in environments of secrecy. Because of gender norms and limitations on women's movement and participation in the public sphere, women may find it particularly difficult to leave the home or take their medication in secret, which may lead them to abandon treatment altogether.

Experiences of all women are not equal. However, young women with MDR-TB reportedly experience more stigma than other groups. Scholars find that gender roles and status in a family are indicative of the type and amount of support extended to people with TB by families, which impact patients' adherence to prescribed treatment (Fagundez *et al.* 2016; Johansson 2000). Women's status in African families and communities determine how they are treated, with detrimental implications for lower-level females (Johansson 2000). Men with TB are supported and respected in families while, conversely, women may be threatened, humiliated, abandoned and divorced once diagnosed with TB (Maswangayi *et al.* 2014; Munro *et al.* 2007b; Johansson 2000). Age plays a role in status and women's experiences of stigma, with some research finding that young patients are better supported by family and friends while being treated for MDR-TB (Cramm *et al.* 2010). This finding is useful for the approach to analysing data on women's experiences with MDR-TB treatment presented in Chapter Seven, as the case study of this research sought the perspectives of very young adult women, in the 18 to 23 years age range, and more mature women aged 24 to 34 years.

Often, failure by people with MDR-TB to divulge that they are receiving treatment finds explanation in their experiences and fears of stigma in the workplace and losing their jobs should their employers discover that they are infected, with negative



implications for their full adherence to treatment (Dias *et al.* 2013; Munro *et al.* 2007b). A study in Brazil found that people in permanent employment are less affected by job losses while being treated for TB because of workplace discrimination than people in semi-skilled, seasonal or part-time employment, who often lose jobs during treatment or soon after returning to work after they are cured (Dias *et al.* 2013). This may be reflective of the situation in eThekweni Metro. High unemployment rates and the historical sub-education of the Black population stemming from apartheid-era policies established in Chapter Two imply that many people without health insurance who access MDR-TB treatment at public hospitals would be employed in lower skilled jobs with fewer protections. Lack of knowledge drives fear, which leads to stigma and discriminatory behaviours towards perceived threats and positions MDR-TB treatment and active employment as mutually exclusive.

That cured TB patients, or those still on treatment and no longer infectious are ostracised and cut off from their sources of livelihoods illustrates the necessity of increasing knowledge about MDR-TB treatment timelines and its effectiveness among the public. Failure to disclose TB status at work hinders patients' adherence to treatment. Practically, patients who have not disclosed that they are receiving treatment for TB may find it difficult to take doses at work, or to take time off frequently to collect medication as necessary. A consequence of ignorance and fear, which forces populations from marginalised backgrounds to choose between their health and an income, is that patients may stop medication altogether to return to work and secure their livelihoods (Akeju *et al.* 2017; Munro *et al.* 2007b). Key to the discussion in this section is that higher levels of knowledge about TB are correlated to lower levels of stigma and discrimination (Mishra *et al.* 2014), which further substantiates objectives of studies such as this one to develop evidence-based responses to the TB epidemic that amplify dissemination of health communication about the disease to increase knowledge levels, as done in Chapter Ten.

### **'Criminalisation' of tuberculosis patients and quality of care**

As discussed in detail later in this chapter, MDR-TB patients disapprove of being observed while taking treatment as part of the DOTS approach because they feel policed and distrusted by healthcare providers and family members to control their own treatment (Munro *et al.* 2007b). Additionally, other arguments are that the language and terms commonly used by medical personnel globally – TB control as opposed to patient care, TB suspect instead of patient with presumptive TB, TB case versus TB patient, defaulter instead of failure to adhere to medication, compliance

versus adherence – criminalise people with TB and are intrinsically judgemental (Daftary *et al.* 2015; Zachariah *et al.* 2012). Using these words, instead of their more empowering and sensitive alternatives, is imputed for unfairly apportioning responsibility for transmission of TB infection and low treatment adherence and cure rates solely on patients, to the exclusion of other stakeholders. The terminology in use contributes to stigmatising people with TB and their families and affects their acceptability in their communities (Zachariah *et al.* 2012). It influences attitudes and behaviour at every level, discouraging patients from seeking or staying on treatment, or influencing how some, like the media, view and communicate TB to the public, with implications on the positions of patients within their communities.

The reality that MDR-TB patients can be involuntarily admitted and held in hospitals to receive treatment is suggestive of not only MDR-TB, but people with MDR-TB being bad, and needing to be purged from society for the protection of others. Moves such as this are incapacitating for patients, who are often viewed as not having rights or power over their own treatment, beyond how it benefits public health. Indeed, Frick *et al.* (2015) insist that reluctance by those concerned to endorse global policy to change terms and the treatment of TB patients, and to align practices to policy is due to TB being a disease of the poor, whose rights can be trampled with little fear of censure. Patients like those in the case study of this research are already poor; being Black, female and young as well only further disenfranchises them and is indicative of their being more prone to poor treatment outcomes induced by sub-optimal adherence on treatment.

### **Experiencing serious side effects or starting to feel better**

Within the context of race, gender, age-determined and poor socioeconomic impediments to full adherence to treatment discussed above, MDR-TB patients must contend with treatment regimens with heavy pill burdens, anything from 12 and 15 tablets daily for the duration of treatment, as well as a daily intramuscular injection of the debilitating and side-effect-inducing drug *Kanamycin* for the first six months of treatment for some patients (Hughes and Osman 2014; Tanguis 2000). As explained in Chapter Two, addition of *Bedaquiline* and *Delamanid* to MDR-TB treatment regimens reduce treatment timelines to about nine months and remove the need for *Kanamycin*. Nonetheless, drugs to treat MDR-TB, including the newest ones, are toxic and can result in side effects serious enough to be singled out as the single most significant hinderance to adherence.

Anti-MDR-TB drugs are foul-smelling and their psychedelic colours, including bright orange and purple, are off-putting, causing patients to skip doses to avoid ingesting them (Tanguis *et al.* 2000). A study in Limpopo province, South Africa, found experiencing side effects in the absence of knowledge about what to do should they occur diminishes TB patients' adherence to treatment (Maswangayi *et al.* 2014). Dizziness, nausea and vomiting make patients more likely to skip doses, especially since many people are not educated that they should continue taking medications even when they cause adverse events (Maswangayi *et al.* 2014). On top of feeling awful because of side effects, treatment fatigue resulting from the large number of tablets and unrelenting treatment schedule is another factor for consideration in understanding reasons for sub-optimal adherence to MDR-TB treatment.

Coupled with the unpleasant fact of side effects and numerous tablets is that patients often start to feel better soon after starting treatment, so they stop taking medication in the belief that they must be cured, only to resume taking treatment again once symptoms resurge (Akeju *et al.* 2017). This start-stop-start approach undermines efforts to prevent development of drug-resistance and new DR-TB infections (Munro *et al.* 2007b). In Nepal, researchers reported that 61 per cent of non-adherent patients interviewed stopped taking their medication because they felt better and did not know that they were supposed to continue with treatment until the course was complete (Newel *et al.* 2006). It can be assumed that this challenge can potentially be mitigated by enhancing MDR-TB patients' treatment literacy through scaling up and prioritising education in healthcare settings and via mass mediated communication and social media.

The most serious side effects of MDR-TB medication are permanent hearing loss and deafness (Variano 2013) caused by *Kanamycin*. Treating side effects can be expensive and many patients from low socioeconomic backgrounds cannot afford remedies (Maswangayi *et al.* 2014). Out of desperation, some patients stop taking this one medication to preserve their hearing (Variano 2013). Patients may also not take treatment continuously and routinely as prescribed, but instead take doses only when they feel unwell or are in pain (Munro *et al.* 2007b). Notwithstanding arguments against surveillance of patients during treatment discussed above, this study contends that DOTS provided by household contacts has a place in MDR-TB treatment as skipped doses are more commonly reported among patients who take treatment in the absence of direct observation by a treatment supporter (Akeju *et al.* 2017). This

approach also provides opportunities for personalised health education via interpersonal communication.

Common erroneous interpretations by patients about how medications should be taken can be linked to the quality of treatment information that patients receive in healthcare facilities, how adequately they are prepared for the treatment journey before they embark on it, and how well they are supported during (Tola *et al.* 2015). Some argue that problems around getting patients into care can be partly attributed to healthcare providers failing to account for patient's daily lives and routines, beliefs, opinions, and existing knowledge about their disease and its treatment among others when devising a treatment plan, and that information provided is insufficient to support full adherence (Tola *et al.* 2015; Terra and Bertolozzi 2008). Some studies demonstrate that simply providing information about side effects of TB treatment prior to initiating patients on their regimens improves individuals' commitments to adhere to it (Akeju *et al.* 2017). This bears considering and is incorporated in the development of the evidence-based counselling plan presented in Chapter Nine and incorporated into the communication model proffered in Chapter Ten.

### **Traditional and cultural beliefs and practices**

Beliefs mediate the normalisation and legitimisation of individuals' and communities' understanding of diseases, based on pervasive interpretations of meanings and values within specific societies (Michau *et al.* 2014). Remedies to ill-health are predicated on individual, community, cultural and/or religious beliefs about the aetiology of TB disease, which is why it is critical to probe these in studies such as this one. Harmful cultural beliefs and practices deleteriously impact discrete health-seeking behaviour and treatment adherence among TB patients (Llongo 2004). A study in Vietnam concluded that patients' beliefs negatively impact TB cure rates. To illustrate, patients who believe that TB is inherited or caused by hard work and worrying may feel it is unhelpful to take biomedical treatment (Phuong Hoa *et al.* 2003). Research such as this one, which examines treatment adherence patterns in a specific context must, therefore, acknowledge research participants' social, economic, cultural and geographic contexts and how they influence their beliefs (Cramm *et al.* 2010). The importance of context-specificity in this research is supported by findings that social, economic and other demographic considerations impact the conclusions that can be reached in studies on adherence in different locations (Sumartojo 1993).

Additionally, there is a case to be made that understanding the cultural contexts and traditional beliefs of people in a society, and their views about causes of specific diseases is crucial to understanding why and when they might choose to abandon biomedical treatment in favour of traditional or faith-based remedies, or no treatment at all (Variano 2013; Phuong Hoa *et al.* 2003). Also, as behaviour is understood contextually, in relation to its entrenchment in the cultures where people are socialised and nurtured, any intervention to address social and behaviour change in relation to adherence to MDR-TB treatment should necessarily be based on understanding patients' contexts and cultures. In much of South Africa, cultural and religious beliefs filter how individuals and communities understand and experiences ill-health, oftentimes resulting in the privileging of home-grown solutions to pathology. Variano (2013) writes about the tendency of many isiZulu-speaking people, who are native to KwaZulu-Natal province, to use traditional healers, known locally as *sangomas*, for important traditions and rites when they are ill. People with TB in communities with strong cultural values also hold stout convictions that there are alternative treatments for TB, depending on what their beliefs are concerning the origin of the disease in the first instance (Phuong Hoa *et al.* 2003).

Because of the influence of traditions and cultural beliefs and practices, not all people diagnosed with MDR-TB believe that they have the disease. Denial and difficulty accepting a diagnosis of MDR-TB impacts uptake of services and medication, and adherence to treatment. Some patients accept treatment in the short-term to cure symptoms of illness; and abandon it once these ease (Munro *et al.* 2007b). Substantiating the centrality of health education and communication to treatment adherence, some researchers explain that patients turn to traditional health practitioners and faith healers because of ignorance that medical treatment provided in healthcare facilities is the only effective cure for TB (van der Werf *et al.* 1990; Maswangayi *et al.* 2014). Others, however, argue that faith in the effectiveness of anti-TB medication and its uptake is directly related to patients' confidence (or lack thereof) in the health system (Akeju *et al.* 2017), which is moderated through perceptions of how responsive healthcare personnel are to their needs.

Examining issues that impact TB patients' adherence to treatment, Matebesi and Timmerman (2012) found that communicating the importance of lifestyle changes to prevent TB and targeting dissemination of accurate information could challenge erroneous beliefs about causes of MDR-TB and its treatment and result in better outcomes. Dias *et al.* (2013) advance the argument, which is foregrounded in this

study, that communication about MDR-TB treatment needs to subsume interventions that account for the idiosyncratic realities of groups of patients on the backdrop of their lived contexts.

## **Summary**

This chapter established that young women's sub-adherence to MDR-TB treatment in eThekweni Metro is precipitated and sustained by variant structural, socioeconomic and cultural factors, among them poverty, unemployment, inequalities at various levels, inadequate access to education and amenities, poor nutritional status, gender inequality and migration, all of which increase poor people's vulnerabilities to TB, and HIV (SANAC 2017). These factors affect individuals' abilities to protect themselves from contracting diseases, to seek medical attention as necessary, and to adhere to prescribed treatment for the required length of time (SANAC 2017). They are located at the centre of this study's attempt not only to understand young women's experiences with MDR-TB treatment, but also to suggest a communication model with potential to impact them positively and contribute to improving their adherence to prescribed MDR-TB medication until completed as set out in the NSP and other TB policies and guidelines.

As global TB stakeholders have set the goal of ending TB by 2035, improving treatment adherence among MDR-TB patients is more urgent. It is with this and the foregoing context that, in the chapters that follow, this thesis continues to probe and discuss how health communication on television, radio, social media and via interpersonal communication in use can be improved and repositioned to enhance the effectiveness of biomedical responses in controlling the MDR-TB epidemic. Researchers emphasise the importance of weaving approaches and strategies from multiple perspectives to understand and explain where efforts to strengthen MDR-TB management efforts should be focused (Michau *et al.* 2014; Matebesi and Timmerman 2012; Munro *et al.* 2007a). This study aims to contribute evidence-based knowledge to improve adherence to long-term treatment among young women resident in marginalised communities. It urges that the specific and pressing issue for public health researchers interested in health promotion now is to study how theories can be applied to the development of effective multi-disciplinary interventions to improve adherence to treatment for MDR-TB, as very few theory-backed interventions are in current use (Tsozdo 2011; Munro *et al.* 2007a). The conceptual framework of this study, which attempts to do this, is presented in Chapter Five.

# CHAPTER FIVE

## HEALTH COMMUNICATION CONCEPTUAL FRAMEWORK

### Introduction

This thesis contends that adherence to treatment may be the single most important facet of the MDR-TB care cascade because of its potential to exponentially reduce new and re-infections and mortality. Investigating this hypothetical idea through research, however, requires substantiation with theory if it is to contribute trustworthy and contextual knowledge to the public health promotion field. I was a public health communication practitioner and not an academic researcher at the time of commencing doctoral studies. Although my theoretical sensibilities were not as robust initially, what I possessed was detailed understanding of the multifaceted challenges effective management of MDR-TB nationally, and in eThekweni Metro specifically. Analysis of 2016 MDR-TB treatment outcomes data for eThekweni Metro and related literature indicated the point in the MDR-TB treatment care cascade where, if disruption occurs, turning the tide of the TB epidemic could be achieved. I was firmly convinced early in the research process that adherence to treatment was *the* point to study for reasons expatiated in Chapters Two and Three, and duly focused the study in this area.

This chapter discusses how theory and literature, and the professional and academic foundations of this study which are explained in Chapters One and Two are weaved to contribute a cogent frame within which to understand the study (Berman 2013). The conceptual framework delineated here considers the utility of one-way communication through mass media, two-way communication using interpersonal communication in face-to-face interactions, and social media as an additional feedback and discussion mechanism in MDR-TB treatment in low socioeconomic contexts. It explores combining the three mediums to achieve cyclical communication that is moderated through individuals and groups in a specific context, and which emphasises dialogue among audiences, akin to what Clamptt (2001) termed the 'circuit approach to communication'.

Clamptt's term is derived from Osgood and Schraam's (in Schraam 1954) proposal of a circular model of communication, in which messages are passed between information senders/coders and receivers/decoders, with no endpoint. In this conceptualisation, true communication requires feedback and engagement, and is not

merely a top-down approach whereby health promoters are framed and positioned as 'experts' in communication and individuals and communities as 'receivers' of messages (Cross *et al.* 2017). This study's conceptual framework is designed to advance the aspiration to establish an effective health promotion approach to transpose treatment adherence and MDR-TB treatment literacy to the centre of MDR-TB management in eThekweni. In so doing, it incorporates considerations of social norms and structural challenges in healthcare service delivery which affect MDR-TB health promotion initiatives in eThekweni, as discussed in Chapter Four. The conceptual framework is based on a constructed epistemological approach (Grant and Osanloo 2014) to studying the potential of health promotion to enhance MDR-TB treatment outcomes among a vulnerable population. The framework is the pivot of the study. It outlines the genesis and organisation of the research (Grant and Osanloo 2014) and the conceptual parameters within which the study answers the three research questions outlined in Chapter One and proffers the communication model in Chapter Ten.

### **Theorising a health communication approach to enhance MDR-TB treatment promotion**

The transdisciplinary field of health communication derives from areas as varied as 'mass and speech communication, health education, marketing, journalism, public relations, psychology, informatics, and epidemiology' (Bernhardt 2004:2052). The importance of understanding these foundations is clarified in discussions of the nursing health practice, mass media and select health behaviour theories that comprise this study's health communication conceptual framework. Scholars Cross *et al.* (2017) critically appraise some ideologies and theories used in health communication, to influence better practice. They assume a position on the social construction of health and health-related decision-making and encourage health promotion scholars to critically analyse commonly accepted assumptions about effective approaches to communicating with individuals and communities about health issues. The scholars discuss health communication with reference to diverse theories and models and their applicability to research. Cross *et al.*'s (2017) approach is considered invaluable to studies like this one and this thesis adopts their constructed health communication approach to articulate the conceptual approach to this research. Emphasis is on foregrounding the importance of development and theory-based methods in enhancing treatment literacy and public health promotion around MDR-TB treatment adherence in low socioeconomic contexts.



## **Outlining the conceptual framework**

This study's conceptual framework is informed by wide reading of select formal theory, published literature and new research and perforce incorporates my professional experience (Pearson Casanave and Li 2015; Grant and Osanloo 2014) in the fields of public health communication, media and TB management in South Africa. The framework is a researcher-developed edifice that illuminates associations between the discrete variables (Andrews 2012) of young women's motivations for not adhering to treatment within their socioeconomic and cultural context, shortcoming of health education in facilities, mass media use and preferences, as well as opportunities to optimise the potential of health promotion to contribute to improving public health. The edifice braces the research approach employed and discussed in Chapter Six. It mediates the approach adopted for data analysis discussed in Chapter Seven, to ensure that the interpretation of data is meaningful 'with respect to the theory and reality of the study' (Knight and Cross 2013, in Berman 2013:13), before connecting the findings presented in Chapters Eight and Nine to knowledge in the health promotion field (Merrill *et al.* 2016; Grant and Osanloo 2014).

The conceptual framework outlined in Figure 9 presents the 'mind map' that emerged from this reflective process. It is unpacked and expatiated in detail in the sections below. It is utilised in identifying, making associations between and explicating 'the system of concepts, assumptions, expectations, beliefs and theories that supports and informs public health communication research' (Maxwell 2005:33). The expatiated conceptual framework incorporates encouragements for health promotion studies to categorise people, especially the marginalised, into defined groups to understand their health communication needs and effectively respond to them (Cross *et al.* 2017). Further, Cross *et al.* (2017) urge researchers to subscribe to health promotion values like empowerment, participation, addressing social determinants of health and tackling health inequalities, which is the underlying philosophy of the VPCM (Flaskerud and Winslow 1998; Grabovschi *et al.* 2013; Rawlette 2011; Cooper 2011; Leight 2003). Their health communication approach critiques the conjecture that increasing knowledge, through enhancing MDR-TB communication for example, directly results in changes in behaviour (Cross *et al.* 2017).

The Knowledge Gap Theory (Tichenor, Donohue and Olien 1970; Gaziano 2016; Jäntti 2014; Bekalu and Eggermont 2013; Mutz and Martin 2001; Kwak 1999) is responsive to health promotion practice which is concerned with addressing inequalities in healthcare and access and tackling gaps between higher income and

lower income groups in a society Cross *et al.* 2017). This theory is included to help account for factors that hamper certain groups' access to health communication more than others', and to establish how to close gaps between those with access and those without. Finally, addition of the Two-Step Flow Theory (Lazarsfeld and Katz 1955; Hughes and Osman 2014; Gleave and Smith 2009; Bennet and Manheim 2006; Hirowaka and Lowe 2002), and its later interpretations as the Multi-Step Flow (Southwell and Yzer 2007; Burt 1999) and One-Step Flow models recognises the need for health communication to move from 'monological information transfer towards dialogical information exchange' (Cross *et al.* 2017:17). This is position is critical of those who position health promoters as effective communicators and expert witnesses in health, because there are important social and cultural norms that must be considered in implementing health communication (Cross *et al.* 2017). It instead urges for health promotion practices that privilege lay perspectives by applying a social model of health to research in this area (Cross *et al.* 2017), as outlined in Figure 9.

Figure 9: Research health communication conceptual framework

### **Research problem**

Low treatment adherence and poor outcomes among MDR-TB patients in low socioeconomic contexts in KwaZulu-Natal Province, South Africa, results in poor treatment outcomes and increased infection transmission and development of disease

### **Target for research**

Vulnerable young women (18 to 35 years) from marginalised communities in eThekweni Metro in the continuation phase of treatment for primary MDR-TB

- TB is a disease associated with poverty
- TB prevalence is higher among the majority Black population
- MDR-TB infection is more prevalent among younger age groups
- Gender parity in MDR-TB infection incidence

### **Objective**

Contribute to implementation of communication initiatives as a viable contributor to improving treatment adherence among vulnerable young women with MDR-TB

### **Research design**

**Quasi-ethnographic** case study explores cultural phenomena from participants' points of view

### **Epistemology**

**Social constructionism** argues that meaning is socially constructed and, therefore, dependent on contingent aspects of the society in which it is mediated

### **Theories of public health communication, media and behaviour change communication**

- Vulnerable Populations Conceptual Model
- Knowledge Gap Theory
- Two-Step Theory and Multi Step-Flow Theory
- Social and behaviour change communication theories

### **Data collection**

- Three focus group discussions with 13 participants
- Eight key respondent interviews
- Elements of observation

### **Data analysis**

- Interpretivist (using thematic data analysis)

The theories are applied as outlined:

- i. Vulnerable Populations Conceptual Model (VPCM) (Flaskerud and Winslow 1998) is applied to uncover challenges that place young women from marginalised communities at risk of contracting MDR-TB and which impact their abilities to fully adhere to treatment until cured.
- ii. Knowledge Gap Theory (Tichenor, Donohue and Olien 1970) The Knowledge Gap Theory is employed to probe and uncover which media (including radio and television channels and programmes) are deemed most effective for disseminating relatable messages and reaching young women in eThekweni with relevant information about MDR-TB prevention and treatment.
- iii. Two Step Flow Theory (Lazarsfeld and Katz 1955) and its later reinterpretation as the Multi-Step Flow Theory are applied to uncover who, in the MDR-TB patients' family and social circles, should be targeted with communication for onward transmission to influence patients to take their medication. The One-Step Flow Theory is considered in assessing use of social media in health promotion.
- iv. Health and social behaviour change theories (biomedical, behavioural (learning) and cognitive).

The theories are applied together to frame this study's examination of how health communication can be enhanced to positively impact vulnerable young women's attitudes and behaviours in relation to long-term treatment for serious communicable illnesses in eThekweni Metro. By so doing, it aims to understand how health communication via patient education and counselling and mass mediated messages can be effectively targeted and disseminated in marginalised urban communities with high MDR-TB burdens.

Figure 10: Relationship between theories and research objectives and questions

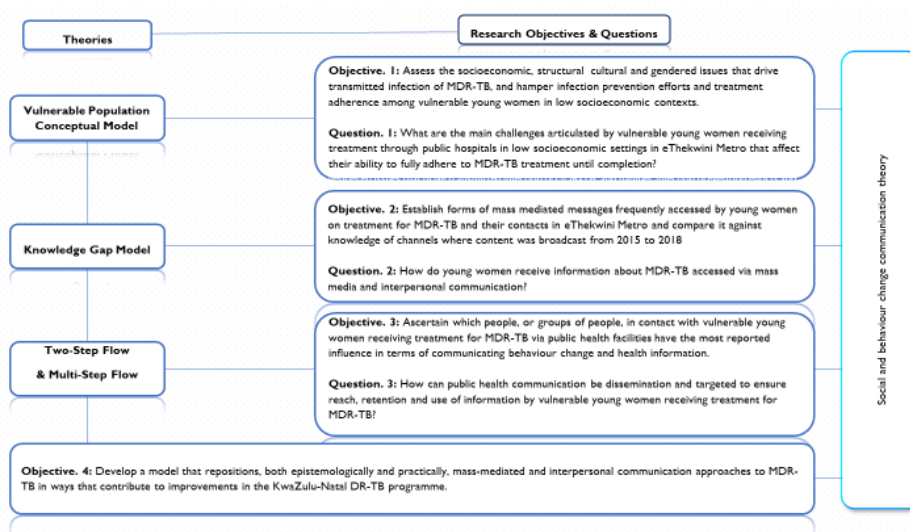


Figure 10 summarises the relationships between the select theories and research objectives and explains how these are applied to investigating how public health communication and MDR-TB treatment education approaches can be enhanced to impact vulnerable young women’s attitudes and health intentions during long-term treatment. These links are explained in detail below, beginning with the main theories applied to this research.

### Vulnerable Populations Conceptual Model

The VPCM (Flaskerud and Winslow 1998) is a community-focused mid-range nursing theory. Mid-range theories have limited scope and are useful for explaining a specific set of phenomena (Rawlett 2011; Leight 2003). The theory postulates that access (or lack of) to healthcare, acceptance and use of health promotion services, and disease states among susceptible and disenfranchised groups are linked (Rawlett 2011; Leight 2003). Certain groups, termed ‘vulnerable populations’ are theorised as being at increased risk of unfavourable health outcomes because of their deficient environmental and socioeconomic assets (Rawlett 2011; Leight 2003). Some disparities studies that apply the VPCM find that vulnerability is uroboros-like, vulnerable groups are disproportionately prejudiced in their ability to access healthcare services, while challenges accessing care are significantly correlated with development of or increased vulnerability and poor outcomes among members of some groups (Grabovschi *et al.* 2013).

The VPCM comprises three concepts. The first, ‘resource availability’, assesses the societal and environmental resources at individuals’ disposal. It considers human

capital, which encompasses income levels, employment, educational attainment, housing, health insurance, social status (power), social connection (related to an individual's integration into society), and access to social networks and how these potentially influence group's health-seeking behaviours, access to and retention in care (Flaskerud and Winslow 1998). The second concept is the environmental notion, which is concerned with individuals' access to health services, and the quality of available amenities (Flaskerud and Winslow 1998; Rawlett 2011). The final is 'relative risk', which considers communities' lifestyles, behaviours and choices when accessing and using health promotion services as an indicator of their comparative risk of experiencing poor health (Rawlett 2011). For instance, if a group chooses not to participate in vaccination programmes, their relative risk of poor health can be assumed to be higher than those who make use of offered services. Relative risk is further conceptualised as the likelihood that groups with fewer resources have of experiencing ill-health, relative to those from wealthier communities (Rawlett 2011; Aday 1993).

Vulnerable populations are defined as 'a social ensemble with an increased risk or disposition to unfavourable health outcomes' (Flaskerud and Winslow 1998). They are largely impoverished, politically marginalised, prejudiced against, stigmatised and generally denied equal and human rights (Flaskerud and Winslow 1998). Extant literature offers guidance for categorising vulnerable populations. Koniak-Griffin *et al.* (2005) specify women and children, Rawlett (2011) adds cultural and racial minorities and argues for the utility of applying the VPCM to nursing practice among rural populations. Further, Grabovschi *et al.* (2013) ruminate on whether multimorbidity and being an immigrant exacerbate vulnerability, while Tangüis *et al.* (2000 in Tsodzo 2011) demonstrate a positive correlation between vulnerability and low adherence to treatment. Some assert that groups' vulnerabilities are not only due to one factor, but that there are a 'multiplicity of risk factors that are often clustered together and acting synergistically in the same individual' (Grabovschi *et al.* 2013:2). This idea is well illustrated in Chapter Four, where an account of the many issues known to affect female MDR-TB patients and their best intentions to fully adhere to treatment is provided. Research which applied the VPCM identifies family caregivers of mentally ill persons as vulnerable populations at increased risk of the ill-effects of diseases (Copeland 2007). This finding coheres with this study, which positions family members of young women with MDR-TB as equally important participants in this research.

Based on categorisations in the literature discussed above, young women receiving treatment for MDR-TB at public health facilities in eThekweni Metro are conceivably a vulnerable population and more susceptible to adverse outcomes of MDR-TB infection. This is notwithstanding arguments by Rawlett (2011) that racial minorities are often vulnerable populations. Although Black women in South Africa belong to the majority racial group, the historical and contemporary marginalisation of Black people in all areas, including access to quality healthcare established in Chapter Two (van Rensburg *et al.* 2005), means that vulnerable populations are more likely to be members of the majority racial group in this context.

The VPCM considers the individual a member of a defined population, contextualises people's experiences of ill-health with reference to their geographic locations and residence, and 'focuses on the *collective* [emphasis mine] health status of the individual and its community' (Flaskerud and Winslow 1998). Indeed, the VPCM describes responsibilities of communities to the broader population as ensuring that conditions necessary for healthy living and reduction of vulnerability to ill-health are present in their areas (Saunders 2007). In this argument, communities shoulder the responsibility of ensuring broader public health, by safeguarding the health of individuals within their ambits (Rawlett 2011).

The VPCM advances that disenfranchised sociocultural, political and economic status predisposes certain groups to ill-health and its negative impacts and positions them as needing special attention (Flaskerud and Winslow 1998). However, vulnerable groups do not always get the consideration they need, partly because of their locations relative to healthcare facilities, and financial difficulties that hamper their ability to use or pay for services (Rawlett 2011; de Chesney 2008; Cooper 2011). In this notion, scholars argue that relative risk (Leight 2003) of experiencing ill-health is greater in communities where proximity and access to healthcare services is a challenge and where financial and structural resources are scarcer (Flaskerud and Winslow 1998). Lack of resources is further linked to the poor treatment that vulnerable populations are often subjected to when accessing services, particularly in public healthcare facilities. Research indicates that where access to and quality of healthcare are compromised, peoples' risk-taking in relation to their health is likely to be higher (Flaskerud and Winslow 1998).

It is worth noting that Flaskerud and Winslow (1998) concede that application of the VPCM in research may be compromised by the large number of intervening variables that influence health outcomes, in this case gender, age, low socioeconomic status,

MDR-TB/HIV co-infection, unemployment, low educational attainment, overcrowded living conditions and others. Studies like this one, which aim to identify strategies with potential to culminate in the transfer of authority to at-risk populations to act to remedy their self-articulated impediments to good health, would do well to consider this (Copeland 2007; Koniak-Griffin *et al.* 2005). Towards this end, and as explained in the next chapter, this research employs data collection methods that position research participants as equal and fully informed stakeholders in the study, to uncover ways of eliminating health disparities experienced by vulnerable young women with MDR-TB (Koniak-Griffin *et al.* 2005).

The VPCM is useful for this research, which employs participatory methods to understand what is needed to eliminate health disparities experienced by a case study of women with MDR-TB aged 18 to 34 years-old. This case study is characteristic of groups that are particularly vulnerable to experiencing the ill-effects of MDR-TB infection and treatment, compared to those in the broader population. The study incorporates a community focus to maximise the theory's impact (Rawlett 2011), based on arguments that reducing health disparities demands application of a socioecological approach, one which considers the contexts in which patients receive healthcare services (Cooper 2011). To be effective and impactful, special interventions for vulnerable populations need to be implemented within environments and settings that care for them (Cooper 2011).

This research also probes the extent to which existent health education and counselling of patients in healthcare and community settings, and exposure to additional messaging in their homes and congregate settings, has potential to increase effectiveness of mass mediated health communication and positively impact treatment adherence among the case study of this research. The VPCM cannot account for the communication element, which is integral to this study. The Knowledge Gap Theory, first proposed by Tichenor, Donohue and Olien in 1970 and explained in the next section, is applied for this analysis.

### **Knowledge Gap Theory**

The pith of the Knowledge Gap Theory is that 'as the infusion of mass media information into a social system increases, segments of the population with higher socioeconomic status tend to acquire information at a faster rate than lower status segments, so that the gap in knowledge between these segments tends to increase rather than decrease' (Tichenor *et al.* 1970:159-160). Establishing a close fit between knowledge, education and socioeconomic status, proponents of the theory insist that



much like wealth, access to knowledge is unevenly distributed, with more educated audiences in higher socioeconomic contexts better positioned to attain information, to the detriment of those in marginalised areas (Tichenor *et al.* 1970; Gaziano 2016; Jäntti 2014; Weng 2000). This contributes to widening social inequalities (Ettema and Kline 1977) as those who are better informed can use information to secure advantages, relative to those without (Jäntti 2014). The theory is informed by findings by researchers Paul Lazarsfeld, Bernard Berelson and Hazel Gaudet (1944) of weak empirical evidence that mass media messages could directly influence voting intentions.

The Knowledge Gap Theory directly challenges Katz and Lazarsfeld's (1955) Hypodermic Needle Theory, which postulated that mass media in the 1940s and '50s could directly and immediately encourage behaviour change in large groups. Instead, Lazarsfeld, Berelson and Gaudet (1944) had earlier found that media audiences mentioned informal personal contacts far more frequently than exposure to radio or newspaper as sources of influence on voting behaviour. This finding informs this study's linking of the Knowledge Gap Theory to the Two Step Flow and Multi-Step Flow Theory as explained later in this chapter. It is important to note growth in scholarly interest in the Knowledge Gap Theory, as evidenced by four studies by Gaizano (1983), Viswanath and Finnegan (1996), Gaizano (1997) and Hwang and Jeong (2009) which apply it. A recent paper by Gaizano (2016) traces the historical application of the theory and substantiates its continued relevance in contemporary communication research.

The Knowledge Gap Theory advances five differences to account for widening gaps. These are: communication skills between people in higher and lower socioeconomic groups; existing knowledge from prior exposure, amount of social contact relevant to the topic being studied (in this case MDR-TB management and treatment), exposure to and retention of information, and the middle-class orientation of the print media, which are the primary source of the public affairs information that was the focus of studies which culminated in the proposal. The theory is helpful for couching explanations of whether and how young women from marginalised contexts access mass mediated information about MDR-TB. For this study, it is instrumental in guiding the formulation of the communication model presented in Chapter Ten through illuminating the extent of possible knowledge gaps among young women with MDR-TB as a vulnerable population. Knowledge Gap Theory further supports explanations of what motivates marginalised young women on treatment for MDR-TB to access

health information via television and radio and use it (if they do) to improve their adherence to medications.

The research that resulted in the Knowledge Gap Theory is challenged by subsequent studies. Some contend that explanations of the causal factors and contingent conditions for the various studies that apply the model are absent (Etemma and Kline 1977). Indeed, later work by the model's progenitors (Tichenor *et al.* 1973) found that while knowledge gaps were more evident with international media coverage, increased coverage of local news and communication via mass media was not associated with knowledge gaps, suggesting that culturally proximate mass media content is less likely to create knowledge gaps. Cultural Proximity Theory was first articulated by Joseph Straubhaar in 1991 and is helpful for understanding this finding. The philosophy emerged from a line of inquiry by de Sola Pool (1977) into whether media audiences prefer locally produced content. It posits that audiences prefer media content which reflects their own culture regionally and nationally and that they are more likely to consume and be invested in content that reflects their languages, cultures, histories and values (Straubhaar and LaRose 1996).

Studies in developing countries that apply the Knowledge Gap Theory demonstrate mixed results (Etemma and Kline 1977). Some recommend positioning application of the model by first understanding the social, economic, cultural, racial, age and gender-based considerations likely to impact certain groups' access to and reception of mass mediated MDR-TB communication (Gaziano 2016; Etemma and Kline 1977). The basis of this understanding for this study is established in Chapters Three and Four. It launches from an appreciation that vulnerable young women receiving treatment at King Dinuzulu Hospital may generally be poorly educated and unemployed single Black mothers from historically marginalised backgrounds characterised by poverty, strong cultural beliefs and practices and poor health service access. Associated costs would also probably hamper their abilities to access free biomedical MDR-TB treatment.

In a recent study, Gaziano (2016) maintains that results of studies that apply the Knowledge Gap Theory are not that different. She is clear that 'Hundreds of studies on numerous topics have been carried out worldwide. The majority tend to find knowledge gaps. The strongest interest has been in the areas of public affairs, elections, science, and health, including epidemics, natural disasters, and public health' (Gaziano 2016:7). Other studies, however, observe inconsistencies in the original findings that informed Tichenor, Donohue and Olien's formulation of the theory, sparking investigations by others to establish the value of mass media for dispersing

information. The resultant literature somewhat challenges the foundational assumptions of the model (Bekalu and Eggermont 2013) with insights that are applied to this study. Some scholars argue that mass mediated messages do not always create gaps between groups with higher and lower socioeconomic status within defined populations. Other investigations found that mass media had the effect of *closing* knowledge gaps (Douglas *et al.* 1970; Shingi and Mody 1976) and some researchers identified additional factors, apart from socioeconomic scales, which increase knowledge gaps between classes. These include personal motivation-predicated factors like concern, attention, salience and participation (Genova and Greenberg 1979; Ettema and Kline 1983; Viswanath and Finnegan 1996; Weenig and Midden 1997; Kwak 1999).

The above suggests that motivation and better education shrink knowledge gaps. Also, size and complexity of groups and perceived usefulness of information disseminated are better predictors of whether knowledge gaps will be discernible or not (Gaziano 2016; Viswanath *et al.* 1993). Other studies associate widening knowledge gaps with dissemination of complicated information that is beyond the comprehension of some audiences and not others (Ettema and Kline 1977), particularly via print media (Kwak 1999). Still others argue that notwithstanding the nuanced and obvious ways in which mass media creates or aids knowledge differentials, it remains relevant for its ability to expose people to views that are unlike their own than personal networks are and should therefore not be side-lined (Mutz and Martin 2001). These arguments inform this study's consideration of the more accessible broadcast mass media, specifically television and radio, as an important resource for public health promotion among underserved populations (Gaziano 2016). Mass media is also considered for its ability to introduce new topics and ideas to inattentive sections of a society (Jäntti 2014).

Application of the Knowledge Gap Model will aid this study's attempt to establish how knowledge differentials ostensibly created by mass mediated MDR-TB health promotion communication affect the health outcomes of a defined vulnerable population resident in a marginalised community. Discussions in line with this aim will assess young women's reported access to and reception of MDR-TB messages known to have been disseminated in South Africa from 2015 to 2018 as established in Chapter Four. An assumption of this study is that disparities in access to mass mediated content exist among residents of eThekweni Metro, not least because competition among the many national and community radio and television stations that broadcast there means that not everyone has an equal chance of receiving the same information.

Furthermore, because some TB information is disseminated via mediums like DSTV, Mindset Television and red-carpet screenings, some remains generally inaccessible to vulnerable groups. Since they are vulnerable populations characterised by low socioeconomic status and educational attainment, young women with MDR-TB in eThekweni Metro could be even more susceptible to experiencing knowledge gaps in relation to accessibility and understanding of information about the disease and its treatment. This is also as being female is associated with failures to benefit from information disseminated via mass media (Katzman 1974). Indeed, information gaps have been observed between men and women in marital relationships, who are believed to be information-rich and -poor respectively (Katzman 1974).

The Knowledge Gap Theory advances the narrative in this investigation, specifically the need to understand whether and how young women from lower socioeconomic contexts receive mass mediated content and information about MDR-TB and treatment. The study is less concerned with understanding occurrence of knowledge gaps across communities and socioeconomic classes to establish the differential effects of mass media as originally proposed by Tichenor and colleagues in 1970. It instead supports probing how much of the limited TB/MDR-TB health promotion content discussed in Chapter Four is accessible to the defined vulnerable population that is the focus of this study. Its application will also guide understanding of which media would be most effective in reaching the specified population, to inform the communication model proffered in Chapter Ten.

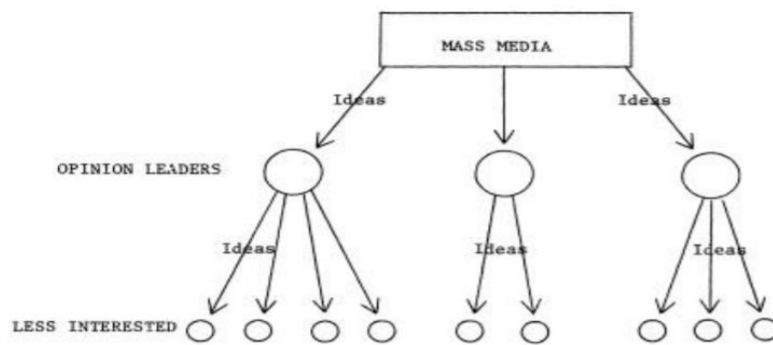
The Knowledge Gap Theory is not applied in isolation, however. Chapter Four noted that interpersonal communication, including counselling of patients in healthcare and community settings, is used to support MDR-TB treatment. Clearly, the VPCM and the Knowledge Gap Theory cannot account for the person-to-person health literacy and behaviour change communication aspects in MDR-TB management. Katz and Lazarsfeld's Two-Step Flow Theory, and its later interpretation as the Multi-Step Flow Theory, are added to the conceptual framework to aid explanations of the links among mass media, interpersonal influence and social and behaviour change in health communication research.

### **Two-Step (Multi-Step) Flow Theory**

The Two-Step Flow Theory derives from the debunked premise that mass media messages can directly influence voting intentions. Personal contacts are instead considered more persuasive than mass media in influencing audiences' election choices. Elihu Katz and Paul F. Lazarsfeld (1955) introduced the Two-Step Flow

Theory in their seminal paper entitled ‘Personal influence: The part played by people in the flow of mass communications’. The article discredits ideas about the automatic stimulus of potent mass mediated messages on captive audiences. It posits that informal personal contacts are more influential on voting decisions and behaviours than exposure to radio or newspaper (Katz and Lazarsfeld 1955; Katz 1957). This view sparked the theorisation of a two-step process in which media messages are filtered from media to opinion leaders, who cascade their own interpretations of the messages, as well as the original content they receive, down to audiences within their ‘primary groups’. This information flow process is illustrated in Figure 11 below.

Figure 11: Two-Step Flow Theory conceptual model



Source: Katz and Lazarsfeld (1955)

Three factors characterise the Two-Step Flow Theory: impact of personal influence, flow of personal influence, and relationship of opinion leaders to mass media (Hughes and Osman 2014). The theory postulates that the individual opinions, beliefs, attitudes and behaviours that media programmes and campaigns seek to alter are moderated through interactions in ‘primary groups’ – systems of interconnected interpersonal relationships among friends, co-workers, family and others with whom media audiences regularly interact (Katz and Lazarsfeld 1955:44). In this conceptualisation, ‘ideas often flow from radio and print to designated opinion leaders [within primary groups] and from these to the less active sections of the population’ (Katz 1957:61). With these insights, this study deems it important to establish who or which categories of people influence vulnerable young women’s media consumption and reception, so they can be deliberately targeted with MDR-TB treatment health promotion communication.

Two categories of influential participants within primary groups are considered integral to the Two-Step Flow Theory: gatekeepers and opinion leaders. Gatekeepers pass on messages or, alternatively, block information that goes against prevailing

opinions, attitudes, norms or behaviours of their groups, while opinion leaders mediate information before they pass it on (Hirowaka and Lowe 2002). The theoretical assumption is that many people acquire information and opinions from others and that the success of mass mediated messages in specific contexts depends on whether the ideas they advance are upheld by others in primary groups. Chief among the influencers are gatekeepers and opinion leaders (Katz and Lazarsfeld 1955). In this formulation, information does not pass freely to make an impact, but is filtered as it cascades down. Audiences ultimately decide whether to accept the meanings in mass mediated communication or not, but only after measuring them against views circulating within their groups (Hirowaka and Lowe 2002; Katz 1957).

It must not be assumed that primary groups and the members within are acquiescent. They too are a source of social pressure (Katz 1987) and gatekeepers are not passive relayers or blockers of information in their primary groups (Hirowaka and Lowe 2002). Indeed, authoritative and influential gatekeepers are vital to the success or failure of mass mediated communication through impacting the values, norms and behaviours of primary groups. This is because they can 'exert their own biasing effect on mediated messages by either reinforcing or counteracting the messages they relay to others in their primary groups' (Hirowaka and Lowe 2002:8). Some scholars find that if mass media advocates a behaviour counter to established group norms, gatekeepers most likely attempt to block them from permeating into their groups, while opinion leaders actively advocate against the behaviours proposed (Katz and Lazarsfeld 1955). It is thus evident from their roles that while gatekeepers can also be opinion leaders, and *vice versa*, they are often different (Hirowaka and Lowe 2002). By this reasoning understanding any external influences that may interfere with mass mediated messages from the time they are broadcast to when they are used to adjust behaviour or discarded by audiences is important. This understanding advances this study's aim of understanding how young women access, understand and retain MDR-TB information disseminated via mass media.

Identifying potential gatekeepers and opinion leaders within vulnerable young women's spheres of influence in low socioeconomic communities in eThekweni Metro is key to the above understanding. This is particularly because it allows for segmenting and targeting messages in the design of MDR-TB treatment literacy and health promotion messages, and in the development of communication models like the one proffered in Chapter Ten. There can be no doubt that disseminating MDR-TB information with wide appeal and which is generally acceptable to gatekeepers and

opinion leaders in a community can increase chances that patients taking treatment at home can do so in contexts where the people around them, particularly members of their primary groups, have the same knowledge about the importance of treatment adherence as they do.

Opinion leaders, as they are conceived of in the Two-Step Flow Theory, exercise greater influence horizontally in small communities (Katz and Lazarsfeld 1955; Hirowaka and Lowe 2002). They interpret and contextualize mass mediated messages for members of their groups to internalise and act on where necessary (Bennet and Manheim 2006). Opinion leaders in specific groups are selected based on age, sex and social status, as well as consideration of the sociocultural values of specific groups (Hughes and Osman 2014). Every socioeconomic class and occupation has its own equal distribution of opinion leaders (Katz 1957). To wield influence, opinion leaders need to be close to those they seek to influence; usually as friends, peers, relatives and co-workers, and to share similar characteristics, values and beliefs with group members (Katz 1957). Crucially, designated opinion leaders need to be substantially more exposed to mass media than those they seek to influence if they are to exercise power (Katz 1957).

The power commanded by opinion leaders is well established. The Hawthorne Studies into human behaviour in organisations demonstrated the influence of close interpersonal relationships on people's attitudes, values and behaviours as early as the 1920s (Hirowaka and Lowe 2002). Importantly, however, the Decatur Study (1945-1946), established that opinion leaders are influential at certain points and circumstances, and only because they are empowered to exercise this influence by members of their groups (Katz 1957). It is argued that because of opinion leaders and how they mediate meanings, media content is understood differently across social classes (Bennet and Manheim 2006). Attempts made to link influence of opinion leaders directly to the actions, or changes in actions, of those in their primary groups have been futile. This makes it hard to definitively conclude that they are as powerful in mediating mass mediated messages as suggested by the Two-Step Flow Theory (Katz 1957), although this study accepts that they can be persuasive if those they seek to influence acquiesce. The Rovere Study (1949) proposes that researchers should ask respondents who influences them (Katz 1957). If an individual in an identified primary group is mentioned four or more times, it can be confidently assumed that they are influential and can be considered an opinion leader in their group (Katz 1957). This convention is applied to findings presented in Chapter Nine.

Additionally, the Decatur Study sought to understand the flow of influence in everyday decision-making using a sample of 800 women (Katz 1957). It probed whether influence typically flows from the upper classes downward, and whether opinion leaders and those they ostensibly influence are likely to share characteristics such as sex, age and class (Katz 1957). The research found that without the consent of the influenced, opinion leaders cannot wield the necessary power in their designated social circles, supporting arguments for the agency and social power of primary groups (Katz 1957). It must be noted, however, that this study did not examine how influence occurs in mixed-sex and -age groups, as those naturally occurring in societies, although it concluded that age, sex and social status do inspire who is mandated, and accepted, as an opinion leader in a specific community (Katz 1957). Finally, the study established that opinion leaders are themselves influenced by other people, and that their views are not universally influential; they are persuasive only in specific circumstances and contexts and those they seek to influence can reject their influence (Katz 1957).

While it is true that there are numerous media stations and programmes in eThekweni, and that radio and television penetration is good, resource constraints and the scarcity of mass mediated TB/MDR-TB information may mean that individuals are not always able to access all available stations and information when needed. This leaves many reliant on filtered meanings from mass mediated MDR-TB communication from others. For women with MDR-TB especially, poverty, ill-health and incapacitation, and demands on their time to work in both the private and public spheres may make them reliant on recommendations for programmes to watch, or on hearing information second-hand from others.

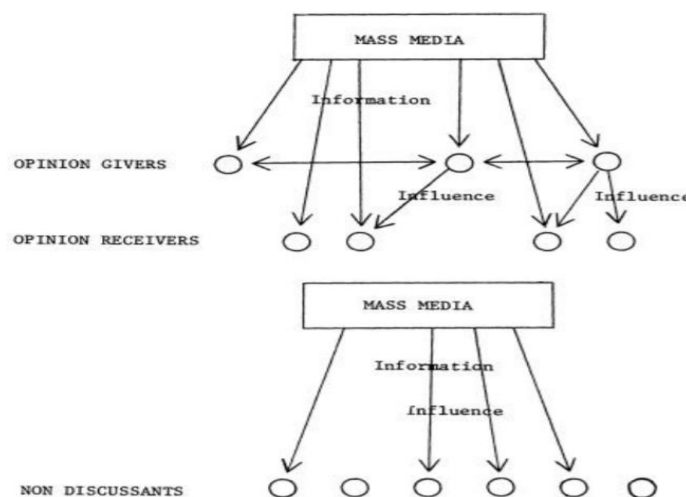
There are many and varied critiques levelled at the Two-Step Flow Theory, and a few re-imaginings of it that have been proposed. Responding to appraisals of limitations of the theory, Katz concede that over the years, the hypothesis has been 'amended in a dozen ways to prefer influence over information, talk between equals over opinion leaders, multiple steps over two steps, etc.' (Katz 1987:26). Weimann (1982) suggests that the Two-Step Flow Theory has four weaknesses. Firstly, the model is accused of ignoring research that establishes direct flows of information based on evidence that mass media can directly convey new messages to audiences (Westley 1971). Interestingly, this position was resurrected several decades later to explain the direct influence of Internet content on audiences (Bennet and Manheim 2006). Secondly, the hypothesis fails to consider the existence of different stages in the message diffusion process (i.e. awareness, interest, evaluation, trial and adoption) where certain sources



are more likely to be used than other (Rogers 1962). Thirdly, Troidahl and van Dam (1965) insist that the model ignores evidence of horizontal flows, in which opinion leaders share information and opinions amongst themselves, and how these intersections of influence impact messages and perspectives disseminated onwards to primary groups. Finally, studies that examine the model criticise it for perceived methodological weaknesses, including failing to differentiate between information provision and flow of influence (Weimann 1994), as well as its use of the same measurements to collect information about topics that are as varied as trends and political issues.

Backed by the arguments above, some researchers insist on the utility of a multi-step process of information flow, in which information goes through several interpretations and layers before it eventually reaches intended audiences (Burt 1999; Harik 1971; Robinson 1976; Weimann 1982; Southwell and Yzer 2007). Influence in the proffered Multi-Step Flow Theory is not necessarily only from top to bottom; it can be multi-directional and is as effective when it is peer-to-peer, for instance among MDR-TB patients. In this conceptualisation, there is communication between opinion leaders who give information and information receivers who ask for it. These groups then mediate information at their levels and channel it down to non-discussants, who are normally inactive individuals of a primary group. Because of the interactions, and their prestige in their groups, opinion leaders in the Multi-Step Flow Theory presumably have greater opportunities to directly influence audiences than mass media.

Figure 12: Multi-Step Flow Theory conceptual model



Source: Robinson (1976)

More recently, however, others have argued that only one step is necessary for information flow and influence in the digital age. Critiquing the relevance of the Two-Step Flow Theory in the age of new media, Bennet and Manheim (2006) propose a One-Step Flow Model as an alternative thesis. They argue that the popularity of social media and new media and communication technologies changed how audiences access and use mass media, to the extent that underlying assumptions of the Two-Step Flow Theory can be confidently challenged (Bennet and Manheim 2006). It is argued that individuals no longer need to look to others in their circles to mediate their media consumption and use. This is because contemporary media messages are more effective and better targeted; and modes of dissemination more varied, easier, cheaper and faster to use; and because characteristics of media audiences and how they live (often in isolation from broader communities) have changed so much (Bennet and Manheim 2006). The influence of mass media on individuals is thus conceived of as being direct, as access has become more straightforward.

While Bennet and Manheim's appraisal of the Two-Step Flow Theory is valid in extant times, in resource-poor African metropolitan communities it may not be as applicable. For one, the hierarchical and patriarchal arrangement of families and communities such as those in eThekweni Metro often mean that even outside of discussions about mass media, communities are organised around centres of influence; people whose roles extend to swaying common beliefs, attitudes and practices within their communities. Indeed, Bennet and Manheim (2006:216) explain that in some contexts, there remain 'residual pockets of two-step communication scattered throughout contemporary society. Some of these pockets are sustained by highly localized social networks and by the identification of individuals with them'. Many families in South Africa still practice communal living, even among extended families. This strongly implies that many individuals belong to, live, work, socialise and congregate in primary groups where opinion leaders exist, even if their influence may be diluted in some circumstances.

Notwithstanding critiques of the Two Step-Flow Theory discussed above and its decline in popularity during the past few decades, the original philosophy remains a commonly accepted account of media effects (Gleave and Smith 2009) and is utilised as such in this study.

The Two-Step Flow, Multi-Step Flow and One-Step Flow theories are applied to this study with the aim of understanding the 'power, credibility and attractiveness' of relayers of culturally relevant and acceptable mass mediated health communication in

low socioeconomic contexts. It is hoped that doing this can bridge any knowledge gaps, by encouraging people close to MDR-TB patients to make meanings from health promotion communication in an analytical process that results in cyclical, rather than one-way or two-way communication (Cross *et al.* 2017). The theories are applied to identify who young women in eThekweni Metro consider influential and acceptable in terms of mediating and transmitting health communication about MDR-TB. They are further applied to probe who, or which groups of people in their circles, should ideally be targeted with information about MDR-TB prevention and treatment that they can share with patients themselves, and others. This is particularly important for reaching other vulnerable individuals and populations – through shared structural, sociocultural and economic contexts within the MDR-TB patient’s networks – who might be at risk of becoming infected or failing to complete their treatment. Application of this and the two other principal theories helps unpack how patients’ behaviours can be impacted – which necessitates discussing social and behaviour change theories that may provide some insights.

Researchers insist that even though communication is critical to improving access to information and capacities to apply knowledge, health communication research should be underpinned by understanding of theory-based behavioural considerations that drive and restrain individuals in their implementation of positive changes for improved health outcomes if it is to be effective (Munro 2007a; Nutbeam 2006). Insights from communication and behaviour change theories discussed below inform the analysis of data for this study and the findings presented in Chapters Eight and Nine. They also ensure that associations made in the data discussed in Chapter Seven to understand the ‘patient perspective’ of adherence to TB treatment are informed by theory. This is the first step to suggesting context-specific health communication approaches with potential to impact attitudes and intentions towards treatment for enhanced adherence rates (Matebesi and Timmerman 2012).

### **Social and health behaviour change theories**

This study avers that health communication and health promotion are necessary for improving MDR-TB patients’ and others’ low knowledge about treatment and basic infection prevention measures (Mishra *et al.* 2014). Considering the history of TB, the rise of MDR-TB and the multifaceted reasons for low adherence to treatment discussed in Chapter Four, however, this study acknowledges that communication alone is unlikely to improve adherence to treatment (Munro *et al.* 2007a; Matebesi and Timmerman no date). This study incorporates insights from social and behaviour

change theories for their utility in mediating study participants' responses about the potential of mass mediated and interpersonal communication to impact their health intentions and practices (Corcoran 2007). It must be noted at the outset that although there is little empirical evidence of the effectiveness of social and behaviour change theories in promoting adherence (Munro *et al.* 2007a), several models exist with potential to both improve understanding of adherence behaviour and contribute to the design of more effective interventions. It is hoped that applying appropriate insights from social and behaviour change theories, together with the VPCM, Knowledge Gap Theory and Two-Step Flow and Multi-Step Flow Theory to this study will enrich findings proposed in Chapter Eight and Nine, and the communication strategy proffered in Chapter Ten.

Few studies have applied health behaviour theories and theories of change to inform the promotion of long-term adherence to treatment for communicable diseases (Michau *et al.* 2014; Munro *et al.* 2007a). Munro *et al.* (2007a) rues that theory-based approaches are largely absent in TB behaviour change research and Tsodzo (2011:40) asserts that 'no communications theories have been 'pin-pointed and linked expressly to treatment adherence studies'.

Literature indicates that there are more than 30 health behaviour change theories, all of which, except for the Biomedical Theory, assume that people are motivated to avoid and treat threats to their health, and that they are self-regulating problem solvers (Munro *et al.* 2007a). With the backdrop of the multitude of available theories and their perceived usefulness, scholars urge for researchers to have academic curiosity about which of them have the greatest potential to improve long-term adherence (Munro *et al.* 2007a). Leventhal and Cameron (1987) suggest five perspectives – each encompassing several health behaviour theories – that are useful in addressing non-adherence to treatment. These are: (i) biomedical, (ii) behavioural (learning), (iii) communication, (iv) cognitive and (v) self-regulating. In this study, the communication perspective is foregrounded as 'the cornerstone of every patient-practitioner relationship' (Munro *et al.* 2007a:57). Discussions below considers insights brought to this study by the biomedical, behavioural and cognitive perspectives.

### **Biomedical**

Biomedical Theory was advanced during the mid-19<sup>th</sup> century and is derived from Louis Pasteur's Germ Theory of disease (Johnson 2012). It is still in dominant use in Western medical practice in contemporary times (Johnson 2012; Kagee 2004). Biomedical Theory was the first cogent philosophy of disease; considering that it was

preceded by demonic theory, which put forward that disease was caused by demons, and punitive theory, which contends that antagonising the gods makes them angry, and leads them to punish perpetrators with ill-health, respectively (Feezer 1921). Curing disease was only achievable through incantation and sorcery to encourage demons to exit their hosts according to beliefs in the former model, and by placating the deity and repenting of sin in the latter thinking (Feezer 1921).

Biomedical Theory is the chief model used by physicians and clinical personnel to guide patient management. It is widely credited with ending the reign of diseases, among them TB and diarrhoea, that were leading causes of death in the early 20<sup>th</sup> century (Johnson 2012). The theory advances that the causes and, naturally, solutions to health problems can only be biomedical in nature (Johnson 2012; Munro *et al.* 2007a; Wade and Halligan 2004). Consequently, treatment is exclusively concerned with the patient's body, to the marginalisation of any other factors (Kagee 2004; Leventhal and Cameron 1987), including considerations of how patients' socioeconomic status impacts their health. In this automatous approach to dealing with disease, patient failures to follow instructions or comply with treatment regimens are exclusively attributed to patient characteristics, among them age and gender (Munro *et al.* 2007a).

The management and treatment of MDR-TB in South Africa is predominantly biomedical, as discussed in Chapter Two. On this basis, the necessity of including healthcare workers and KwaZulu-Natal Department of Health personnel in the study sample outlined in Chapter Six was undisputable. Insights from biomedical theory are discussed here for insights they lend to the interpretation of findings from healthcare providers and policy makers and implementers presented in Chapters Eight and Nine. Tenets of punitive theory are invaluable to understanding young women's experiences of being treated for MDR-TB in eThekweni Metro and some motivations for sub-optimal adherence. Understanding Biomedical Theory and its predecessors here is critical for framing explanations of how individual and group beliefs about the genesis of illnesses might influence whether and where MDR-TB patients seek help; at a hospital, traditional healer or church for instance, and the ways in which they receive and use information about treatment that foregrounds the importance of adhering to biomedical treatments for the ailment until cured.

Biomedical Theory disregards supplementary patient physiognomies, among them socioeconomic or environmental considerations that may contribute to patients being unable to take medication for the required time (Leventhal and Cameron 1987). This is at odds with discussions in Chapter Four, which clarify the varied reasons that may

account for vulnerable young women's sub-optimal adherence to treatment in eThekweni Metro. Kagee (2004) cautions that failing to engage patients as equal partners in their care may lead individuals to feel like they are being managed in an authoritarian way that does not fully include them. Further, failures by clinicians to consider factors external to patients that may contribute to their defaulting on treatment may be viewed by patients as medical personnel placing the blame for treatment failure squarely on their shoulders (Kagee 2004).

In Biomedical Theory, ownership of the medical problem, its solutions, and any changes in behaviour necessary on the part of the patient are often not viewed as being the joint responsibility of physicians (to explain and motivate) and patients (to internalise and practice) towards improving adherence to medication and the health of patients (Kagee 2004). Patients are assumed to be inert recipients of doctors' orders who must act on instructions without question to ease symptoms and effects of disease (Leventhal and Cameron 1987). As the role of conduct – of both patients and healthcare providers – in disease prevention and management gains prominence globally, the dominance of the biomedical perspective has waned (Johnson 2012).

Scholars contend that the biomedical model 'is reductionist, seeking to explain all disease in biologic terms' (Johnson 2012:5). Critiques of the model, which is seldom used explicitly or on its own in contemporary times (Leventhal and Cameron 1987), focus on its narrowness, and that it does not factor in the agency of patients (Johnson 2012; Munro *et al.* 2007a; Kagee 2004). Scholars insist that people, even those receiving medical care, are generally engaged decision-makers who do not timidly receive and follow all health instructions given to them without interrogating it to some extent and reaching their own conclusions about how to proceed (Munro *et al.* 2007a:56). The necessity of progressing towards more patient-centred care provided by multidisciplinary teams with good communication skills is also highlighted when discussing shortcomings of this model (Johnson 2012).

A practical consideration relevant to this study is that physicians' failures to consider the whole patient when consulting with individuals who are not completely adherent to TB medications present missed opportunities to improve adherence rates, because there are demonstrated strong associations between good doctor/patient relationships and improved adherence to treatment (Kagee 2004). This section argues that the training of clinicians impacts how they relate with patients, the emphasis they put on identifying symptoms and how to treat them, and probably results in low levels of communication with patients (Wade and Halligan 2004) because they do not

appreciate the need to. It proposes that the perceived general failure of healthcare staff to consider and incorporate information about socioeconomic, environmental, cultural, gender and age-related factors, among others, to improve individual patients' MDR-TB treatment regimens and adherence is due to their allegiance to Biomedical Theory (Wade and Halligan 2004). This understanding and accounting for the positioning of health workers is important for the development of the communication strategy advanced in Chapter Ten.

### ***Behavioural (learning)***

Despite constant reminders via public health campaigns and healthcare providers of the prominent role of behaviour in attaining and maintaining good health (Koenker 2014), studies indicate that the majority of people report difficulties in consistently performing actions conducive to safeguarding and improving their health status, even as they report commendable intentions to practice protective behaviours (de Ridder and de Wit 2006). Indeed, changing a harmful habit is reportedly more challenging than persevering in practicing a good one (de Ridder and de Wit 2006). In the behavioural (or learning) perspective (Leventhal and Cameron 1987), the individual is considered in relation to his or her environment, and their behaviour is believed to derive from their use of internal thoughts or environmental cues to direct how they act (Munro *et al.* 2007a). The behavioural perspective supports the development of a contextualised communication strategy, one that keeps the lived realities of vulnerable young women in eThekweni Metro and how these may affect adherence to treatment at the fore.

In this conceptualisation understanding the environment of the studied and using enhanced health education and health communication to teach patients the necessary skills to help them better manage their medications and adhere to treatment leads to improved health behaviour (Leventhal and Cameron 1987). In their examination of the effect of a combined strategy of patient-centred interviews and an education booklet on TB patients' adherence to prescribed treatment, Dick and Lombard (1997) found that non-adherence significantly reduced among patients who received the intervention when compared to patients assigned to a control group. Other contextualised adherence-promoting strategies informed by this perspective, including patient reminders via short message service (SMS) and electronic pill boxes for instance, contribute to improving adherence (Tsodzo 2011; Munro *et al.* 2007a:56). Dick and Lombard (1997), suggest further research to inform development of standardised health education strategies to support adherence to treatment among

patients who require protracted treatment regimens, such as those incorporated into the communication strategy presented in Chapter Ten.

### **Cognitive**

Theories such as the Health Belief Model (Hochbaum 1958), Theory of Reasoned Action (Fishbein and Ajzen 1975), Theory of Planned Behaviour (proposed by Ajzen (1985) as a refinement of the Theory of Reasoned Action), Social Cognitive Theory (derived from Albert Bandura's Social Learning Theory (1977)) and the Protection Motivation Theory (Rogers 1975) are positioned under the cognitive perspective. By framing intellectual variables as comprising behaviour change, the cognitive perspective proposes that in the face of alternatives, patients will choose actions they are confident will result in positive outcomes (Munro *et al.* 2007a). Insights provided by the Theory of Reasoned Action to the examination of findings of this study are applied to explanations of how health communication can be designed and targeted to impact attitudes and intentions to adhere to MDR-TB treatment. The theory is useful for studies that seek to understand individual health behaviours through investigating individual motivations for performing certain actions, or not. By doing this, it may be possible to develop a health communication strategy to impact these attitudes and intentions. This is important as there is evidence that motivation is the single best predictors of health behaviours (Munro *et al.* 2017).

Some contested weaknesses of this perspective include failures to account for non-voluntary factors, for instance those which diminish vulnerable populations' decision-making agency and abilities to act. Critics also argue that the Theory of Reasoned Action does not factor in considerations of whether individuals have necessary behavioural skills to, for instance, ensure that patients with intentions to adhere to treatment do so (Sniehotta *et al.* 2014; Ogden 2003; Kippax 1993). The theory is also accused of ignoring other influences on adherence behaviour, including power relationships, social reputations and possibilities that risky behaviour may involve and be influenced by other people (Munro *et al.* 2007a). Although it is outside the scope of this study to establish whether behaviour change can directly result from enhanced health communication, tenets of the Theory of Reasoned Action are important for accounting for vulnerable young women's attitudes to and MDR-TB treatment intentions. It is also helpful for informing how health communication can be enhanced for a population for whom external influences might be more significant than others, especially considering vulnerable young women's lowered agency in the cultural context of low-income communities in eThekweni Metro.



Studying the 'intention-behaviour gap' and keeping it in mind during data analysis helped to better situate understanding of what makes people who know the benefits of and are fully committed to adopting and practicing a good behaviour not do so. Linking the communication and cognitive perspectives urges for research such as this one to consider patients' contexts and lived realities, especially in examining and explaining why well-intentioned patients may fail to fully adhere to their treatment regimens. The cultural context and socioeconomic circumstances of the researched emerged as significant in this study.

## **Summary**

The conceptual framework outlined both my personal conceptualisation of the research problem, initially from a professional practitioner perspective, and the steps taken to refine and contextualise it theoretically until it was a topic worth studying academically. This was done to support academic analysis of the potential effectiveness of applying communication strategies, informed by select community nursing, communication, mass media and social and behaviour change theories, to increase chances that young women from poor communities will likely take all doses of their MDR-TB medication until they are cured. The framework was proffered to also partly validate relevance of the research design and approach and its suitability for this study.

Discussions in this chapter pave way for discussions of the methodological approach adopted to collect data through fieldwork, particularly as they introduced the design of this research in Figure 9. They also lend credence to the academic contributions of findings of this study which are presented in Chapters Eight and Nine to existing knowledge in the field. Indeed, development of the communication model proffered in Chapter Ten, which aims to respond to a practical challenge identified from professional curiosity, is theoretically underpinned by literature and analysis in this chapter.

# **CHAPTER SIX**

## **METHODOLOGICAL FRAMEWORK**

### **Introduction**

This chapter outlines the methodological approach employed for this research, which sought to understand the social conditions of a case study comprising vulnerable young women as they influence the group's treatment for MDR-TB via a public health facility in a metropolitan area. The study concerns itself with understanding participants' interpretations of a phenomenon at a particular time and within a specific context (Snape and Spencer 2003; Merriam 2002). It was approached with the aim of achieving rich and nuanced descriptions of the subjective and context-determined motivations advanced by research participants (Snape and Spencer 2003) to explain vulnerable young women's sub-optimal adherence to MDR-TB treatment, and the situated and complex factors occurring over time that impact their abilities to take medication as prescribed until completion.

Qualitative research methodology approaches were applied in conceptualising the research design and implementing the data collection and analysis processes employed. Decisions about methodology were influenced by the objective of the research to comprehensively explain how communication can support improvements in adherence to MDR-TB treatment among a specified vulnerable population. A flexible and iterative research style was adopted, and a multi-pronged recruitment strategy and various data collection methods employed. This study included purposively selected participants and applied a naturalistic, inductive, interpretive approach to collect data (Snape and Spencer 2003). Discussions of the data analysis process in Chapter Seven and the presentation and analysis of findings in Chapters Eight and Nine are rooted in my collection, analysis and interpretation of personal accounts of human participants obtained via focus group discussions and key informant interviews, as well as some observation and reference to the reflexive journal kept during data gathering (Snape and Spencer 2003; Merriam 2002).

This study's methodological and data analysis procedures are presented in separate chapters, to allow for ample attention to laying firm enough foundations to shore up the research findings presented later in this thesis. While this chapter presents the methodological approach, Chapter Seven presents comprehensive discussions of the application of Braun and Clarke's (2006) six-step approach to thematically analyse data for this study. Discussions in both chapters are equally essential for linking the

research questions and objectives to findings of this study which are presented in later chapters. They provide directions that make clear how this research was conducted and how it arrived at the conclusions advanced in Chapters Eight and Nine. To achieve this, unabridged explanations are offered.

### **Research paradigm – qualitative research methodology**

Strategies, methods and approaches applied in this study are informed by an ontological position that qualitative research aims to produce culturally and historically specific knowledge (Jankowski and Wester 1991; Jensen 1991) that can only be understood through appreciating the socially constructed meanings that study participants make of it (Starman 2013; Snape and Spencer 2003). Qualitative research's emphasis on examining participants and their contexts of communication as socially specific objects of analysis (Jankowski 1991; Jensen 1991; Green 1991) influenced the decision to utilise this methodology for this study. The relationships among the research epistemology, theoretical perspectives, methodology and research methods adopted for this study is highlighted in Figure 13.

Qualitative researchers apply theories as research progresses and are not particular about using philosophies to guide the design of research. This is unlike quantitative research studies, which deductively advance hypotheses that must be proved through further research and testing (Merriam 2009). Qualitative research is useful for studies which aim to discover novel or unanticipated findings (Jensen 1991; Freedman *et al.* 1974). Research in this tradition results in reports in the following forms: '(i) descriptions which make little or no reference to theoretical perspectives; (ii) analytical discussions based on concepts emerging from the study; and (iii) substantive accounts intended to contribute to general theory' (Jankowski and Wester 1991:69). This research is written in line with the tenets of the third category, insofar as it adopts a communication model-building approach.

Describing the epistemological positioning of research is important for, among others, supplementing researchers' perceptions when defining the focus and aims of studies, when collating and designing the research approach, and in articulating characteristics of participants, or groups of participants sought to contribute to specific research (van Nierkerk 2005). Van Nierkerk's (2005) argument that all models of clinical intervention are couched in epistemology, and that none exists in a vacuum influenced this study's involvement of human participants to unlock knowledge about a case study of vulnerable women resident in low socioeconomic urban communities. Hoffman

(1981) explains that epistemology reflects rules that people use to make sense of their world. Aurswald (1985:1) expands this by explaining that ‘epistemology is a set of imminent rules used in thought by large groups of people to define reality and is the study or theory of the nature and grounds of knowledge’. This study’s epistemological position derives from Munro *et al.*’s (2007b) claim that there exist ‘lay theories’ about TB treatment adherence within those taking treatment, and that only by engaging patients in their environments and in line with an appropriate conceptual framework, can we unlock and uncover these theories and build them into practicable models.

Figure 13: Relationship between epistemology, theoretical perspectives, methodology and research methods

Epistemology	Theoretical perspectives	Methodology	Methods
Social constructionism	Interpretivism	Quasi-ethnography	Observation Interview Focus group Case study

Source: Adapted from Gray 2004; Crotty 1998

Research that aims to close observed gaps in available theory is termed ‘inductive’ and derived from an approach introduced by Isaac Newton and Francis Bacon in the 17<sup>th</sup> century (Snape and Spencer 2003). They suggested that it was possible to secure knowledge about the world through direct observation, as opposed to through testing abstract theories (Snape and Spencer 2003). Inductive research such as this one denotes scholars designing and developing research studies and undertaking data collection with the primary objective of amassing information that results in the development of ideas, premises or theories ‘from observations and intuitive understanding gleaned from being in the field’ (Merriam 2002:5).

Assertions that qualitative researchers often implement academic inquiry to probe specific fields or issues because of observed lack of relevant theory to explain a phenomenon or develop responses to it partly influenced the decision to undertake this study as a qualitative investigation (Merriam 2002). The idea also informed this study’s aspiration to contribute an inductively derived health communication model

to hopefully improve adherence to long-term treatment among vulnerable populations in South Africa (Merriam 2002). There are arguments that 'Because theories are uncovered through the researcher listening and becoming immersed in the research experience and findings ... theory developed in this way provides more sophisticated explanations than those derived from other studies' (Chong and Yeo 2015:258). This view impacted the study's design and implementation, including choice of research participants and their recruitment, type of data collected and location of data collection, as well as the analysis of data and presentation of findings.

### **Epistemology of research: Social constructionism**

Social constructionism was selected because studies within its tenets adopt a social, rather than individual focus (Young and Colin 2004, in Andrews 2012). Researchers argue that information and understanding is ultimately derived from a 'knowledge community' of people who agree on a truth, and dispute narratives that foreground the validity of individual accounts of reality (van Nierkerk 2005). Indeed, proponents of this epistemology postulate that single explanations of reality do not carry equal weight, and that some instead result in complications (Dickerson and Zimmerman 1996, in van Nierkerk 2005). Social constructionism was deemed compatible with the approach to this research due in part to its ability to compel me to contemplate and remain aware of my social class, socioeconomic status, nationality/culture, gender and age, among other factors, as they influenced my perspective during research (van Nierkerk 2005).

As the name suggests, social constructionists consider knowledge as created or constructed, rather than discovered (Andrews 2012), and are concerned with understanding phenomenon from the perspective of the researched (van Nierkerk 2005). They foreground contributions of social and cultural contexts to how individuals perceive, make sense of, and articulate the world (van Nierkerk 2005). In this school of thought, society is viewed as existing as both a subjective and an objective reality. Proponents strive to understand experiences and lived realities of individuals and groups studied from their own standpoints (Andrews 2012) but with the understanding that there are no independent facts that can be known, because facts, together with ideas and assumptions, are social constructs, or inventions of socially promoted discourse (van Nierkerk 2005). Because meaning is believed to be shared between individuals and social groups in specific contexts, it assumes a taken-for-granted reality (Andrews 2012), which allows for research findings to be generalised to groups situated in defined social and cultural contexts. It was

considered necessary to contemplate the potential of these issues to affect interactions with marginalised women of predominantly Zulu ethnicity who contributed to this study.

The epistemological positioning impacted how data was collected and analysed, as well as the approach adopted for data presentation and discussion. Analysis of findings presented in this thesis is guided by appreciation that social constructionism is principally concerned with how research participants define or elucidate their experiences, rather than dwelling on whether their accounts precisely replicate 'reality' (van Nierkerk 2005). Social constructionists' acknowledgement of the equal participation of research participants and researchers as 'co-creators of shared reality' during research (van Nierkerk 2005) is important to mention, as it influenced how data collection was handled, what was deemed important to include during engagement with the raw datasets, and decisions taken in analysing data as outlined in Chapter Seven.

### **Research design: Single descriptive case study**

One of the main aims of this research – to understand the various and context-specific reasons why vulnerable young women receiving treatment for MDR-TB may find it difficult to take all treatment until completion – could have been satisfied by employing one of eight types of qualitative research approaches. These include (i) grounded theory, (ii) phenomenology, (iii) narrative analysis, (iv) ethnography, (v) case study or (vi) basic interpretive study, (vii) critical, and (viii) postmodern/post-structural (Merriam 2009). Denzin and Lincoln (2000) also identify eight qualitative research strategies: (i) case study, (ii) ethnography, (iii) phenomenology, (iv) grounded theory, (v) biographical, (vi) historical, (vii) participatory, and (viii) clinical.

From these approaches, this study employed a single interpretive quasi-ethnographic case study situated in the social constructionism paradigm (Murtagh 2007; Merriam 2002; Yin 1984) as the research design (Starman 2013; Verschuren 2011 in Simmons 2009). Social constructionism advances this study's aim to articulate participants' concerns and experiences in-context and, through my interpretation of data gathered for this study to say, 'what it's like' (Larkin *et al.* 2006:104) for young poor Black isiZulu-speaking women to take treatment for MDR-TB in marginalised modern urban communities where, some might say paradoxically, cultural beliefs and traditions remain central to health-seeking behaviour as discussed in Chapter Eight. Data gathering was approached carefully to privilege what participants wanted to share about the phenomenon under investigation and to obtain detailed accounts. This

influenced the data collection tools used and the data collection approach, which is explained in detail later in this chapter.

In the initial stages of data collection, core theoretical concepts were identified, and weak connections made between central concepts and data (Simmons 2014). The first stage of research was open, and followed by verification, summarising and analysis of findings in an iterative process (Simmons 2014). Analysis and data collection informed each other in a cyclic fashion, with early analysis pointing to specific strands of inquiry to follow and highlighting what to look for next in the data collection process (Research Methods Knowledge Base no date), was integral to the research process of this study, into an area where little was known about how health promotion can contribute to improving treatment adherence and outcomes in the KwaZulu-Natal MDR-TB programme.

This study does not consider case study a type of qualitative research as advocated by authors such as Simmons (2009); it instead defines case study as a 'general term for the exploration of an individual, group or phenomenon (Sturman 1997:61, in Starman 2013:31). I am more sympathetic to Merriam's (2009:2) definition of qualitative case study research as 'an intensive, holistic description and analysis of a bounded phenomenon such as a programme, an institution, a person, a process or a social unit'. A small group of culture-sharing young women aged 18 to 34 years resident in marginalised socioeconomic contexts and receiving treatment for primary MDR-TB at King Dinuzulu Hospital, eThekweni Metro, was this study's distinctive case of investigation. In framing this investigation as such, I considered the delineated sample and research objectives which together converge with Goetz and LeCompte's (1984:2) position that a case study is ethnographic if it presents a sociocultural interpretation of data that unpacks the 'shared beliefs, practices, artefacts, folk knowledge and behaviour of some group of people' in relation to a phenomenon under investigation. The approach employed is defined as quasi-ethnography due to the relatively short time span of data collection, when compared to true ethnographic investigations, and the element that while I made frequent visits to eThekweni Metro for data collection, I did not aim to fully immerse myself in communities where MDR-TB patients live for extended periods (Murtagh 2007).

The single descriptive quasi-ethnographic case study approach adopted complements the qualitative research methodology utilised. The approach was invaluable for supporting probing of the developmental and practice-oriented factors surrounding MDR-TB communication and health literacy initiatives in eThekweni Metro, and long-

term treatment adherence challenges among a heterogenous group of people, especially as it focused on a unique case and subject in-context (Starman 2013; Simmons 2009; Yin 1984). It also informed the research design and its implementation, to support appreciation of the 'particularity, the uniqueness of a single case' (Simmons 2009:3); in this instance vulnerable young women with primary MDR-TB in the continuation phase of treatment as outpatients.

### **Selecting participants and determining the study sample size**

Qualitative research aims to learn about phenomena of interest that usually include people as research participants by understanding everyday life and topics of investigation from the perspectives of the researched (Palton 1991; Bryman 1988:61). The research methodology was employed towards achieving comprehensive understanding of subjective motivations driving MDR-TB female patients', household contacts', healthcare workers' and KwaZulu-Natal Provincial Department of Health personnel's perspectives and conduct in-context. It was applied to support understanding complex human behaviour occurring over time, to emerge with detailed explanations about the phenomenon of low treatment adherence among MDR-TB patients and the role of communication in enhancing adherence rates.

It was important for the research to understand, from the perspective of the researched, how health literacy approaches and content could contribute to improvements in MDR-TB treatment completion and cure rates in the metro. The study thus primarily sought contributions from young women aged 18 to 34 years being treated for MDR-TB at King Dinuzulu Hospital who had no history of having been treated for TB in the past and could, therefore, confidently be assumed to have acquired, rather than developed, MDR-TB infection. Although the recruitment strategy did not specify that participants should be from marginalised communities, the epidemiology of MDR-TB in eThekweni Metro established in Chapter Two and the fact that the recruitment site was a public hospital, conspired to ensure that many women with MDR-TB who participated in the study reported residing in townships such as Avoca, KwaMashu and Inanda (North Service Area) and Umlazi (South Service Area), among others. A World Bank report defines townships and informal settlements as large, underdeveloped communities where 38 per cent working-age people reside (Mahajan 2014). The same report estimated that approximately 50 per cent of South Africa's urban population lives in a township or informal settlement, areas which house 38 per cent of working-age citizens and are home to nearly 60 per cent of the unemployed (Mahajan 2014).



The DR-TB Unit at King Dinuzulu Hospital was purposively selected as the recruitment site for participants (Guetterman *et al.* 2015) because it houses the largest specialised DR-TB Unit in KwaZulu-Natal, which also handles all complicated cases in the province. Each month the hospital initiates on average 250 new patients onto MDR-TB treatment and provides services to an estimated 2,500 patients (Maharaj *et al.* 2016). Additionally, patients receiving treatment at other DR-TB decentralised sites in KwaZulu-Natal are also periodically reviewed at King Dinuzulu Hospital. Based on this, I believed that the sheer number of MDR-TB patients accessing services at King Dinuzulu Hospital positioned this facility as a particularly rich site from which to identify and recruit the total number of young women with primary MDR-TB anticipated to be adequate for this study.

### **Sampling participants to the study**

Clearly articulating steps taken to define and recruit samples for academic research is critical to ensuring the validity and replicability of qualitative studies, and for avoiding the introduction of bias into research findings via poorly selected participants (Benoot *et al.* 2016; Guetterman *et al.* 2015). This study utilised a combination or mixed purposeful sampling strategy as proposed by Patton (2002) to identify different categories of participants. He proposes 16 purposeful sampling strategies for primary research, and describes the logic of purposeful sampling techniques as lying

in selecting information-rich cases for study in-depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling. Studying information-rich cases yields insights and in-depth understanding rather than empirical generalisations (Patton 2002:230).

Responding to criticism in literature and considering assertions that the 'how' of purposive sampling is not always explicated in academic studies, this research considers it imperative to explicate how the sampling criteria and sample size were determined and participants recruited into the study. This is also done in response to scholars' critiques that 'researchers who claim to have used a purposeful sampling approach often fail to create a transparent audit trail on the review process' (Benoot *et al.* 2016:2). Explanation are thus provided to avoid this documented flaw, by expatiating the step-by-step process of how participants were decided and selected, recruited and reached.

The sampling strategy employed primarily aimed to recruit vulnerable women on treatment for and in remission of MDR-TB. The ideal sample emerged firstly, organically during development of the study's conceptual framework and research questions (Palinkas *et al.* 2015). Secondly, the decision to recruit only young women aged 18 to 34 years being treated for primary MDR-TB at the time of data collection, and at a specific public healthcare facility in an urban setting served to increase the homogeneity of this category of research participants, allowing for the sampling strategy delineated below to be more confidently applied (Benoot *et al.* 2016; Palinkas *et al.* 2015; Patton 2002).

Because this investigation sought to comprehend the challenge of sub-optimal adherence to MDR-TB treatment among a group of culture-sharing young women, it was of primary interest to achieve depth of understanding of the phenomenon being investigated (Palinkas *et al.* 2015; Benoot *et al.* 2016). This could be accomplished by including other stakeholders as participants, to triangulate data about the varied reasons for women's difficulties with MDR-TB treatment from multiple perspectives (Palinkas *et al.* 2015). Sourcing data on from a cross-section of participants in horizontal and vertical connexion to each other, and to women being treated for MDR-TB became necessary (Palinkas *et al.* 2015).

The inclusion of more respondent strata to contribute to this research naturally flowed from the identification of vulnerable young women as the principal group of interest to this study. Research which samples a cross-section of participants avoids the risk of missing out on the viewpoints and experiences of other groups that are involved in and/or are affected by specific phenomenon under investigation and lends breath of understanding to research (Palinkas *et al.* 2015). This consideration influenced interest in the contributions of other participant categories, such as health department personnel, nurses, healthcare providers and family members of women with MDR-TB.

KwaZulu-Natal Department of Health personnel were sampled because of their involvement in MDR-TB management policy development and implementation. Nursing staff and health educators were interviewed for their potential to contribute unique insights about reasons for young women's sub-optimal adherence to MDR-TB treatment. Finally, household contacts of women being treated for MDR-TB were included. The research sought to identify convergence in collected data, with that inchoate information then analysed and applied to developing the communication

model presented in Chapter Ten. Participants were selected through combination approaches as explained below.

### **Combination purposive sampling strategy**

In line with encouragements of researchers (Patton 2002; Benoot *et al.* 2016; Palinkas *et al.* 2015; Guetterman *et al.* 2015), this research combined purposive sampling strategies to identify, select and recruit participants judged most suitable to supporting efforts to respond to the three research questions outlined in Chapter One. Care was taken in selecting appropriate strategies from the 16 sampling techniques suggested by Patton (2002 in Benoot *et al.* 2016), to ensure that the research process still culminated in a thesis that would be considered reliable, ethical and well-organised (Benoot *et al.* 2016; Guetterman *et al.* 2015; Palinkas *et al.* 2015).

Table 1: Purposeful sampling strategy by Patton (2002) and Benoot *et al.* (2016)

Purposeful sampling strategy	Purpose (Patton 2002)	Qualitative evidence sought (Suri 2011)
Extreme of deviant case	Learning from highly unusual manifestations of the phenomenon of interest	Focusing on how things should be or could be, rather than how things are  Suitable for realist synthesis
Intensity	Information-rich cases that manifest the phenomenon intensely, but not extremely, such as good students/poor students, above average/below average	To develop a comprehensive understanding of the phenomena being researched by the synthesis
Maximum variation	Identifying key dimensions of variations and then finding cases that vary from each other as much as possible  Identifying important patterns that cut across variations	To identify essential features and variable features of a phenomenon among diverse contexts  To construct holistic understanding of the phenomenon
Homogenous	Picking a small, homogenous sample Reduces variation, simplifies analysis, facilitates group interviewing	To overcome the critique of 'mixing apples and oranges', i.e. to overcome the epistemological incommensurability of different qualitative methods
Typical case	Illustrates or highlights what is typical, normal, average	To study how common themes recurring in published literature might be related to the relative strengths and weaknesses of the typical methodologies or theories underpinning the typical studies
Critical case	Allows for logical generalisations and maximum application of information to other cases	To assist stakeholders in making informed decisions about the validity of a certain innovation
Snowball	Seeking details of other information-rich cases in the field from key participants	To identify highly valued study participants  To identify participants not commonly accessible

Criterion	Selecting all cases that meet some predetermined criterion of importance	To obtain comprehensive understanding from participants who meet predetermined criteria considered critical to the study
Theoretical	Selecting cases that meet some predetermined criterion	For research that employs constant comparative methods or grounded theory approaches
Confirming	Selecting cases as additional examples that fit already emergent cases; these case	To advocate a stance for ethical, moral and/or
Disconfirming	Selecting cases that do not fit. They are a source of rival interpretations as well as a way of placing boundaries around confirmed cases	Chosen to shake out complacent acceptance of popular myths and generalizations in a field
Stratified purposeful	Sampling within samples where each stratum is fairly homogenous	To examine variations in the manifestations of a phenomenon. These factors may be contextual, methodological, or conceptual
Opportunistic	Adding cases to a sample to take advantage of unforeseen opportunities after fieldwork has begun	For use in a research area in its exploratory stages or when researcher lacks an insider status in the relevant field of research
Purposeful random	Adding cases to a sample to take advantage of unforeseen opportunities after fieldwork has begun	To locate most of the primary research reported on a topic and then randomly select a few reports from this pool of in-depth discussion
Sampling politically important case	Selecting a politically sensitive site or unit of analysis	To gain the attention of different stakeholders and the findings get used
Convenience	Involves selecting cases that are easy to access and inexpensive to study	Not a recommendable technique, as it is neither purposeful nor strategic
Combination or purposeful sampling	To use a combination of two or more sampling strategies to select evidence that adequately addresses their purpose	To facilitate triangulation and flexibility in obtaining input from multiple stakeholders

To allow for comparisons across data collected from the five respondent groups and to support the theoretical triangulation of research findings, this research utilised different strategies from options outlined in Table 1 to select participants for each category (Guetterman *et al.* 2015; Patton 2001). Scholars argue that it is not always possible to achieve and articulate an explicit sampling approach in qualitative research (Palinkas *et al.* 2015). This observation was considered, and efforts nonetheless made to present a coherent sampling approach using a combination of strategies; envisaged as a way of further increasing the efficiency, validity and replicability of this research and its findings (Palinkas *et al.* 2015). This study braided hybrid homogenous/criterion, purposive and snowball sampling techniques to emerge with the combination sampling approach illustrated in Table 2, the application of which is discussed in detail below.

Table 2: Combination purposeful sampling approach employed in this study

Research group	Identification of research partners relevant to the study
<b>Hybrid homogenous/criterion sampling strategy</b>	
<p>Female participants aged 18 to 34 years with similarities in terms of their treatment for MDR-TB at a public health facility, and lived realities in low socioeconomic contexts in an urban metro in South Africa</p> <p>Pre-determined criterion set in relation to potential respondent's first diagnosis of TB, history of previous treatment for TB, duration on treatment at the time of the research, gender, age and treatment site</p>	<p>Use of EDR.Web to identify potential participants who fit the strict criteria set</p> <p>Recruitment in the hospital setting, and in homes as part of a parallel process to locate MDR-TB patients' homes using geospatial mapping technology</p> <p>Phone calls to recruit participants into the study</p>
<b>Purposive sampling strategy</b>	
<p>KwaZulu-Natal Provincial Department of Health personnel</p>	<p>Recruitment of Director of the Tuberculosis Programme of the KwaZulu-Natal Provincial Department of Health, Deputy Director in charge of advocacy, communication and social mobilisation and the Technical Advisor for Tuberculosis in the same department, to get their input from a policy and practice perspective</p> <p>Three nurses at various levels in the MDR-TB Unit at King Dinuzulu Hospital: professional</p>

Nursing and healthcare staff at King Dinuzulu Hospital

nurse, enrolled nurse and enrolled nursing assistant, to get a cross-section of perspectives from these professionals based on the interaction with MDR-TB patients during their work. One volunteer employed by South African Red Cross Society and seconded to the DR-TB Unit at the hospital and tasked with providing health education to patients while admitted in hospital and on clinic days

#### **Snowball sampling strategy**

Household contacts of young women currently or previously treated for MDR-TB.

Young women with MDR-TB who consented to contribute to focus group discussion were asked to identify prospective participants to take part in key respondent interviews

It would have proved incredibly difficult to identify these participants, who were deemed critical to this research, in the general population

### **Hybrid homogenous/criterion sampling to identify suitable female patients**

This investigation was concerned with achieving deep and nuanced understanding of reasons why vulnerable young women in eThekweni may be unable or unwilling to fully adhere to their prescribed anti-MDR-TB treatment. Criterion sampling was employed to recruit participants with similarities in terms of their treatment for MDR-TB at a public health facility and residence in low socioeconomic contexts in an urban metro in South Africa (Patton 2002; Palinkas *et al.* 2015). Criterion sampling is a variant of purposive sampling. The research sought the participation of young women aged 18 to 34 years with pre-determined qualities in relation to their first time being diagnosed for TB, no history of treatment for TB or MDR-TB, and duration on treatment at the time of data collection. Purposive sampling was employed to identify willing and available information-rich participants in the relatively short timeframe allocated for fieldwork, and with limited resources (Palinkas *et al.* 2015).

The sampling approach targeted specific participants with an expectation that 'each participant will provide unique and rich information of value to the study' (Etikan *et al.* 2016:4). Women with MDR-TB selected to contribute were largely unified by their race, gender, MDR-TB diagnosis, their treatment at King Dinuzulu Hospital, and their residence in eThekweni. All participants in this category were Black, most were Zulu-

speaking, with a shared culture and low socioeconomic status. The study recruited 13 women aged 18 to 34 years with MDR-TB.

Clear inclusion and exclusion benchmarks were employed to rationalise and guide the recruitment of young women with MDR-TB into the study, and to eliminate selection and information bias (Palinkas *et al.* 2015). This approach challenges assertions by Palinkas *et al.* (2015:534) that sampling strategies used in qualitative research 'are less explicit and often less evident'. Only young women receiving treatment for primary MDR-TB in the continuation phase, who were not very unwell or in palliative care were of interest to this study. This decision was taken to avoid unnecessarily straining indisposed women, and to protect the research team and all participants from possible reinfection with MDR-TB if some participants in early stages of treatment still had infectious MDR-TB. Sampling participants in the continuation phase of treatment reduced risks of participating in the study for all.

Participants were accordingly selected because, at the time of data collection, they had been on MDR-TB treatment for more than six months; were no longer infectious, as evidenced by a culture negative sputum test; and were in the continuation phase of treatment (South Africa National Department of Health 2013). Participants were disqualified from recruitment into the study if they:

- i. self-reported having received treatment for TB 30 or more days prior to being diagnosed with MDR-TB;
- ii. had a recorded medical history of treatment for TB before being diagnosis with MDR-TB; and
- iii. reported having a medical record verifying 10 or more days of treatment using anti-TB drugs for conditions other than TB, or any previous results of drug-susceptibility testing showing resistance to the drugs *Isoniazid* and *Rifampicin* (Shah *et al.* 2017).



Figure 14: Inclusion and exclusion criteria for young women with MDR-TB

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>✓ Female</li> <li>✓ From 18 to 34 years-old</li> <li>✓ Treated at King Dinuzulu Hospital</li> <li>✓ Recorded hospital diagnosis of MDR-TB</li> <li>✓ Six months+ on MDR-TB treatment</li> <li>✓ Not infectious (with recorded culture negative sputum test)</li> <li>✓ In continuous phase of treatment</li> <li>✓ Outpatient</li> </ul>	<ul style="list-style-type: none"> <li>- Self-reported treatment for TB 30 or more days prior to MDR-TB diagnosis</li> <li>- Recorded medical history of previous treatment for MDR-TB</li> <li>- Reported medical history verifying 10+ days of treatment with anti-MDR-TB drugs</li> </ul>

Once they had satisfied the requirements, women recruited into the study were assumed to have primary MDR-TB and were invited to participate. As explained in more detail below, the recruitment strategy ensured that women with MDR-TB who contributed to the study were drawn mainly from eThekweni Metro.

### **Department of health personnel, nurses and healthcare staff**

The three nurses and one volunteer health educator who contributed to this study were identified via purposive sampling. The researcher's professional knowledge of the TB programme of the KwaZulu-Natal Department of Health paved way for purposively sampling personnel deemed most able to contribute information of relevance to the study. My professional acquaintance with the three participants from the department made it relatively easy to gain access to them and secure their participation in the study. These three interviews were among the first to be conducted in March 2018, providing the foundation on which further data collection events were planned and implemented.

Recruitment of the three nurses who participated in the interviews was informed by suggestions by the matron in charge of the DR-TB Unit at King Dinuzulu Hospital that the research would benefit from insights of nurses at different levels: professional nurse, enrolled nurse and enrolled nursing assistant. This, it was surmised, would result in the generation of more rounded information because nurses in different categories have varying responsibilities of care and treatment education towards patients. Notwithstanding these distinctions, however, practically there were no

discernible differences in the roles of the three nurses interviewed in communicating with MDR-TB patients and in how they carried out these duties, as explained in Chapter Seven.

Indeed, the homogeneity of responses and roles of nursing staff that emerged early during data collection necessitated the identification of another category of healthcare worker to provide a different, and it was hoped detailed, account of how information was provided to patients to improve their MDR-TB treatment literacy. In May 2018, a volunteer health educator employed by the South African Red Cross Society, was identified and purposively sampled into the study to close gaps in data collected in March about how, when, for what purpose and by whom communication about MDR-TB is done in the DR-TB Unit at King Dinuzulu Hospital.

### **Snowballing to find household contacts of women with MDR-TB**

Snowball sampling is useful for identifying highly valued study participants who are not easily identifiable or accessible in the general population (Patton 2002). The approach is useful for finding information-rich cases based on recommendations from key participants already participating in a study (Benoot *et al.* 2002). Household contacts of women with MDR-TB were identified and recruited into the study using this strategy. Young women with MDR-TB who consented to participate in focus group discussions were asked to name prospective key participants who fit the criteria of 'household contact' who could be invited to participate in interviews.

Household contacts were defined as all individuals above the age of 18 years residing in the same households as young women previously or currently on MDR-TB treatment of any duration and able to give informed consent to participate in the research. They could be relatives, or not, of patients. Only participants who fit the criteria and were considered able to contribute valuable insights to the research were invited to contribute to the study (Etikan *et al.* 2016:4).

### **Determining the sample size**

Sampling in qualitative research comprises iterative decisions made throughout the research process. Reflexive researchers adjust their sampling strategies based on their success, or not, as research progresses (Guetterman 2015). Iterative sampling decisions made in this research and discussed in the previous sub-section were shaped through constant reference to the research questions (Pope *et al.* 2000) and insights from data collected during initial stages of field research, which were used to adjusting the processes that followed (Palinkas *et al.* 2015). Analytical requirements to reach

data saturation and application of precedents were key considerations that influenced the sample size.

### ***Applying precedents to set the sample size***

Determining sample sizes in qualitative studies is influenced by precedents (Palinkas *et al.* 2015). Guetterman *et al.* (2015:5.1) encourage keeping sample sizes smaller, arguing that excessive samples cause three challenges: 'First, as data tend to become repetitive, the qualitative analysis will lose depth. Second, the study will consume more resources than needed. Finally, I question the ethical implications of burdening more research participants than we actually need as researchers'. This is echoed by others, who insist that because qualitative studies do not aspire to result in statistically generalisable findings, there is little motivation to use larger sample sizes; the only outcome of which is bloated datasets that are cumbersome for researchers to handle (Pope *et al.* 2000). Urging researchers to use smaller more representative samples, Polit and Beck (2010) insist that sampling in qualitative research is not meant to be representative of broad populations but is largely purposive to collect diverse perspectives, which aid understanding of phenomena of investigation.

### ***Using the principle of saturation to estimate the prime sample size***

As the principle of saturation was employed, a concern of this research was to guarantee that enough data was collected to ensure that the research could demonstrate patterns, without accumulating so much that interpretation became unmanageable (Palinkas *et al.* 2015; Pope *et al.* 2000). Saturation involves collecting complete data of good quality and of enough quantity to be assured that all relevant themes have arisen in planned interviews and focus group discussions (Martins 2008).

Towards ensuring academic rigor in qualitative studies that apply the concept of saturation, some maintain the importance of ensuring that sample sizes are small enough that the researchers can manage the data, and large enough to provide a 'new and richly textured understanding of experience' Sandelowski (1995:183). Pope *et al.* (2000) echo these sentiments. These considerations, they argue, are always determined by subjective judgement (Sandelowski 1995). There are findings that support arguments for smaller sample sizes for academic studies such as this one. Among them is Mason (2010), whose review of PhD theses found that doctoral candidates generally employ larger sample sizes than needed to achieve theoretical saturation; the mean sample size was 31. With reference to the discussion in the previous section, and the findings by Mason (2010) and others (Palinkas *et al.* 2015),

this research delineated a maximum sample size of 29 participants and ended up collecting and using information from 20 informants.

Some scholars insist that the more homogenous a study sample is, the fewer the participants and data collection events required before saturation is reached (Guetterman *et al.* 2015; Fugard and Potts 2015; Palinkas *et al.* 2015). More homogenous groups lend themselves well to data collection through focus group discussions and allow for easier analysis of data (Palinkas *et al.* 2015). This was an important consideration in selecting the data collection methods for this research, especially considering its scope and duration, the language barrier between me, a non-isiZulu-speaker, and primary participants, as well as the time and resource challenges experienced, and which are discussed later in this chapter.

In their examination of literature on the topic, Fugard and Potts (2015) suggest that saturation can be reached after two to four focus group discussions, or as few as six interviews if the aim is to understand the essence of a phenomenon (Guetterman *et al.* (2015). While some sources recommend conducting at least 12 interviews (Martins 2008, Guest *et al.* 2000), still others insist that broad themes are obvious after just six (Benoot *et al.* 2016), strengthening the argument for smaller samples in qualitative studies (Palinkas *et al.* 2015; Mason 2010; Pope *et al.* 2000; Sandelwoski 1995). With this wisdom and embracing these influences, this research decisively leaned towards using a smaller sample, employing a mix of eight one-on-one key respondent interviews and three focus discussions involving 13 participants.

This approach aimed to ensure that saturation was reached and, towards this end, the 'jumping off point' (Benoot *et al.* 2016) for this study, when data collection could be halted, was informed by a high target of at least 20 research participants having contributed to the research. I erred on the side of caution, preferring to collect too much data than too little. This was due in large part to concerns that all potential themes should have a chance to emerge during the period set aside for data collection, which was achieved, as illustrated by a reading of the raw data in Appendix 12. The eventual total number of participants who contributed to this study took into consideration recommendation to undertake three additional interviews to ensure that no new themes emerge after saturation is believed to have been reached (Martin 2008 in Fugard and Potts 2015).

## **Recruiting participants to the study**

I employed a multi-stage recruitment procedure to recruit female patients into the study via the DR-TB Unit at King Dinuzulu Hospital, and by taking advantage of scheduled geospatial mapping activities in eThekweni Metro, through a team tasked with handing out flyers to MDR-TB patients at home from 19 to 30 March 2018. The second layer of the sampling procedure evolved serendipitously, as explained later. The fact that I resided in Pretoria, located more than 500km from the research site, and had to travel to eThekweni periodically to collect data had a bearing on the recruitment decisions taken, which aimed to maximise each visit to Durban for data collection. Careful planning was a factor in the success of the procedure, as was winning the buy-in of administrators at the hospital, as well as colleagues from work, to explain the purpose of the research before they handed over the recruitment flyers to prospective participants in a process explained later in this chapter.

## **Recruiting patients with MDR-TB to the study**

During the research design stage, I was concerned that the significance of KwaZulu-Natal to South Africa's MDR-TB epidemic, implementation of the considerable initiatives aimed at reducing TB incidence in the province, as well as King Dinuzulu Hospital's status as a centre of excellence handling the largest number of MDR-TB patients (and all complicated cases) would have resulted in research fatigue on the part of hospital staff (and perhaps patients), posing a potential challenge that would require mitigating against in this study's design and approach. As anticipated, I did experience these challenges, beginning when I arrived at the hospital in early March 2018 to introduce the study to hospital administrators and nursing staff in the DR-TB Unit at the hospital.

In the planning phase, my recruitment strategy relied heavily on nursing staff in the DR-TB Unit identifying – through review of patient records – those MDR-TB patients on treatment who fit the selection criteria outlined. I then required them to hand out recruitment flyers inviting select patients to SMS their interest in participating in the study to me. The reality of data collection was, however, that there were significant impediments to getting nursing staff to pledge time to helping with the study. I was unable to obtain firm commitments to assist with physically accessing patient records as the first step to checking them for details of individuals who fit the criteria for inclusion into this study.

Obstacles to recruiting patients in line with the planned strategy were two-fold. Firstly, patient charts are not stored in the DR-TB Unit, so a clerk with authorisation is required to select all files of female patients and bring them to the unit to be opened and checked against the research criteria. Secondly, reading and understanding patient charts is best done by nurses trained in nurse-initiated drug-resistant TB treatment (NIMDRT) initiation, or doctors. Without the necessary training, I was unqualified to read the files for the required information. This challenge threatened the research. A solution in the form of the web-based Electronic Drug-Resistant software (EDR.Web), however, became apparent as I discussed challenges with implementing this study's recruitment strategy with a colleague proficient with TB data management systems.

### ***Identifying female patients with primary MDR- TB through EDR.Web***

An obstacle to the application of the recruitment strategy as envisioned arose because I had not applied for authorisation to access confidential patient information or handle files from either hospital administrators or the Biomedical Research Ethics Committee at University of KwaZulu-Natal. EDR.Web provided an avenue to access patient information and generate lists of potential participants with desired characteristics. EDR.Web is used in the management of MDR/XDR-TB in 85 DR-TB units in all nine provinces of South Africa. The platform is accessible only to authorised users through a central database (Wam Technology 2014). Providence provided me with an opportunity to access information from this database, through three of my work colleagues who were reviewing patient charts at King Dinuzulu Hospital and had the necessary clearance and expertise to access information on the platform at the time of fieldwork for this study. They acquiesced to sift through patient information and generate a list of women who fit the criteria of my study.

From 12 to 16 March 2018, team members reviewed patient files at King Dinuzulu Hospital, and then, using EDR.Web, generated lists required for a process they would later undertake to pinpoint the exact locations of MDR-TB patients using geospatial mapping technology between 20 March and 20 June 2018. By inputting the three inclusion criteria for participating in this research into the database, the team was able to generate a list of patients resident in eThekweni Metro alone possessing the exact criteria of participants needed for this study. Chief among these was a confirmed diagnosis of MDR-TB without prior TB or MDR-TB treatment and falling in the correct age range. Details in EDR.Web were verified by checking physical copies of patient files. This cancelled the requirement to look through multiple files

to find a few potential participants. A list with MDR-TB patients' names, dates of birth, residential addresses and phone numbers was generated and availed to the researcher.

As anticipated during the design of the study, a lot of research was underway in the DR-TB Unit at King Dinuzulu Hospital, as explained in the discussion about the CAPRISA studies in Chapter Two. Indeed, when my colleagues were reviewing patient files to identify patients to be geo-mapped, as well as those fitting the criteria for inclusion in this study, they found that a lot of files were missing – taken offsite by other researchers for their own studies. This meant that a less than optimum number of files was available for them to check to identify potential participants for this study. Consequently, the process was repeated multiple times to identify more patients as files became available.

From a total of 823 MDR-TB patients being treated at King Dinuzulu during this period, only 443 files were available in the hospital for review. On examination of the files, 31 patients fit the criteria for participants to this study and were resident in eThekweni. You will recall that the process primarily aimed to identify participants whose MDR-TB was most likely acquired, as opposed to developed because of failure of previous DS-TB or MDR-TB treatment. A list with these names was duly generated and given to the researcher. Upon further review and telephoning participants to inform them about the study it was discovered that three names on the list were of men and appeared due to capturing errors on EDR.Web, and one patient did not have a phone number listed. These four names were removed, leaving a pool of 26 key participants with MDR-TB to sample from.

While useful for increasing the rigor of the study, I must concede that the strict inclusion and exclusion criteria set for women with MDR-TB to participate in this study presented a challenge because they shrunk the potential pool of MDR-TB patients I could recruit into the study, which contributed to the smaller total sample utilised in this study. This sample size inspired utilisation of the case study approach, so the sacrifice of breadth of data could be mitigated by depth of findings (Smith and Osborn 2007).

### ***Recruitment at homes***

During a week, from 20 to 27 March 2018, my colleagues visited the homes of many patients with MDR-TB to conduct the geospatial mapping exercise in eThekweni that was their main assignment. Through this process, four women fitting the research criteria were reached (see Table 3). Names, full addresses, birth dates and telephone

numbers have been removed from the table to ensure MDR-TB patients' anonymity. The team handed out recruitment flyers to prospective participants, and they also explained the research in isiZulu. In this way, the recruitment of female patients being treated for MDR-TB was done both in the DR-TB Unit at King Dinuzulu Hospital and in patients' homes as part of a parallel, but linked process.

### **Recruitment at the hospital**

Overall, the approach employed to enrol participants into the study via the hospital was a variation to the one envisioned during development of the research proposal. I had planned to ask nursing staff to lead in enlistment by handing out flyers to patients who fit the criteria set. However, after visiting the hospital to introduce the study and get their buy-in, I quickly realised that staff shortages and nurses' responsibilities to patients meant that recruiting participants into this study would not be a priority for them. It was thus necessary to identify someone else in the unit with daily access to patients to support enrolment of participants into this study. With the permission of management at King Dinuzulu Hospital, I asked an administrator working in the DR-TB Unit and proficient in isiZulu to hand out recruitment flyers in both isiZulu and English. This individual also explained the purpose of the study to female patients whose names appeared on the list generated from EDR.Web (see Table 3) during their monthly visits to the outpatient department of DR-TB Unit. Prospective participants were directed to SMS their interest in contributing to the research to a dedicated number. From March to July 2018, flyers were handed to 12 eligible prospective participants.

Table 3: Recruitment process for women with MDR-TB by list generated on EDR.Web

	Initials	Date of Birth	Physical Address	Date reached for recruitment			Date of participation in research
				@ home	@ hospital	via phone	
1	BN	Apr-82	Umlazi		2018/05/22		
2	DX	Aug-85	Sydenham				
3	GST	Jan-95	Durban Central				
4	HCN	Feb-98	Durban Central				
5	KXC	Oct-96	Inanda	2018/03/22	2018/04/12		2018/05/26
6	KNP	Sep-84	Umlazi		2018/05/12		2018/05/26
7	MA		Female			2018/05/27	2018/07/21
8	MN	Nov-87	Lamontville				
9	MPN	Aug-94	Clare Estate		2018/04/12		



10	MN	Dec-88	Verulam	2018/03/23	2018/04/04		
11	MN	Jan-96	KwaMashu			2018/05/27	2018/07/21
12	MN	Dec-93	KwaMashu		2018/05/22		2018/05/26
13	MAN	Nov-90	Umlazi		2018/04/12		
14	NN	Apr-85	Umlazi				
15	NLB	Feb-98	Enganyameni		2018/06/05		2018/07/21
16	NN	Sep-84	Clare Estate				
17	SP	Mar-91	Chatsworth				
18	SZ	Dec-82	Ohlange		2018/07/02		2018/07/21
19	SS	Sep-89	Ntuzuma			2018/05/26 2018/07/20	
20	SZB	May-87	Inanda		Male		
21	WKES	Apr-82	Brighton Beach		2018/05/22		
22	ZAN	Dec-91	KwaMashu	2018/03/21	2018/04/04		
23	MZ	Dec-90	Burlington Heights	2018/03/21			
24	SMT	Jan-84	Mayville		Male		
25	SN	Jan-91	Chesterville				
26	NPN	Feb-92	Inanda				
27	SN	Apr-89	Inanda				
28	SN	Feb-84	Umlazi				
29	TBJ	Feb-93	Mayville				
30	YK	Jul-87	Umgeni		2018/04/12		2018/05/26
31	ZSY	Dec-82	Pinetown		Male		

The decision to distribute recruitment flyers in the two languages was informed by a curious finding in the first round of interviews with KwaZulu-Natal Provincial Department of Health staff, one of whom mentioned that isiZulu speakers in eThekweni seemed to prefer to receive written materials about TB in both English and isiZulu. They reportedly first read the isiZulu copy, then refer to the English copy to verify that they understood the isiZulu version correctly. Research information, including consent forms to participate in focus group discussions, was subsequently made available to research participants in both languages.

### **Recruitment via telephone**

Handing out recruitment flyers to all eligible participants at the hospital proved challenging because some patients who appeared on the list as being managed at King Dinuzulu Hospital in April 2018 were reportedly no longer receiving treatment at the facility by June of the same year. Some were transferred to other, decentralised, healthcare facilities, to be treated closer to home after the intensive phase of treatment, or because their treatment became less complicated (Loveday *et al.* 2015).

As specific women were included in the sample of this study, it became necessary to reach them via other means.

I had the contact numbers of patients fitting the criteria set, so after some time had elapsed, I telephoned potential participants who did not SMS me to indicate their willingness and availability to contribute to the study. A decision was also taken to telephone participants who had not received a flyer after three months had elapsed. For good reasons, this strategy was unsuccessful at encouraging potential participants to sign up to the study.

A reading of Table 3 above demonstrates that prospective participants were more likely to take up the invitation to contribute to the research if they had received a flyer prior to being telephoned by the researcher or research assistant for purposes of recruiting them into the study. It is understandable that young women resident in an urban area with high levels of serious crime, among them sexual violence and human trafficking (U.S Department of State 2017) would be cautious about commuting from their homes to meet strangers who contacted them via telephone. To reach potential participants who had not been to the hospital without causing discomfort, a strategy was implemented where the administrator at King Dinuzulu Hospital would call potential participants first to introduce the study in isiZulu, confirm that it was sanctioned by the hospital and explain that a research assistant would telephone then to recruit them into the study. If potential participants indicated interest in contributing to the study, the research assistant telephoned them to share details of the date, time and venue of the discussions in isiZulu. Finally, once they had been recruited into the study, I personally followed up immediately with an SMS in English, identifying myself and confirming details of the study and focus group discussion or interview in writing. This strategy was more successful.

### **Household contacts of young women with MDR-TB**

After the first few interviews and inaugural focus group discussions, snowball sampling was applied to identify and recruit more participants to the study. The strategy was used to find household contacts of young women currently or previously treated for MDR-TB. Focus group discussants were asked to suggest members of their households as prospective participants, people who it would have been difficult to identify and locate in the general population (Adler and Clarke 2011). Snowball sampling was repeated until data saturation was judged to have been achieved.

## **Data collection methods**

The location of this study within the qualitative research tradition entailed using different research techniques to explore phenomenon of social significance, which could only be achieved if the data collected was handled competently. Consequently, the data collection process and outcomes of this research are largely predicated on my skill and perceptiveness as the primary instrument for data collection (Snape and Spencer 2003; Merriam 2002). An explanation of the data gathering process employed is included later in this chapter. Primary data gathered via direct observation in an objective and unbiased way is considered central to the validity and objectivity of research findings. It also contributes to views of qualitative research such as this one, as empirical research of high quality (Snape and Spencer 2003; Freedman *et al.* 1974). With this knowledge, field research was undertaken following the process described in Figure 12 in the next sub-section.

## **Practical considerations**

As I am not a native of KwaZulu-Natal, and not proficient in the main indigenous language – isiZulu – I secured the services of a research assistant to provide isiZulu/English interpretation and translation services to support data collection and transcription. I hired a young Zulu woman and University of KwaZulu-Natal postgraduate scholar born and raised in KwaZulu-Natal for this role. She assisted with recruiting participants to the study, translated the focus group discussion guide into isiZulu as she familiarised herself with the research tool, and interpreted focus group discussions and key respondent interviews with contacts while I, as primary investigator, led the discussions.

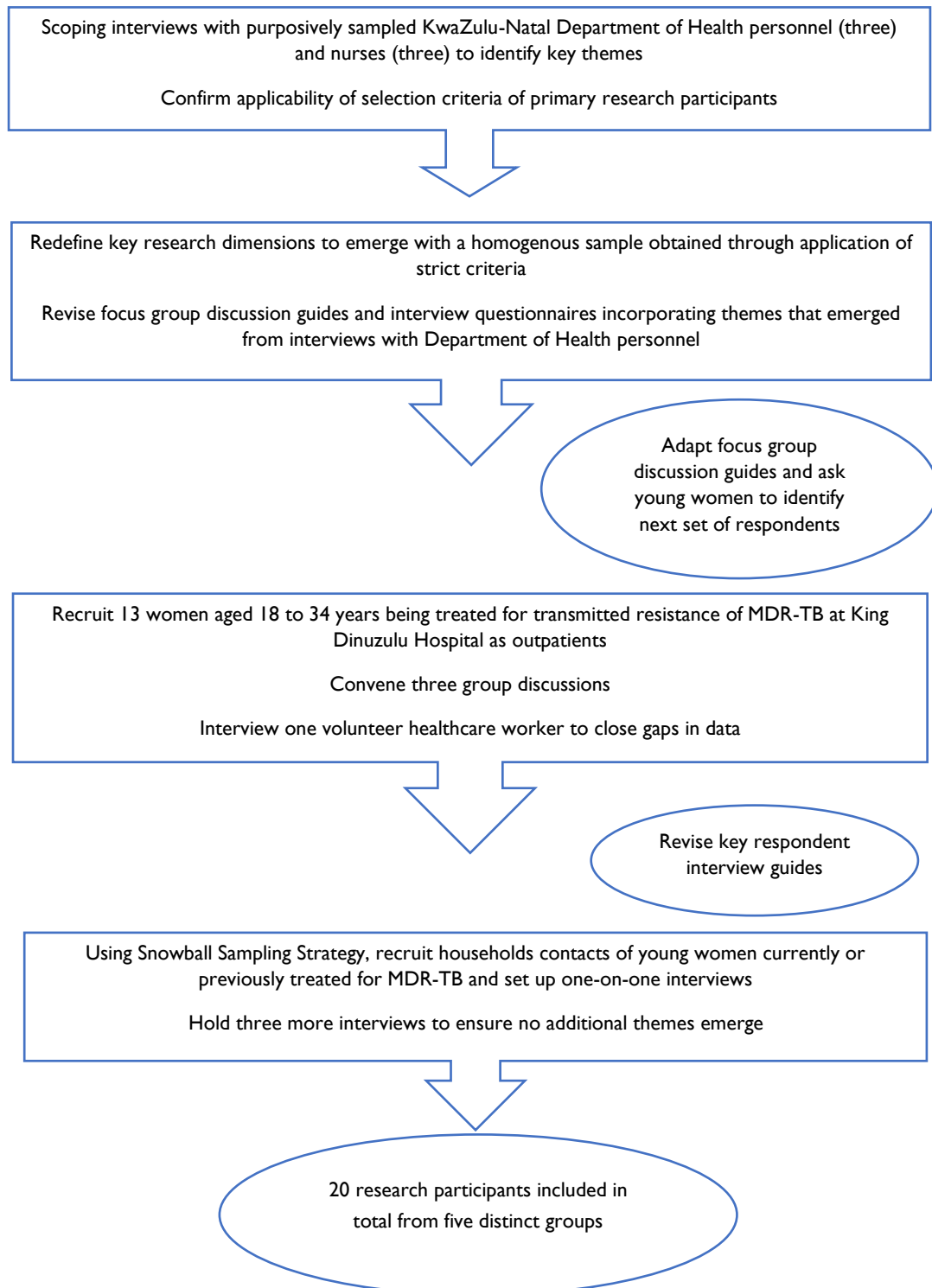
The assistant transcribed the resultant notes in isiZulu, then translated them into English before submitting typed transcripts to me for analysis. I conducted key respondent interviews with healthcare staff at King Dinuzulu Hospital, and key personnel employed by the KwaZulu-Natal Department of Health in English without assistance, however. I worked alone during the first stage of data collection and analysis, but this changed during the second phase, as language barriers between me and female patients with MDR-TB and their contacts necessitated the co-option of the research assistant to support the recruitment of identified participants to the study in line with the process explained above.

This research adopted and utilised the process approach, which involves a series of structured interactions, discussions and outcomes between the research assistant and primary researcher regarding the data collection process and phenomenon of

investigation (Chong and Yeo 2015). I used interactions over mobile initially, and in person later during visits to eThekweni Metro to familiarise the research assistant with objectives of the research and content of the data collection tools, and to appraise her of the themes emerging from the first phase of data collection and the threads I was interested in following up and probing during subsequent data gathering events.

I utilised multiple data collection methods and processes with participants selected through combination purposive sampling techniques to understand factors that hamper vulnerable young women's abilities to fully adhere to MDR-TB treatment, and how these can be addressed through enhanced communication methods (Snape and Spencer 2003). Furthermore, a flexible, multi-stage and iterative data collection procedure, as illustrated in Figure 12, was utilised to support the inductive approach to data collection and analysis employed. Information was gathered in phases, with rest periods in-between to review and assess the data for evidence of impending saturation (Palinkas *et al.* 2015; Lin *et al.* 2008, in Guetterman 2015). This also allowed for emergent issues to be explored during subsequent phases of data collection (Snape and Spencer 2003). By analysing data as it was gathered, I could keep a firm handle on the voluminous information collected, and adjust the research tools as necessary, especially where I believed that interview questionnaires and focus group discussion guides would not yield strong or comprehensive enough findings unless they were altered.

Figure 15: Data collection approach – application of the combined purposeful sampling approach



The flexibility of qualitative research allowed me to revise the research tools and adjust the study design during data collection to follow unanticipated, novel or interesting threads of emerging information, and to render the research tools more responsive to contributing to preliminary outcomes in the first stages of the research process. Instances of this are discussed in Chapter Seven. Data collection was halted once repetition was observed during the analysis of gathered information (Guetterman 2015).

### **Focus group discussions**

The original plan was to organise group discussions by age range, with women aged 18 to 24, 25 to 30 and 30 to 34 years respectively, to achieve an across-case case study analysis approach for more nuanced findings and to understand similarities and differences by age range. However, the small number of potential participants fitting the criteria of the research, and challenges encountered in recruiting participants to the study early during fieldwork dissuaded me from attempting to implement this plan. This may be an interesting approach to further research in this area.

Three focus group discussions were eventually conducted with young women aged 18 to 34 years receiving treatment for primary MDR-TB and resident in eThekweni Metro on 26 May, 21 July and 29 September 2018 respectively. The number of group discussions was influenced by Horn *et al.*'s (2008) finding that saturation was achieved by the fourth focus group discussion conducted, obliging them to abandon the other planned discussions. A minimum of four participants were required for each group discussion to take place. Focus group discussion as a data gathering method combines features of individual interviews and participant observation. The discussions provided important opportunities for me to observe a select group of people discussing the topic that most interested me (Maykut *et al.* 1994). One woman who shared particularly detailed and interesting information in group discussions was invited to participate in a one-on-one interview after the third group discussion, so I could probe specific lines of inquiry. While interviews with health workers took place on hospital premises, to maintain the anonymity and confidentiality of patients, in-depth interviews with contacts and focus group discussions with patients were conducted at the Durban Mission Church near South Beach, in the South Central service area of eThekweni Metro.

Interviews lasted between 30 and 90 minutes, while group discussions lasted between one and two hours. The first group discussion was the longest and refreshments were served in the middle rather than at the end, to give participants a break. This proved

problematic though, as participants' energy levels significantly dipped after they had eaten. The discussions that occurred after the break were less animated. In subsequent discussions, only water and fruit were offered before and during focus group discussions, with light snacks set out after the discussions had concluded.

I declined an offer from administrators at King Dinuzulu Hospital to host focus group discussions with patients in the waiting area of the DR-TB Unit on a non-visiting day to protect the anonymity of participants. Assertions by de Oliveira (2011) that the context of research influences the data that culminates from the process were also considered in relation to participants' potential discomfort with contributing to the study if they thought staff at the DR-TB Unit could identify them and know that they had participated. Qualitative research emphasises conducting studies in natural contexts, to ensure that participants feel comfortable as researchers attempt to produce unique explanations about a given situation or individual (Jankowski *et al.* 1991). Research in this tradition should ideally be conducted in real-world, rather than experimental or manipulated settings (Spencer and Snape 2003). In line with these tenets, I took care to ensure that data collection was conducted in an atmosphere that was not too alien to research participants, while being conducive for the video and audio recording of conversations. The church was considered ideal.

Process-wise, while the research assistant interpreted during the discussion, I led the discussions and asked the questions. In the introductory phase of the focus group discussions, I tried to get participants comfortable with contributing to the research since we would be discussing sensitive topics for the women (de Oliveira 2011). To achieve this, I stimulated informal general discussion about participants' demographic information, backgrounds, experiences with MDR-TB treatment and their views about the utility of treatment education for encouraging enhanced adherence to treatment. I began the discussions by asking participants to share their hopes and fears around treatment and to explain how MDR-TB affected their lives and their radio and television viewing habits. Once they seemed more relaxed, I proceeded to ask questions from the focus group discussion guide in Appendix 3. After the initial discomfort at being asked about incidences of non-adherence to MDR-TB treatment had been addressed, the focus group discussants were very engaged and responsive to the process, which resulted in minimal silences. Also, because the groups were quite small, where silence did occur, it was relatively easy to ask each respondent to contribute in turn until good flow of conversation was restored.

The silences that did occur may find explanation in suggestions that a shortcoming of focus group discussions as a data collection method is that participants may be reluctant to disclose information they consider confidential, such as that pertaining to health status, in group situations, especially where trust is low (Hollander 2004). Assuring participants that their contribution to the study would be treated confidentially and their identities kept anonymous in this thesis was done at the outset, partly to build trust within the groups. Further, the non-existent prior relationships among the participants who did not know each other, the initial awkwardness between participants and me as non-isiZulu-speaking researcher, and the need for interpretation services may have made the group discussions seem more formal than was desired initially (de Oliveira 2011). These factors may have made some participants less willing to share information, as evidenced by one respondent's spirited unwillingness to be video recorded (which was solved by having her sit behind the camera) and to contribute to early discussions about how low socioeconomic status affected her adherence to treatment. I was however able to gain the respondent's participation as the discussion progressed by periodically asking her if she had something to share. It was also helpful that in this group, there was another respondent who, although she didn't speak often, when she did, she provided detailed explanations and descriptions to explain her experiences of being treated for MDR-TB and ideas about how public health communication can be strengthened and targeted to make an impact in TB responses. This participant's willingness to be candid may have influenced the first respondent to be more trusting of the process and she gradually relented.

Generally, however, participants contributed rich findings, as presented in Chapters Seven, Eight and Nine, which may have been encouraged by my being their peer in some respects. As a young, Black woman and a mother resident in South Africa, I share some of the participants' context and frames of reference. Indeed, I framed the focus group discussions with young women as 'girl talk' sessions, to try to further break down barriers between us. Morgan (1995, in Hollander 2004:609) suggests that having a moderator 'whose background will put the participants at ease' is important for sensitive topics. For example, a moderator who shares similar characteristics with participants will more easily promote rapport, trust, or both. I used language to build rapport with participants and assure them that I was attentive and interested in what they had to say. I greeted participants in basic isiZulu and used opportunities where I understood exchanges in isiZulu to repeat contributions shared and confirm that I had understood the discussion correctly without waiting for the interpretation. This



strategy was not necessary, however, during interviews with nurses and Department of Health personnel as these were conducted in English.

### **Key informant interviews**

Through semi-structured one-on-one interviews with key participants using an interview guide, this research sought insights into the MDR-TB programme management and healthcare provision experiences of seven informants who included the KwaZulu-Natal Department of Health Tuberculosis Programme Manager; Advocacy, Communication and Social Mobilisation Manager; Technical Advisor, and healthcare providers working in the outpatient department of the DR-TB Unit at King Dinuzulu Hospital. Interviews with these participants were held between 6 March and 24 May 2018 in Pietermaritzburg and Magaliesburg, South Africa. Three household contacts currently or previously residing in the same households as young women being treated for MDR-TB also contributed to the study.

I deemed it unnecessary to film KwaZulu-Natal Department of Health personnel during interviews, even though they all gave written informed consent. Conversely, all three nurses at King Dinuzulu Hospital declined to consent to being video recorded during interviews. Among the healthcare workers interviewed, only the volunteer, who was interviewed last, was willing to have the interview video recorded. The nurses' reluctance to be filmed be explained by the conditions in which the interviews were conducted – in the matron's office in the DR-TB Unit at King Dinuzulu Hospital during work hours. Further, the fact that the matron assisted with identifying and recruiting nurses to take part in interviews annulled the anonymity of these participants, although measures are still taken to maintain their anonymity in this thesis. The nurses' awareness that their managers and colleagues knew that they contributed to the study may have affected how comfortable and willing to share information with me they were. This may have contributed to the homogeneity of responses from nurses alluded to earlier. An analysis of their interview transcripts brought up new themes which justified the need to add another respondent to the list; a volunteer health worker. I identified this respondent and arranged the interview without the participation of hospital administrators.

### **Observation**

Ethnography as a research approach includes observation and documentation of human cultures in-context as an important data collection tool (Carthey 2013). Opportunities to add insights to this study through observation were presented when I went to introduce the study to administrators at King Dinuzulu Hospital and

interview healthcare professionals. The waiting area at the DR-TB Unit is outside, where there is plenty of ventilation. Reports were that a projector is used to disseminate audio-visual content in isiZulu about MDR-TB infection, testing and prevention in the waiting area. The conditions in which the projector would be used during the day would most certainly result in grainy viewing, particularly when it is sunny or bright outside. Also, as the benches are set in rows, not all patients would be able to clearly see the screen from where they are seated. As I did not visit the DR-TB Unit on a clinic day – I visited on non-clinic days to cause the least amount of disruption to healthcare services provision – I cannot confidently describe how MDR-TB education is practically provided. In hindsight, this was an oversight of this research. No television screens were observed inside the ward, which implies that after patients make their way inside, opportunities to gain information are further reduced.

Information materials displayed inside the ward included ‘open doors’ and ‘open windows’ stickers, meant as a reminder to healthcare facility staff to ensure adequate ventilation in the unit. Additionally, a few posters bearing the tagline ‘I protect you, you protect me. Always wear a mask when you cough’, which were designed to communicate prevention of hospital-acquired airborne infections were displayed on the walls of the unit. It is significant that no leaflets or pamphlets about the importance of adherence to treatment were visible anywhere, although the volunteer health educator interviewed for this study indicated that print materials were availed to patients after they received health education while they waited to see nursing staff.

The area designated for the counselling of patients and members of their families described in Chapter Eight is in the centre of unit, in front of the administration desks and with at least four pathways leading away from the area into passages that lead to other rooms, offices and wards. As it is this area, which is essentially a thoroughfare, does not provide any privacy and would not be conducive for patients and healthcare workers to freely discuss successes and challenges of adhering to MDR-TB treatment.

### **Keeping a reflexive journal**

I considered it important to this investigation to ‘situate’ my perspectives and observations in the field prior to commencing the study, and to remain keenly aware of this prior knowledge, which was brought to the reflexivity of the research process during the data collection process (Snape and Spencer 2003; Malterud 2001). Towards this end, I kept and used a reflexive journal to increase diligence and consistency in the research process and its documentation, and to ensure that data that emerged was reliable (Simmons 2009; Malterud 2001). The journal was particularly useful during

the data collection, coding and analysis stages of this research and was employed in line with interpretivist beliefs that the researcher and social world impact each other (Starman 2013), and that ‘facts and values are not distinct, and findings are inevitably influenced by the researcher’s perspective and values’ (Snape and Spencer 2003:19). The journal was also convenient for noting and keeping track of tentative findings emerging from the data, tenuous links made prior to deeper analysis of information, and new and unheralded lines of inquiry to be followed in subsequent research events.

### **Credibility and trustworthiness of data**

The epistemological position that knowledge is socially constructed and not discovered informed the collection and analysis of data and influenced my perceptions and mediation of context- and case study-specific meanings emerging from the findings (Van Nierkerk 2005). The idea that researchers generate knowledge about social phenomenon from the perspectives of study partners resident in specific times and contexts, however, has been known to raise suspicions about the validity and trustworthiness of findings of qualitative studies (Andrews 2012). Some argue that qualitative research’s reliance on subjectively handled data and interpreted findings weakens the validity and trustworthiness of outcomes (Andrews 2012). In response, proponents of qualitative data analysis argue that clearly articulating a study’s conceptual framework and research methods utilised and extending these to data analysis contributes to substantiating and legitimising the validity of research findings (Ritchie and Lewis 2003).

This study’s conceptual framework, which is discussed in Chapter Five, provides the wireframe for application of the ‘named and claimed’ data analysis process applied to this study, which is explained in Chapter Seven. It provides the lens through which vulnerable young women’s experiences with MDR-TB treatment and their reasons for sub-optimal adherence are analysed and meanings made to emerge with the situated findings reported in Chapters Eight and Nine, and the communication model proffered in Chapter Ten (Ritchie and Lewis 2003; Merriam 2002). How data was organised and analysed, as well as a presentation of nascent findings of this study, is explained in the next chapter.

Although findings of qualitative studies are not generalisable, results of credible research are transferable. As well as clearly articulating the data analysis method and process followed, researchers can also achieve trustworthiness by providing thick enough descriptions of findings to allow readers to make up their own minds about a study’s relevance to their research and implementation needs (Nowell *et al.* 2017:1).

Indeed, scholars insist that the qualitative researcher, no matter what data analysis process they employ, is solely responsible for ensuring the fidelity of their research (Nowell *et al.* 2017). This, they argue, can be achieved by the researcher clearly demonstrating 'how data analysis has been conducted through recording, systematising, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible' (Nowell *et al.* 2017:2). Chapter Seven attempts to provide the required level of detail and in so doing, strengthen the validity, reliability and replicability of this study. Below is a discussion of more practical considerations pertaining to the research.

### **Ethical considerations**

This study was approved by the Biomedical Research Ethics Committee at the University of KwaZulu-Natal and assigned protocol number BREC 379/17 (Appendix 8). The KwaZulu-Natal Health Research Committee also authorised the study and allocated it protocol number KZ\_201711\_047 (Appendix 9). Gatekeeper letters to conduct the study at King Dinuzulu Hospital, and to engage nurses to support the process of identifying and selecting participants were issued by the Medical Manager (Appendix 10) and the Nursing Manager (Appendix 11) respectively. The study adheres to important ethical principles in research such as the principle of voluntary participation, informed consent, confidentiality and non-maleficence.

Participants were not remunerated for their contributions to the study, Refreshments were provided for focus group discussions and reimbursements provided to cover the costs of public transport (bus or minibus taxi) incurred by participants who travelled to take part in the research.

### **Informed consent, and maintaining participants' confidentiality and privacy**

Earlier I discussed challenges I encountered in implementing the recruitment strategy for young women with MDR-TB due to lack of authorisation to access patients' files. Apart from my incapacity to 'read' the information in the files, two other factors influenced my decision not to request authorisation to access patient files. These were to: (i) avoid unnecessary access to confidential information of a medical nature of no relevance to this research, and (ii) minimise chances of researcher bias, brought up for instance by knowledge of specific patients' non-adherence to medication, impacting data collection and analysis. I considered it important to remain as 'blind' to facts unrelated to the research as possible prior to focus group discussions with women with MDR-TB (Freedman, Carlsmith and Sears 1974).

Participation in this research was entirely voluntary for all participants, who had full control over whether to contribute or not. Written informed consent was obtained from each participant prior to contributing to the research. Participants signed a detailed informed consent form after it had been explained to them verbally in English or isiZulu and as they read along on their own copy. Opportunities to ask questions and to seek clarity were provided before participants appended their signatures. The consent form was structured into three sections. The first section was the information sheet, which provided comprehensive information about the research process. The second and last sections were for research participants to consent separately to: (i) contribute to the study in a focus group discussion or key informant interview, (ii) photographs and audio and video recordings being taken during the data collection process (see Appendix 2). Participants could consent to participate in the study but decline to be included in photographs or videos.

All written information was made available to participants in either isiZulu or English, or both if they preferred. For this study, all focus group discussions were conducted in isiZulu, although discussants often mixed isiZulu and English, which helped me to follow the discussions better. Key respondent interviews with nurses and Department of Health personnel were conducted in English. Participants who chose to withdraw from the study for any reason were free to do so at any point, in line with the concept of non-maleficence (do no harm principle), and to guard against potential emotional and other risks to both participants and researchers that the study topic could pose. Although participants could opt-out of answering any questions they did not wish to respond to, no one exercised this entitlement. There were no negative consequences for participants' from participating in the research, nor for potential participants who chose not to contribute.

Confidentiality and anonymity were assured in recording and reporting. Save for office-bearers from the KwaZulu-Natal Provincial Department of Health who gave their permission, no personal details or names of research participants are included in the thesis or any papers published from it. Participants' names have been substituted with pseudonyms or numbers (e.g. Zukiswa or Nurse #1) to ensure the anonymity of participants, to safeguard their confidentiality and to protect them from harm that may arise from their contribution to this study. Only my PhD supervisors and I have knowledge about participants' identities. Information identifying participants is securely stored and would not be shared with anyone outside the research and supervision team.

## **Protecting research participants from harm**

Due to the air-borne and highly infectious nature of MDR-TB, I had planned to host focus group discussions outdoors, to avoid transmission of MDR-TB by ensuring adequate ventilation. Practically this idea was not implementable, because noise levels around the venue in central Durban affected the quality of audio and video recordings. All windows and doors to the room where group discussion were held were opened an hour before participants arrived to let in fresh air and were kept open during the discussions.

Facemasks were provided to participants and the team at the start of each focus group discussion. Unsurprisingly, considering how stigmatised having MDR-TB is, none of the participants wore the masks. This caused a conundrum for the research team about whether to wear their own masks, and risk alienating participants, or to leave the masks off and risk infection with MDR-TB. The research team did not wear masks in the end. Deciding to wear a mask would have been impractical anyway, because of the difficulty of being audible while speaking with a mask on and recording the group discussion would have been practically impossible. I was satisfied that reasonable measures had been taken to reduce risks of infection to not be concerned about the non-use of masks.

I had anticipated that discussions about failures to adhere to treatment and lived experiences of stigma and discrimination, among other issues, could raise negative emotions within participants. I had also feared that some participants would feel judged for defaulting on treatment, and that this would negatively impact their contributions to group discussions and, consequently, the richness of data collected. The 'do no harm principle' was applied, considering findings that qualitative studies into sensitive topics can potentially pose significant emotional and other risks to both participants and researchers (Sanjari *et al.* 2014; de Oliveira 2011). An opportunity with one respondent who I felt had particularly valuable experiences to share was used to address challenges where this respondent looked like she was uncomfortable talking about her experiences in the group.

## **Security and storage of data**

While the study was on-going, study research data in the form of signed consent forms, recordings, transcripts, photographs and video recording were kept on my personal laptop and backup storage in the form of an external hard drive that was

kept in a secure location. Copies were made available to my supervisors as data collection progressed. Once the research was concluded and the findings presented, it was planned that these materials would be kept by the principal supervisor for five years, after which they would be disposed by shredding of documents, incineration of any electronic recordings, and deletion of e-mail correspondence.

### **Responsibility to research partners: Sharing findings of the study**

I committed to submit a copy of the final thesis to the KwaZulu-Natal Provincial Department of Health and King Dinuzulu Hospital, together with a link to the electronic version after publication of the final thesis. A summary of findings has been prepared for sharing with staff at King Dinuzulu Hospital for dissemination to research participants and other patients who might be interested in the findings.

### **Summary**

This chapter discussed the multi-step sampling procedure applied to identify study participants and explained the recruitment strategy applied. I presented the research procedure I followed, as well as the locations of data collection strategies applied to ensure that rich qualitative data was collected. I explained how I utilised research methods that include key respondent interviews, focus group discussions, survey questionnaires and the reflexive journal to collect data from a cross-section of participants about experiences of vulnerable young women being treated for MDR-TB and their treatment literacy needs. Studies in the qualitative research methodology deem it important to faithfully represent respondent's words, actions and accounts in the research report (Palton 1991), a consideration that influenced the data collection methods and approaches, development and application of research tools, as well as the analysis of data in this research. The research adopted an inductive approach to identify patterns in and make associations between data to reach conclusions about the research problem (Snape and Spencer 2003). In Chapter Seven, I discuss the data analysis process adopted with reference to the conceptual framework presented in Chapter Five.

To reiterate, primary data for this research was collected through in-depth interviews with eight participants, and three focus group discussions with 10 culture-sharing women aged from 18 to 34 years being treated for MDR-TB via the DR-TB Unit at King Dinuzulu Hospital, eThekweni Metro. Because data was collected in eight 'events' over a seven-month period beginning in early March and ending in late September 2018, a lot of time was allowed between data collection sessions. This time was used to analyse the available data to make tenuous links in emerging themes before the

next stage of data collection, allowing for emergent themes to be followed and probed in subsequent information gathering sessions (Pope *et al.* 2012; Braun and Clarke 2006). Crucially, this time was also used to identify divergent data that ran counter to the emerging hypothesis, and which was, therefore, essential to investigate further (Ke and Wenglensky 2010; Pope *et al.* 2000). Where these occurred, they were considered essential to the research and initially recorded as 'other' (Ke and Wenglensky 2010; Pope *et al.* 2000). These themes were set aside for analysis and interpretation in later stages of data analysis but framed and included among coded themes as soon as they were identified so they would not be inadvertently lost or excluded.

Audio recordings of interviews and group discussion were meticulously transcribed verbatim; the notes were available for analysis in Microsoft Word documents within a few hours or days of data collection events (Gale 2013). Chapter Seven discusses the iterative thematic data analysis process employed to make meanings from auditable triangulated primary qualitative data that informs this study. As with other studies in the same tradition, this qualitative study generated voluminous textual data in the form of interview and focus group discussion transcripts and observational field notes documented in a reflexive journal (Merriam 2002; Pope *et al.* 2000; Merriam 2009). Similar studies suggest tracking, arranging and presenting research data thematically (Chong and Yeo 2015). In line with these ideas, findings of this study were analysed using interpretive thematic analysis, as explicated in the next chapter.



## CHAPTER SEVEN

### DATA ANALYSIS PROCEDURE AND DISCUSSION OF NASCENT FINDINGS

#### Introduction

Scholars contend that once the methodology is clear, explicating the data analysis process used to make meanings from collected data is the most important facet of any research (Chong and Yeo 2015). This chapter explains the iterative thematic data analysis process employed to make meanings from auditable triangulated primary qualitative data that informs findings of this study. Braun and Clarke's (2006) thematic analysis approach was used to examine findings of this research, to address the three research questions as follows:

- i. What are the main challenges articulated by vulnerable young women receiving treatment at public hospitals in low socioeconomic settings in eThekweni Metro that affect their ability to fully adhere to MDR-TB treatment until completion?
- ii. How do young women in eThekweni Metro receive information about MDR-TB accessed via television and radio and interpersonal communication?
- iii. How can health communication be relayed and targeted to ensure attention to and reach of information by vulnerable young women receiving treatment for MDR-TB in eThekweni Metro?

This chapter discusses how I engaged with the ample data collected and organised it using a defined coding procedure as the first step to understanding relationships among emerging categories in the raw data and the conceptual framework of this study (Chong and Yeo 2015). Adjustments made to the envisaged data collection approach in response to realities on the ground during fieldwork are discussed. Although the chapter primarily expatiates how data was analysed, nascent findings that validate the topicality of MDR-TB treatment adherence research in eThekweni Metro and which substantiate the focus of this research in this area are also discussed. Findings of this research which address question one are presented in Chapter Eight, while questions two and three are addressed in Chapters Nine and Ten. The presentation of findings in these chapters is based on discussion in this chapter.

Braun and Clarke's (2006) seminal six-step process of interpretive thematic analysis of qualitative data was utilised for this study. Qualitative researchers use thematic

analysis to identify, analyse, link, interpret and report patterns or themes in detail as they relate to phenomenon of interest (Maguire and Delahunt 2017; Nowell *et al.* 2017; Braun and Clarke 2006). The approach is suitable for this investigation in an area where little was known about how public health communication can be improved to enhance MDR-TB treatment literacy among vulnerable patients and their support systems to contribute to improvements in clinical outcomes in low socioeconomic contexts. The analysis of data resulted in the identification of significant broad thematic clusters, including cultural beliefs and practices, environment and socioeconomic status, biomedical and structural considerations, and intrapersonal and relational factors. These are discussed below.

### **‘Naming and claiming’ the data analysis process used in this study**

This qualitative study generated voluminous textual data in the form of interview and focus group discussion transcripts and observational field notes documented in a reflexive journal (Merriam 2002; Pope *et al.* 2000; Merriam 2009). The type and volume of data collected, and insights from literature discussed in Chapter Four informed my decision to track, arrange and present the data thematically (Chong and Yeo 2015). Scholars aver that thematic analysis is a foundational data analysis strategy and that emerging scholars must be instructed in this method first, as it supports acquisition of knowledge and skills necessary to competently conduct other forms of qualitative analysis in research (Braun and Clarke 2006). They do, however, concede that the approach is ‘poorly demarcated, rarely-acknowledged, yet widely-used’ (Braun and Clarke 2006:77).

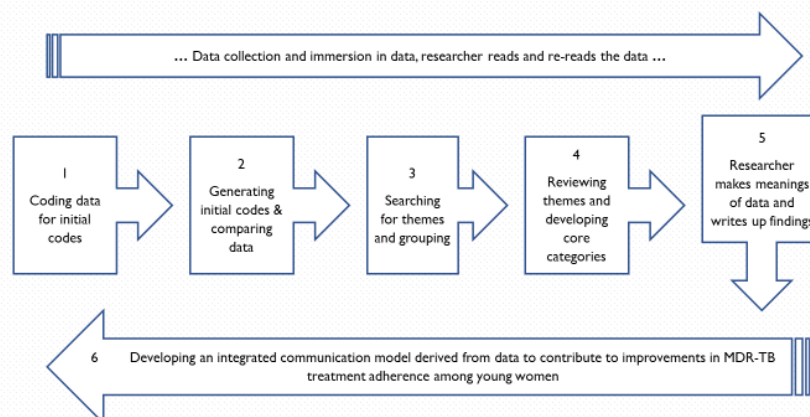
Thematic analysis is equally extolled and criticised for being versatile and flexible, especially because there are several documented iterations of how to scrutinise data using the method (Maguire and Delahunt 2017). Because of this, scholars urge researchers to elucidate what they are doing, and how they are doing it, and to ensure that how they inductively analyse data and infer themes or categories presented as research findings is clearly explained (Nowell *et al.* 2017; Merriam 2009). Achieving this, however, is impeded by the documented dearth of literature on how to practicably analyse data thematically (Nowell *et al.* 2017; Braun and Clarke 2006), although there is no shortage of theoretical discussion on the method (Maguire and Delahunt 2017). To neutralise potential critiques about the integrity, legitimacy and replicability of findings presented, this thesis employs a ‘named and claimed’ purposeful thematic analysis approach to handling data as suggested by Braun and Clarke (2006:8).

This study embraces the suppleness of thematic analysis, even though this quality has attracted reproaches that the approach lacks academic rigour and, therefore, results in studies that are not replicable, threatening the validity of research that applies this approach (Maguire and Delahunt 2017). Notwithstanding some critiques, this study takes the position of Braun and Clarke (2006), who insist that thematic analysis alone is suitable for addressing complex and nuanced themes in primary data.

It is important to note that the quality of thematic analysis is predicated on the skill and perspicacity of the researcher as research tool and that my interpretation of findings from the data was impacted by my outlook, the focus on addressing the research questions, the conceptual framework delineated in Chapter Five and this study's positioning in social constructionism as the research paradigm (Maguire and Delahunt 2017; Nowell *et al.* 2017; Charmaz 2008; Braun and Clarke 2006). Perceived shortcomings in relying on my skills in analysing and presenting findings of this research is mitigated by scholars who urge researchers to incorporate their viewpoints, values and understanding into generating new models for complex problems and phenomenon (Chong and Yeo 2015; Charmaz 2008). Indeed, some insist that scholars must remain open to allowing concerns of participants to take precedence and guide core findings extracted from the data and the meanings made (Holton 2009).

Thematic analysis and social constructionism converge in their insistence that interpreting the meanings that individuals or groups attach to their experiences should be done with consideration for how the social contexts within which they occur influence them (Charmaz 2008; Allan 2003; Braun and Clarke 2006). They were applied to systematically elicit and categorise codes, themes, ideas and concepts emerging from the iterative collection, analysis and write-up of data. Maguire and Delahunt (2017) and Nowell *et al.* (2017) practically demonstrate how to undertake thematic analysis in qualitative studies and their articles influenced how the method was applied to this research. Figure 13 illustrates how data analysis was conducted. The process is amplified in Chapters Eight and Nine, where findings are presented.

Figure 16: Six-step data analysis process



### Step 1: Immersion in and familiarisation with the findings

Step 1 of data analysis spanned from early March to early May 2018, during the preliminary fieldwork phase. In this reading and early coding stage I familiarised myself with the collected data by transcribing interview notes, reading and re-reading typed transcripts and analysing them for nascent themes and tentative associations in a recursive process (Chong and Yeo 2015; Simmons 2014). Interviews were transcribed within a few days of collecting data and simultaneously analysed for findings as I typed them up. I also began keeping a reflective journal at this stage.

Familiarising myself with the findings as they were collected was helpful for establishing knowledge and perceptions of the magnitude of the MDR-TB problem in eThekweni Metro and the contribution of low adherence to the scale of the epidemic. Through this process, nascent ideas about the relevance of communication as a viable response among participants to this study were read. Key participants in these early interviews explained that in KwaZulu-Natal,

Eleven people die each day of a preventable, treatable disease; that tells you something. It tells you that people don't know the signs and symptoms because as soon as anyone has any of those symptoms, they should immediately think TB... why don't they know the signs and symptoms? Because it's [information] not out there. In the early days of HIV, we had a lot of money for education, and we did so much with it. That's what we should be doing for TB now (R. Page, Deputy Director: Advocacy, Communication and Social Mobilisation, Provincial TB Control Programme of the KwaZulu-Natal Provincial Department of Health, Interview, 6 March 2018).

Although the numbers for DR-TB are not as huge as those for drug-sensitive TB ... it [DR-TB figure] is above the national target of where we should be. I think its way above where it should be; the target is that we should have less than five per cent of [patients] lost to follow-up. But at this point we are at more than five per cent (N. Ngomane, Clinical/Technical Advisor, Tuberculosis Control Programme, KwaZulu-Natal Department of Health, Interview, 10 April 2018).

These insights helped to validate the study's viability as they substantiated the premise in this thesis that the intersection of sub-adherence to MDR-TB treatment and insufficient health communication in eThekweni Metro is worth researching.

Data analysed in Step I was derived from six lengthy and broad interviews with three KwaZulu-Natal Department of Health staff and three nurses at King Dinuzulu Hospital. As explicated later, data collection became narrower and more focused as the research progressed. It is important to explain that because of the homogeneity of roles of nurses at different grades in the DR-TB Unit at King Dinuzulu Hospital, commonalities in the information they provided and themes emerging from their contributions were already evident at this stage. The research achieved theoretical saturation in understanding how nurses educate MDR-TB patients about treatment early on. This finds explanation in that treatment education is meagre and informed by a consent form that patients sign to agree to MDR-TB treatment. Nurses did not indicate referring to any standardised content, for instance that in the National Tuberculosis Treatment Guidelines (2014), a copy of which was observed in the matron's office where interviews were occurred at King Dinuzulu Hospital.

Saturation of information from nurses was also reached quickly because nurses spend very little time communicating with patients. Volunteer health educators do this work, although there is still low emphasis on educating patients to adhere to treatment.

There are counsellors outside on clinic days. They've got an electronic flipchart that they use on the TV. And if they have pamphlets, they give those out as well. They first explain what TB is; signs and symptoms, and then they show how the patient is supposed to cough and close the bottle (Nurse #2, Interview, 7 March 2018).

We use the TV in the area outside to give information about how to produce sputum and how long treatment is. We also counsel outside. It happens in groups (Nurse #1, Interview, 7 March 2018).

Finding out about the more significant involvement of volunteer health educators in communicating with MDR-TB patients necessitated the expansion of the respondent list to include someone in this role. This was important to the study's aim of identifying persons or categories of persons within health facility settings able to knowledgeably

discuss how and what sort health communication happens with patients via interpersonal communication in healthcare facilities as this influences how strategies in the communication model proffered in Chapter Ten can be practicably implemented.

### Keeping track of initial ideas

A system to keep track of initial thoughts and ideas about the research findings and emerging themes was developed. Themes were linked to each other and to the content in the literature review and conceptual framework chapters and analysed in the context of the extent to which they helped address research questions 1 and 2 initially. Core theoretical concepts were thematically identified, and weak connections made between central ideas and existing literature at this point (Simmons 2014). As illustrated in the screen grabs in Figure 17, I conducted textual content analysis (Allan 2003; Pope *et al.* 2000), noting early observations in the reflexive journal and the margins of typed research transcripts.

Figure 17: Preliminary reading of transcripts, data analysis and coding

and ask, and it's also about keeping lines of communication open.

There are also issues of **young women and depression**, the psychological component of it [treatment].

There are also issues as to **who now will find the patient attractive** once they know that they've had MDR-TB. The issues of 'is my information **confidential** or do other people know'? Because they [young women] are at a very critical stage of looking at impressing other people, **and also** at a stage where there is courtship, and the person might be in a relationship and whereas females are more accommodative of situations, boyfriends, it could be a factor that **he's not going to hang around and wait for a girlfriend who is admitted in hospital.**

**8. TB is a notifiable disease, so when we do contact tracing, and a woman discloses that she has an intimate partner, but indicates that she is not comfortable telling him she has MDR-TB, what can health workers do?**

I think that's where the counselling is an ongoing issue, but you also need to set the endpoint to **say 'we will get to this point'** - and it's all part of the plan to say [to the patient] 'it's either you do it, and when you do it lets plan how you do it. If you don't do it, because it's in the interest of public health, my job is to make sure that its done'. But let's continue, and it **has to be** upfront from the beginning to say let's give you a month. You can come here weekly, we can talk about it and we can plan which would be the best time to tell him, **but if you don't tell him by the end of one month, then I will be forced to do so, whether or not you come back. But I will be forced to do so.**

**11. Who else should we target with information in the hopes that they can influence young women to adhere to treatment?**

It would be **another person of the same age who is female and has undergone the same process.** An influencer, I would say. But again, **we need to understand who are we dealing with** because for someone else the influencer can be the child motivating the mother to say please do this so you can live. But it also depends on how old the child is. For another one if the husband is supportive, he can be the very same one motivating his wife, for someone else the parent. For another person it could just be the healthcare provider whom they have confidence in and faith.

**PM Petronella Mugoni** April 12, 2018  
MDR-TB treatment, love, sex, relationships and **marriage** – theorise the importance of children in African communities, and the challenges that an MDR-TB diagnosis brings to a woman's life ... particularly if she has not begun reproducing and her fertility has not been proven

**Petronella Mu...** Lack of confidentiality of patient

**Petronella Mu...** Lack of support from intimate

**PM Petronella Mugoni**  
The fact that is a notifiable disease, and the healthcare workers may not prepare the patient sufficiently, or give them enough information to go and inform their partner that they have MDR-TB but that it is treatable and curable, may negatively impact women's ability to stay on treatment long-term, particularly if they do not have the necessary information or vocabulary to explain the treatment modalities, what the drugs do and how important it is take all doses as prescribed. This is related to challenges of communicating MDR-TB in layman's terms, and the difficulty of communicating the long treatment journey in ways that can be easily understood by lowly educated people.

**PM Petronella Mugoni**  
Two-Step Flow

Influencers would be:

- Female
- MDR-TB survivors
- Children in these women's care
- Community leader
- **Healthworker**
- Rich person (latching onto the celebrity status of this individual and the patient's aspiration to be like them)

### 13. Is there anything else you would like to share?

- TB is an old disease. If we can start teaching about TB in schools earlier, because once you know about thing earlier in life, like how we teach things in primary schools, so you don't only know about TB because you have contracted the disease, because now you can't even process properly because you've just heard about it. I feel that if we can target information about TB and drug-resistant TB to young people, when they grow up even if it's not only for themselves, but to support others, if they can get the information that would be great. Because I feel that it gets so confusing for them, and it doesn't give them time to really think about this, because they've got the disease they have to start the treatment now.

PM

**Petronella Mugoni**

Communication about TB should not merely focus on the patient, at the time when the women have been diagnosed with TB and are being initiated on treatment. Rather, information provision should be more far-reaching, to focus on children in their formative years, similarly to HIV education

- Maybe, as I was saying [communicating] by stages because the other challenge is we find that around nine months (on the 24-month treatment regimen) that's where they default. So if it can be really explained that, you know, even at nine months this is the stage that the bacilli is at and unfortunately if you default at this stage, you are making it [bacilli in the body] more aggressive. So using visuals where it's aggressive.
- Because the body at that time [nine months of treatment] feels much much better, so they are like, I'm feeling better now why should I even continue with this medication that causes me this and that feeling. And it might be because, you know, for some of them it might cause a bit of mood swings. There are some, like your Tyridizone and others that cause a bit of psychotic moods. And you might find that women with their hormones already, maybe this can even enhance them even more. So if you are feeling a little horrible all the time it can be a challenge. But if they know the benefits, if the benefits can be enhanced more, they might tolerate it until the end of treatment.

PM

**Petronella Mugoni**

Feeling much better

PM

**Petronella Mugoni**

Mood swings, hormones and psychosis. Is psychosis in women taken seriously when reported, or is it put down as 'mood swings'?

PM

**Petronella Mugoni**

Clear communication that informs the patient about the benefits of staying on treatment by clearly explaining each stage of the treatment journey, what each drug does and what the patient should be feeling at each point

Typing up notes, observations and embryonic analyses in the margins of transcripts and writing in the reflexive journal during the early stages, while the interviews were still fresh in my mind, primed me for writing up the findings, with detailed analyses and associations made in Step 6 (Braun and Clarke 2006). Data was analysed as soon as it was collected and, adopting a repetitive approach, I read transcripts of newer interviews together with earlier ones to re-familiarise myself with the contents and make more tentative linkages between findings. The writing process itself often highlighted other patterns or themes worth scrutinising or pursuing through more fieldwork, as discussed later in this chapter.

The approach to scrutinising data illustrated in Figure 17 supported the incorporation of new lines of inquiry into the research guides that were used with young women and their household contacts from late May to late September 2018. Analysing data and writing up the findings occurred cyclically, with early reviews pointing to new strands of inquiry to follow and suggesting themes to look for in subsequent data collection events (Research Methods Knowledge Base no date). Some research tools were extensively revised to respond to unanticipated themes that emerged from the first round of data collection. The quotation below was among these; a key participant shared:

You would not believe how many people now, 20 years after democracy, have no schooling. And we are talking young people. I was shocked by that, I thought everybody had to go to school. There are a lot of people who've

never been to school and they are only in their early teenage years or their 20s (R. Page, Interview, 6 March 2018).

This insight prompted the revision of questions in the research guides that were too technical and/or pitched at too high an academic level and, therefore, inaccessible to the 'typical' vulnerable young women with MDR-TB in eThekweni Metro as described in Chapter Four. The possibility that unnecessarily complicated language would alienate participants and affect participation was considered. This led to contemplation that nuances in MDR-TB biomedical and technical terms in English would not translate well into isiZulu and that I, a non-isiZulu-speaking researcher, would struggle to expound unclear questions without interpretation during focus group discussions. Some questions were consequently simplified to abridge and elucidate lines of enquiry in the research guides. Furthermore, questions deemed superfluous to the task of gathering sufficient information to address the research questions were excluded altogether at this stage.

## **Step 2: Generating initial codes**

Step 2 involved more reading and re-reading of research transcripts in search of emerging codes and to solidify links identified in the data in Step 1 (Allan 2003). I continued to systematically organise, categorise and list collected data in this step (Braun and Clarke; Maguire and Delahunt 2017; Nowell et al. 2017). Once I had fully immersed myself in the data and was familiar with its contents, I expanded analysis of the information in its textual form via an informal type of content analysis to identify preliminary themes (Ke and Wenglesky 2010; Allan 2003). Identified themes were indexed as the first step to generating analytical categories and theoretical exegeses in subsequent phases of data analysis.

Reading and re-reading of transcripts resulted in the classification of four themes, which were informed by the research questions and linked to the objectives of the study. The themes were used to organise the generation of codes and their indexing in clusters for ease of reference (Allan 2003). The main themes identified at this stage were:

- i. structural, cultural and gendered issues that drive primary infection of MDR-TB in eThekweni and hamper infection prevention efforts and treatment adherence;
- ii. forms of mass media and messages frequently accessed by young women on treatment for MDR-TB and their contacts



- iii. people or groups with most influence in terms of communicating health information to young women with MDR-TB for behaviour change; and
- iv. media programmes/content/messages identified.

Over many months of the research, an iterative process to code and identify themes, often in tandem with data collection was adopted. While engaging with the data, instances where participants used words and phrases that highlighted issues of importance to the research often became clear (Ke and Wenglesky 2010); this also happened during data collection. These axioms were noted verbatim or as paraphrased sentences and associated with a code (Ke and Wenglesky 2010; Allan 2003). It was common for more than one code to be derived from the same text (Allan 2003). Interesting or unfamiliar terms were included in anticipation that they could result in unique analytical categories appearing later in the process (Pope *et al.* 2000). Some inimitable findings identified through this process and how they influenced changes in the research approach are discussed in this chapter. Identified themes were examined against content in new transcripts following each data collection event to ensure their continued utility and representativeness and interminably added codes to the table.

From this process, the shortened phrases that emerged were considered codes and listed as such in the table in Appendix 12, which presents how all data collected and exhaustively interpreted was organised and coded. Table 4 is an abridged version of Appendix 12. As discussed later, thematic analysis in this research did not involve the mere counting of analogous words or phrases in transcripts and presenting the most ubiquitous information as fact. Instead, data coded in Step 2 was analysed further using an interpretive lens to identify latent themes and lay the foundation for deeper analysis in Step 3, where the approach allowed for tentative linkages to be made, as explained in the next section.

Table 4: Coding for initial themes

<p><b>Theme:</b> Structural, cultural and gendered issues that drive transmitted infection of MDR-TB in eThekweni and hamper infection prevention efforts and treatment adherence</p> <p>Codes</p> <p>Failing at sputum-taking</p> <p>“There is so much”</p> <p>Hungry for knowledge</p> <p>Long uncomfortable journey</p> <p>High cost of new MDR-TB drugs</p> <p>‘Like HIV counselling’</p> <p>Can’t make patients wait to start treatment</p> <p>Throw resources at</p> <p>Hectic protocol in government</p> <p>No budget for ACSM</p> <p>All TB budget goes to treatment</p> <p>Outbuilding</p> <p>No schooling</p> <p>Find a job</p>	<p><b>Theme:</b> Forms of mass media and mass mediated messages frequently accessed by young women on treatment for MDR-TB and their contacts</p> <p>Codes</p> <p>High literacy rate</p> <p>TB is a hidden something</p> <p>eThekweni has most media in KZN</p> <p>Community radio &amp; newspapers</p> <p>People listen to community radio</p> <p>Radio &amp; TV</p> <p>Gagasi &amp; Metro FM</p> <p>Five FM or East Coast Radio</p> <p>Age is a big thing</p> <p>Music is a biggie</p> <p>Social media</p> <p>DVD in hospital waiting area</p> <p>Captive audience</p> <p>Edutainment</p> <p>One-on-one</p>	<p><b>Theme:</b> People or groups with most reported influence in terms of communicating behaviour change and health information to young women with MDR-TB</p> <p>Codes</p> <p>Can’t be sure exactly what works</p> <p>Cover everything</p> <p>Churches</p> <p>In bars, pubs and shebeens</p> <p>Hear something 3 times for it to stick, so 3 things</p> <p>Standardised to suit (demographics)</p> <p>Health workers shouldn’t decide what information patients get</p> <p>Teaching TB in schools</p> <p>Ambassadors</p> <p>Role models – ask the young people</p>
<p>Other co-morbidities</p> <p>MDR-TB/HIV coinfection 75% in KZN</p> <p>Inadequate education prior to treatment initiation</p> <p>High workload among healthcare workers</p> <p>60% already on ARVs</p> <p>400 informal settlements in the metro</p> <p>Ventilation is an issue</p> <p>Empty stomach</p> <p>Main five group of meds</p> <p>Injectable medicine for 4 months</p> <p>‘Pills just fill my stomach’</p> <p>Child-bearing age</p> <p>No decent jobs, no sick leave</p> <p>Some meds contraindicated in pregnancy</p> <p>Negotiating sexual activity difficult</p> <p>Dependent on a man</p> <p>By nature, women listen better</p>	<p><b>Theme:</b> Media programmes/content/messages identified</p> <p>Codes</p> <p>TB can be cured</p> <p>Signs and symptoms of TB</p> <p>Early presentation saves lives</p> <p>Treatment adherence is the 1st way to prevent TB</p> <p>MDR-TB diagnosis disclosure plan</p> <p>Explain expected treatment journey upfront</p> <p>Basics of MDR-TB</p> <p>Prevention and cure</p> <p>What each drug in the regimen does</p> <p>Simple language</p> <p>Visual journey of TB infection and treatment on a timeline</p> <p>Communicating by stages</p> <p>Names of specific TB drugs</p>	

Extensive literature reviewed in Chapters Three and Four explains why people may fail to adhere to MDR-TB treatment. It was clear while analysing data at the beginning of fieldwork that this research needed to ask questions differently to avoid regurgitating what was already known and instead contribute new knowledge specific to the researched case study and context. Advancing new or novel findings to understanding of the complexities that impact a defined vulnerable population's suboptimal adherence to MDR-TB treatment was dependent on the questions research participants were asked, and the links and meanings made in the findings during data analysis. Adjustments to the research tools and expansion of the key respondent list as described earlier was undertaken to further improve the quality of information collected.

It is important to clarify here that many of the broad themes that emerged from the preliminary analysis of data in the early stages were discussed in the literature review chapters of this thesis. Indeed, in line with conclusions reached in Chapter Four, one of the first key participants interviewed was clear that:

We know why people default, that information is out there. People default for a lot of reasons and we know what those reasons are. A lot of those reasons are out of the Department of Health's control. For example, people's socioeconomic backgrounds, where they are living, who they are living with, the poverty, those are all socioeconomic things that cause a person to default. We know that (R. Page, Interview, 6 March 2018).

Reading of data to make meanings from it in this phase of analysis was not undertaken in a vacuum. My experiences working in and knowledge of the TB management field in South Africa ineluctably influenced how I interpreted findings. Furthermore, five significant factors in 2017 and 2018 and my involvement in each must be considered in relation to their potential influence on the meanings made from the data. As discussed in Chapter Six, two studies published in 2016 and 2017 established the growing challenge of primary transmission of DR-TB in eThekweni Metro, and influenced the design of this study. Indeed, findings in the study by Shah *et al.* (2017) sparked policy makers, practitioners (including me through my employment) and those in the health fraternity to intensify efforts to assuage the crisis in KwaZulu-Natal through multi-sectoral interventions during 2017 in a process discussed in Chapter Five.

In 2018, however, these same stakeholders, led by the National Department of Health, shifted attention to 'finding missing TB patients' nationally, resulting in reduced momentum on DR-TB infection prevention and treatment efforts in eThekweni. The 'finding missing patients' initiative was launched in reaction to the WHO's (2016)

'Global tuberculosis report', which estimated that 154,000 people with TB in South Africa were undiagnosed or not receiving care. Once 'found', the initiative emphasised ensuring that people with confirmed TB were initiated on treatment and their contacts screened for symptoms of the disease. This was the first factor.

Secondly, at a press briefing in Johannesburg on 30 August, Tamaryn Green, recently crowned Miss South Africa 2018, disclosed that she was TB survivor and launched her #BeatTheStigma social media campaign, which aimed to contribute to alleviating negative effects of TB infection and treatment on children and women specifically. I shared the stage with Miss South and a representative of the Department of Health as a speaker in a panel discussion at the event. The third initiative was topical in September, when the country launched the South Africa Chapter of the Global Tuberculosis Caucus of Parliamentarians. The initiative was formally debated in Parliament in Cape Town on 4 September and the motion to constitute the caucus passed by all political parties. I was present at both the debate and the launch in my professional capacity. The fourth factor is that on 21 September the United Nations convened the first-ever High-Level Meeting on Tuberculosis held in New York, United States of America. An indication of how important the last event was to global and national efforts to end TB is that while this was the first high-level meeting on TB, there had already been three such assemblies convened to discuss the HIV epidemic, in 2008, 2011 and again in 2016.

Fifthly, but not insignificantly, South Africa launched its maiden TB prevalence survey in KwaZulu-Natal province in August 2017; the survey was ongoing nationally at the time of data collection and was scheduled to conclude in June 2019 in Western Cape province. It serves this study to briefly discuss the survey. Many potential participants' responses to the national survey were lukewarm, for various reasons. Besides lack of knowledge about the scientific impetus and national interest in establishing the prevalence of TB in the country and the importance of broad participation, low communication and public awareness about the survey process affected enrolment. Additionally, insufficient public knowledge about how TB is transmitted and the scale of the challenge in South Africa led to many participants who felt their risk of TB infection was low refusing to consent to participate. This was despite that the survey aimed to establish prevalence, not incidence of TB. Low participation in the survey was common in affluent neighbourhoods and areas where the majority of residents were not Black.

The events in 2017 and 2018 discussed above were significant to this study because they contributed to higher than usual coverage of TB in mass media for a year between August 2017 and September 2018. The events also illustrate the multiple and oft-changing priorities of TB stakeholders in South Africa during this period. This study was conceptualised in 2017 when addressing MDR-TB in eThekweni was an urgent priority of the NTP, sparked by Shah *et al.*'s (2017) study, but data was collected in 2018 when national attention had shifted back to TB broadly, and was divided among the four enterprises (excluding Miss South Africa's campaign) discussed above and others. I use this explanation to sign-post that external events had bearing on how I approached the analysis of data for this research.

### **Step 3: Searching for themes**

In Step 3, I applied key-point coding in a process that involved identifying important points from research transcripts then concentrating subsequent analysis on these (Chong and Yeo 2015). The original interview and focus group discussion transcripts were read and re-read, and synthesised identified codes were included in the coding frame in Table 4. Through constant comparison (Gale 2013), each grouping was examined with reference to the rest of the dataset to create analytical categories using a systematic approach (Pope *et al.* 2000). Indexed themes and categories based on phrases, incidents, or behaviours observed during fieldwork were identified through continuously reading the data (Pope *et al.* 2000). Some of these are expatiated in this section.

I referred to quotations from research participants and my own comments and early analyses written in track changes in electronic Microsoft Word documents as illustrated in Figure 17, to progress towards making meanings from the data and presenting them as findings. Broad themes identified in this process were listed on a large flipchart paper that was stuck to a wall in my study space. Because the themes were in my line of vision, I was constantly reflecting on them; analysing, arranging and re-arranging them into narrower more specific themes over many months. The refined themes identified through this process are: socioeconomic factors, biomedical factors, structural issues, gender considerations and communication and health literacy challenges. These are outlined in Table 5.

Table 5: Narrowed codes from initial coding – searching for themes

<p><b>Theme: Socioeconomic factors</b> (Linked to patient's gender, race, age and geographic location)</p> <p><b>Codes</b> Poverty Overcrowded accommodation Poor housing Greater risk of infection Unemployment Employment No employment protections Food insecurity Vulnerability Transport fees Poor access to health services Poor treatment at health service due to marginalisation Greater healthcare needs Co-morbid conditions + risk of infection About to complete treatment</p> <p><b>Communication issues</b> Illiteracy Low formal education Unable to follow treatment instructions Unable to ask relevant questions Poor agency, affecting ability to be own health advocate Less sensitivity towards women patients</p>	<p><b>Theme: Biomedical factors</b></p> <p><b>Codes</b> Pill burden Serious side effects Treatment fatigue Long treatment Physical pain Psychosis Starting to feel better Stopping only specific medication Co-morbidities</p> <p><b>Communication issues</b> Aetiology of disease not adequately communicated Patients inadequately counselled on treatment Stop-start approach to taking treatment Family/friends not counselled on how to support patients Lack of knowledge about what each pill does Side effects explained Side effects not explained Differences of TB, MDR-TB and XDR-TB not well understood</p>
<p><b>Theme: Structural issues</b></p> <p><b>Codes</b> Insufficient financial resources for communication 'Rushing' to treat MDR-TB Poor health worker attitudes Fear of nosocomial infection Lack of confidentiality Stigma Long distance to health facility Lack of support at home Lack of government funding Communication assigned to workers</p>	<p><b>Theme: Gender considerations</b></p> <p><b>Codes</b> Changes to physical appearance Feelings of shame and self-stigma Fear Psychological distress Love, sex and marriage Gendered power dynamics Vulnerability Reliance on men for livelihoods Intimate partner violence Reproductive capacities</p>

<p>Cultural belief systems at odds with biomedical ideas</p> <p>Judgement of young women</p> <p><b>Communication issues</b></p> <p>Poor education of healthcare workers about MDR-TB</p> <p>Contradictory information given</p> <p>No time to educate/counsel patients</p> <p>Low empathy/sensitivity/compassion</p> <p>Lack of confidentiality</p> <p>Failing to co-opt patients as equal partners in own treatment</p>	<p>Expectations on women's productive capacities</p> <p>Denial among men</p> <p>Patriarchy and male dominance</p> <p>Living alone</p> <p>Lack of family support/still expected to provide</p> <p>Child-rearing</p> <p>Abandoned by partner</p> <p>Impact of treatment on social life</p> <p>Immaturity/youth</p> <p><b>Communication issues</b></p> <p>Illiteracy</p> <p>Low formal education</p> <p>Traditionally conformist and non-questioning</p> <p>Low agency to act on knowledge</p> <p>Little time to access information</p> <p>Low resources to access information via other avenues</p>
<p align="center"><b>Theme: Communication &amp; health literacy challenges &amp; gaps</b></p> <p align="center"><b>Codes</b></p> <p align="center">Insufficient public knowledge about the disease broadly</p> <p align="center">Overwhelming to communicate MDR-TB to patients whose existing knowledge is low</p> <p align="center">Difficulties communicating MDR-TB and its treatment in layman's terms</p> <p align="center">Inadequate time to communicate at health facility</p> <p align="center">Communication left to volunteers as doctors and nurses are too busy</p> <p align="center">Treatment literacy communication is not standardised or exhaustive</p> <p align="center">Low focus on patient's support structures in communication</p> <p align="center">Patients are not considered equal stakeholder in their own treatment, expected to 'comply'</p> <p align="center">Lack of privacy in public health facilities</p> <p align="center">Modes of communication not ideal</p> <p align="center">Low communication on MDR-TB via mass media</p> <p align="center">Mass media is largely silent about TB, MDR-TB and XDR-TB</p> <p align="center">TB information is 'boring'</p> <p>Medium of communication</p> <p>Timing of communication</p> <p>Who is communicating</p>	

Approached methodologically and strictly, thematic analysis supports the presentation of valid findings derived from a replicable process (Nowell *et al.* 2017; Pope *et al.* 2000), which is why Tables 1 (in Appendix 12) and 2 are presented in their entirety in this thesis. Thematic analysis demands that the researcher remains cognisant of the importance of 'identifying and describing both implicit and explicit ideas' evident in the data (Guest *et al.* 2012:10). Crucially, the method 'cannot and does not seek to focus

on motivating or individual psychologies, but instead seeks to theorise the sociocultural contexts and structural conditions that enable the individual accounts that are provided' (Braun and Clarke 2006:14), so care was taken in coding to consider what the findings might mean to vulnerable young women within the context of an urban, marginalised community in eThekweni Metro.

With reference to the context of enhanced communication about MDR-TB discussed in Step 2, it was deemed important to firstly establish the perceived seriousness of MDR-TB in eThekweni Metro in 2018. The aim was to establish whether participants who would be required to address questions about this phenomenon were aware of the rising incidence of primary transmission of MDR-TB and the threat it posed to public health in their communities at the onset. This was achieved early on; where an interview participant confirmed that 'It's a known thing, MDR-TB is not just from defaulting now. It's from primary exposure, so people are catching it from somebody else for their first time around' (R. Page, Interview, 6 March 2018). Another respondent explained that,

... a significant amount of the MDR-TB is [the result of] persons getting infected with MDR-TB, of being treated for MDR-TB for the first time. In the past we usually focused on – which is still relevant – that TB resistance is formed through non-compliance to medication, or inadequate treatment of clients. But we've seen that ... we are having issues with infection prevention at community level, and even in households so that is why we see clients presenting for the first time with TB, but more so with MDR-TB (N. Ngomane, Interview, 10 April 2018).

Data analysis clarified that research participants in all categories, not just senior personnel in the Department of Health mandated to manage the epidemic, were aware that transmitted resistance was a significant contributor to the burgeoning DR-TB epidemic in eThekweni Metro. In an individual interview with the volunteer health educator, she demonstrated knowledge about transmission of TB through her explanation that:

TB is contracted through the air. It could be through a window; you might not know who you are sitting next to. As the person coughs you catch the infection. You get both TBs the same way, even though they differ; sometimes by defaulting treatment of simple [sic] TB or not taking the complete treatment. You find that your immune system remains prone to TB because it has been robbed of healing, so it comes back as MDR-TB. (Volunteer, Interview, 24 May 2018)

These findings validate the significance of primary MDR-TB as a public health challenge that was receiving attention from stakeholders in the field at the time of collecting data. Findings at this stage also further substantiated the cogency of the research topic.



They were useful for establishing participants' knowledge about primary MDR-TB and ability to clearly communicate this information to patients in ways they could understand. It also situated volunteer health educators at King Dinuzulu Hospital as potential providers of enhanced MDR-TB treatment education and adherence support, particularly considering the inimical relationship between patients and nurses, as discussed in Chapter Four and presented as part of findings of this study in Chapter Eight. These interesting threads were followed in subsequent data collection events, particularly to ascertain who or which groups of people were best placed to communicate about TB.

Participants to this study generally demonstrated high awareness that MDR-TB can be transmitted. The documented low public knowledge and communication about TB in South African communities, however, still suggests that while people with MDR-TB and those directly affected, among them family members, healthcare providers, and Department of Health personnel, are knowledgeable about the drivers of the epidemic, people in the general population are not as informed. Reflections of a participant that 'People automatically think that because you have MDR-TB you defaulted before' (Nothando, 30 years, Interview, 29 September 2019) implies insufficient knowledge about the scale of primary resistance in eThekweni, particularly when compared to the awareness demonstrated by research participants. This finding pointed to the need for a two-pronged approach to public health communication about MDR-TB: one targeted at patients to increase their adherence to treatment and the other for the public to improve their knowledge about how to prevent and identify symptoms of MDR-TB and how the disease is treated. The latter was especially important to do because, as a key respondent explained:

TB is a hidden something. They share one or two things about it. Our government, I think, is too busy with other things. I think they are too busy because there should be awareness everywhere we go, but it's not there (Nothando, 30 years, FGD#3, 29 September 2018).

Suggestions in findings of this study that dissemination of information to educate the public in eThekweni about MDR-TB transmission is insufficient urges for more deliberate efforts to improve communication and treatment adherence rates as an effective infection prevention strategy. A common thread running through findings read at this stage of data analysis were participants' sentiments that inadequate dissemination of localised information had negative consequences for individuals' abilities to adhere to treatment, and to prevent new MDR-TB infections. This finding

supported the research objectives, particularly the one to develop the integrated communication model presented in Chapter Ten.

### ***Unanticipated findings from the preliminary analysis of data***

Reading data and generating initial codes in Step Two resulted in some findings which had not been anticipated at the onset of the study. The theme of vulnerable young women, their intimate relationships with men, and impacts of financial dependency, gendered power dynamics and intimate partner violence in patriarchal societies with strong traditionally defined gender norms were identified as contributing factors to sub-optimal adherence to treatment among the case study. There are parallels between these findings and what is known about reason for young women's greater susceptibility to HIV infection in countries in sub-Saharan Africa. All subsequent data collection events with young women incorporated these themes and questions were added to the research guides to probe the issues further.

Vulnerable women's agency in intimate relationships with men is reportedly diminished, which contributes to their sub-optimal adherence to MDR-TB medication. Additionally, low socioeconomic status is correlated to truncated agency in decision-making about taking treatment. This is particularly so where women are unemployed or under-employed and reliant on intimate male partners for their livelihoods. This information emerged when participants were asked how it was possible that patients could have left-over medication at the time of visiting the hospital to collect subsequent prescriptions. A nurse explained, 'The woman will say she left her medication at home when she went to her boyfriend's house. Then she will default like that. They say, "my boyfriend said I must leave the tablets". And she leaves the medication at home' (Nurse #2, Interview, 7 March 2018).

Fear of or experiencing abuse in domestic settings is another reason why young women might fail to fully adhere to treatment. A key participant shared that:

It is also important to consider that we know that there are abusive relationships, so in families as well we have to be very careful. We need to find out from the woman, because if she is with a partner who can abuse her verbally or use violence, because of the stigma issues of having MDR-TB, we must know this. And mainly it could be that he himself is just afraid, so he takes it out on her in an abusive manner (N. Ngomane, Interview, 10 April 2018).

Lack of agency, control and fear of violence were not the only reasons offered to account for why women failed to adhere to treatment when they were away from their home. While perceptions of key participants were that intimate partner violence

was a significant factor, when young women with MDR-TB in focus groups were asked about lack of support by intimate partners and experiences of violence to triangulate the finding, many reported being with very supportive partners and explained that being in an intimate relationship was in fact protective and did not compromise their adherence to treatment in any way. While this finding was tracked in subsequent data collection events, less emphasis was placed on its importance by participants than was done initially.

Interestingly, findings from later focus group discussions suggested that expectations of women's submission in patriarchal societies has protective effects for younger women; especially for those in the 18 to 22 years age range for this study. Many women in this bracket reported completing treatment and having fewer challenges adhering to their regimes, when compared to women aged 23 to 34 years. Younger young women (18 to 22 years) who participated in this research typically lived with their natal families and had an older female treatment supporter, typically a mother or grandmother, who reportedly adopted an authoritarian but caring approach to supporting younger women to take treatment, as illustrated in the quotations below:

When she was going to be hospitalised, I emphasised that she is not alone in this treatment, God is with her. I told her 'whatever they instruct you to do, do it' (Precious, mother of MDR-TB patient, 22 years).

When I began my treatment, I went for the injection every day and I had to drink pills before eating in the morning. I remember this one time I fainted on my way to the clinic. I skipped days when it was my clinic days. Sometimes I signed my own card on behalf of the nurses to avoid going there. For two consecutive days I didn't go, then the DOT supporter came and reported to my mother that I wasn't going to get my injection. My mother forced me to go, so I went (Busisiwe, 20 years, FGD#2, 21 July 2018).

These findings informed the revision and refinement of research guides to incorporate questions that probed the relationships that young women have with different people around them, and how they impact their abilities to adhere to MDR-TB treatment. This information helps to address the research question 'Who in vulnerable young female patients' lives should be targeted with relevant treatment education for enhanced adherence to MDR-TB medication in eThekweni Metro', by establishing who has influence over their attitudes and treatment intentions.

#### **Step 4: Reviewing themes**

As explained earlier, I wrote copious notes in track changes in the Microsoft Word document margins of focus group discussion and interview transcripts, indicating ideas and linkages in the data as they occurred to me. Sections of text with notes were



## Step 5: Defining and naming themes

Step 5 of data analysis was approached with the aim of teasing out the case study-specific reasons for sub-optimal adherence to MDR-TB treatment and retention in care, as the first step to establishing which factors could potentially be impacted through improving health communication about MDR-TB at various levels, and how this could best be done. Several interesting themes arose from this process. The themes illustrated in the word cloud in Figure 18 are significant as they inform and provide the frame for the presentation of comprehensive research findings in Chapters Eight and Nine.

Figure 19: Reasons for sub-optimal adherence to MDR-TB treatment – whittled themes



The whittled themes in Figure 19 were written on individual colour-coded post-it notes that were stuck on a wall where I could easily and constantly see them during the entire period of gathering and analysing data. This strategy allowed for further refinement of categorisation and grouping of themes as I became more aware of possible linkages that could be made. The categories were refined with reference to the original transcripts and notes, the contents of Table 4, flip chart papers, sticky notes, and implementing colour coding and weighting in an iterative process. From my reading of these many data sources it was possible to sift out the broad vulnerability-determined themes that affect whether vulnerable young women aged 18 to 34 years with MDR-TB are able to fully adhere to their treatment in the long-term.

As this study utilised inductive thematic analysis in line with Braun and Clarke's (2006) approach, I was conscious to not try to fit themes into pre-existing frames based on the conceptual framework during the process of coding, or to align them with my analytical preconceptions while writing up the findings. This study adopted an *aposteriori* thematic approach to the analysis of data, which aimed to identify patterns in and make associations between complex findings strongly linked to data to address the research questions and reach conclusions on the research problem (Merriam 2009; Braun and Clarke 2006; Snape and Spencer 2003). An iterative data analysis and synthesis process was utilised for its utility in supporting production of detailed descriptions and rounded understandings of perspectives presented in the next chapter, which is also Step 6 – writing the report – in Braun and Clarke's (2006) six-step process.

## **Summary**

This chapter discussed how primary data collected for this research was analysed to emerge with findings presented in Chapters Eight and Nine, and the communication model proffered in Chapter Ten. It explained tentative findings from the data analysis process which took the form of 'themes, categories, typologies, concepts, tentative hypotheses' (Merriam 2002) and referenced literature on what is already known about the phenomenon of suboptimal adherence to MDR-TB treatment among vulnerable groups. The chapter discussed several key external events in the TB management field in South Africa and globally which occurred at the same time as data collection and analysis for this study, which potentially impacted the contributions of research participants and, at the same time, the meanings I made from the data. This discussion was supported by the social constructionists' position that it is important to understand a researcher's values and beliefs insofar as they influence interactions with participants, the data analysis process and the meanings that are made from the data (Chong and Yeo 2015).

Care was taken to link nascent findings discussed in this chapter to the study's methodological approach and research epistemology as explained in Chapter Five (Nowell *et al.* 2017; Berman 2013), to situate the interpretation and presentation of data in this chapter and the ones that follow within a defined framework (Braun and Clarke 2006). What I sought to learn from the research at the outset was also considered (Nowell *et al.* 2017; Braun and Clarke 2006), with data analysis propelled by the objective of addressing the research questions included in the introduction to this chapter. Advice from scholars to analyse data concurrently with collecting it in

order to identify emergent categories and theories from transcripts, and to beginning documenting the findings early in the process was implemented (Merriam 2009; Snape and Spencer 2003; Pope *et al.* 2000). Data from different research participant was carefully cross-analysed (Snape and Spencer 2003, Merriam 2002). Further, study-specific systems to categorise the voluminous data collected and documented were developed and implemented towards ensuring that the data analysis and report writing approach was efficient and replicable.

The documentation of data discussed in this chapter and the presentation of findings in Chapter Eight, Nine and Ten was approached with the aim of theorising the sociocultural settings and structural circumstances that qualify individual accounts shared (Braun and Clarke 2006), towards the development of an integrated communication model for improving vulnerable patient's adherence to MDR-TB treatment. This was done within a constructivist framework, which insists that all meaning is socially constructed by individuals in interaction with their contexts (Merriam 2009, Braun and Clarke 2006, van Niekerk 2005). Theories discussed in Chapter Five were applied for guidance in identifying themes and connecting datasets to write-up the findings presented in the next three chapters.

## CHAPTER EIGHT

### VULNERABILITY IN STRONG CULTURAL CONTEXTS: CHALLENGES TO YOUNG WOMEN'S ADHERENCE TO TREATMENT FOR MDR-TB

#### Introduction

Findings presented in this chapter engage with research question one: 'What are the main challenges articulated by vulnerable young women receiving treatment at public hospitals in low socioeconomic settings of in eThekweni Metro that affect their ability to fully adhere to MDR-TB treatment until completion?'. Chapter Nine engages with questions two and three. The assumption which informs discussions in this chapter is that only when impediments to vulnerable young women's adherence to MDR-TB are understood can it be possible to design practicable evidence-based health promotion responses for specific contexts.

Findings presented here largely substantiate this study's assertions that compromised treatment outcomes among the case study partly result from fallacious overemphasis on sophisticated biomedical responses to a public health problem, which urgently requires a scaled-up multisectoral response if it is to be addressed. Qualitative studies typically present findings with detailed accounts of participants experiences in-context (Merriam 2009; Morley 1992) through incorporating rich descriptions and verbatim quotations (Merriam 2002). This chapter and the next instantiate findings advanced with thick descriptions of research participants' contributions. Research findings are explained done within the context of eThekweni Metro described in Chapters One and Two, and with reference to the culture and traditions of Zulu people of KwaZulu-Natal province, South Africa.

It was established in Chapter Five that vulnerability factors are rarely independent of each other (Grabovschi *et al.* 2013; White *et al.* 2009). Indeed, issues that impact vulnerable young Zulu women's treatment experiences are impossible to summarise simply, because although they are varied, they are also inexorably linked. Broad themes identified in the data and illustrated in Figure 19 were further sifted and clustered for presentation in this chapter. This process aimed to illuminate MDR-TB health literacy challenges specific and peculiar to vulnerable women which contribute to their suboptimal adherence to treatment. Discussions in this chapter firstly focus on revealing if, where and why MDR-TB treatment knowledge gaps occur and secondly, suggest how health communication and promotion can contribute to enhancing treatment adherence among this vulnerable population.



Even though socially disadvantaged groups have the greatest healthcare needs, they have the least access to health communication and healthcare services (Grabovschi *et al.* 2013; White *et al.* 2009). Inverse care law suggests that access to decent medical services and need in a population occur contrarywise (White *et al.* 2009). This led to scholars urging for multi-level responses to decrease groups' vulnerabilities and ensure that public health improvements in generalised populations augment the health of vulnerable populations in specified areas and do not further widen health inequalities between the rich and poor (White *et al.* 2009). This study aims to contribute literature to this area.

### **Reasons for sub-optimal adherence to MDR-TB treatment**

It is not possible to present all findings of this research in a thesis of this scope and length (Nowell *et al.* 2017). To ensure that the most relevant data is shared, findings with parallels to literature presented in Chapters Three and Four are briefly discussed to demonstrate concurrence between this research and published studies. Novel findings and data peculiar to the case study of young women with MDR-TB being treated in eThekweni Metro are more capaciously discussed. Scholars argue that fully appreciating health practices of African groups is predicated on holistically understanding the cultural, social, historical, economic and political contexts where ill-health occurs (Krumeich *et al.* 2001; Burhmann 1984). This study subscribes to this position. EThekweni Metro's social, historical and economic context in relation to the MDR-TB epidemic and the challenge of primary resistance and sub-adherence to treatment was explained in Chapter Two. Accounts of research participants are discussed with this background, and descriptions of the cultural beliefs and practices of the Zulu weaved into discussions of the findings presented in this chapter.

### ***Moralisation of MDR-TB: Convergence of HIV and MDR-TB stigma***

Cultural identity, beliefs and practices among the Zulu, even in urban areas, are strong and impact believers' health principles and practices (Bogopa 2010; Leclerc-Madlala 2009). Research in the social constructivist paradigm aspires to incorporate what cultural narratives signal about ways in which health beliefs moderate groups' experiences with MDR-TB treatment for instance in-context. Indeed, understanding how health beliefs and credence in the supernatural intersect within Zulu culture inform how health communication should be designed for populations in this context, and influenced the development of the communication strategy advanced in Chapter Ten.

IsiZulu-speaking groups venerate ancestors, called *amadlozi*, and believe in their power to punish or reward the living, including by improving health (Henriques 2013). *Amadlozi* are deceased senior male members of a clan or kinship group (Bogopa 2010), an axiom which underpins patriarchal arrangements of Zulu households and communities. Designated custodians of cultural beliefs and practices exist among the Zulu; individuals who dictate normative reactions to threats to communities or households. For this study, these individuals can also be assumed to be gatekeepers or information leaders capable of influencing members' reception of mass mediated health promotion about MDR-TB treatment. It would be important for them to be well informed about MDR-TB and challenges that non-adherence to treatment poses to entire communities. The question of who can be considered a custodian of culture with influence over young women's adherence behaviours is discussed below, with focus on the influence of men and older women in this role.

Within this patriarchal society, women's agency and power are significantly limited, and their culturally expected acquiescence used to gauge whether they should be supported during MDR-TB treatment or not. Participants spoke of '... many support issues in families because of the disobedience of young people. They don't want to listen' (Volunteer Health Educator, Interview, 24 May 2018) to explain why some young women go through treatment alone. She added that:

They [young women] need this support but are not getting it. Reasons for this are because young women love to take to city life and materialistic lives; going to taverns and disobeying their parents at home too. So, upon their return home, when they are now sick with MDR-TB it becomes difficult for families to just accept and adjust to their illness. They are on their own with their treatment, because they were warned about this life of running around with boys. Now they are ill, and they want to make it the family's responsibility (Volunteer Health Educator, Interview, 24 May 2018).

This explanation suggests tensions between tradition and modernity in eThekweni Metro, and highlights how young women precariously navigate between freedom and living in the city when they are well, and acceptance and support at home, sometimes in the rural areas, when they are diagnosed with MDR-TB. Experiences of vulnerable young women with MDR-TB are of a disease that is not well known yet is highly moralised. Data suggests that in low socioeconomic communities in eThekweni Metro it is commonly believed that young women's insistence on exercising agency and failure to maintain sexual purity result in supernatural punishment through infection with MDR-TB. In this idea, it is not disobedience in general that leads to punishment from *amadlozi*; for young women it is perceived subversion against patriarchy as evidenced by sexual liberation that results in this disease. Moralisation of MDR-TB

infection is underpinned by existent knowledge of the sexual transmission of HIV, which leads to assumptions that all TB/MDR-TB infections find their source in HIV infection.

They didn't say it by name but the way they [community members] spoke made it clear what they were talking about. I knew they meant that I was HIV positive. Because my partner was a local, they went to him badmouthing me saying that he should also get tested because I am sick, and that TB always comes with HIV. This happened to an extent that I had to relocate from Umlazi to Avoca (Busisiwe, 20 years, FGD#2, 21 July 2018).

Respondents explained that 'It's widely known that TB commonly comes together with HIV. It's like TB has a baby, which is HIV' (Volunteer Health Educator, Interview, 24 May 2018). This finding is examined with the framework of Zulu people's cultural and moral values (Idang 2015), MDR-TB's relationship to HIV, and how stigmatised having TB is in communities in South Africa. Literature presented in Chapter Four, which is supported by findings of this study, elucidated that because of their gender and age, young women with MDR-TB may experience more stigma than other vulnerable groups, with negative impacts on their medication-taking (Fagundez *et al.* 2016).

Scholars explain that of all the reasons *amadlozi* may be displeased, a family's failure to fulfil rituals and sacrifices concerning marriage is the most serious (Veenstra 2006). This belief may contribute to the shunning of young unmarried women cohabiting with partners in the city, or who have children out of wedlock. Families' refusal to support unmarried women they assume are HIV positive may find explanation in beliefs that *amadlozi* caused the illness and fears that others in the family may be similarly afflicted should they intervene. Punitive theory (Feezer 1921), discussed in Chapter Five, provides a frame within which to read reluctance of family members to support young women with MDR-TB. Eminent ethnographer Ngubane (1977) documented Zulu people's belief in *umnyama*, a state of 'ritual pollution' or bad luck that is contagious, illness-causing and, crucially, known to mostly affect women. This idea is discussed in more detail to explain findings presented later in this chapter.

The centrality of *amadlozi* in Zulu rituals and practices (Henriques 2013; Bogopa 2010; Burhmann 1984) was analysed for its influence on beliefs that people with MDR-TB are (rightly) being punished for disobedience or other infractions. This finding suggests that health promotion has a role in increasing public knowledge about the biological causes of MDR-TB and personal and household TB/MDR-TB protective measures that can be adopted by residents of underserved communities and applied to protect themselves from infection. Widely disseminating MDR-TB information and raising

awareness that MDR-TB is not caused by displeased ancestors is the first step in residents building more supportive communities for people taking treatment for MDR-TB.

### ***Withholding of a family collaborative approach to young women's***

#### ***MDR-TB treatment***

Accepted community norms about the aetiology of MDR-TB necessarily influence individual and collective convictions about how the disease can be prevented, treated and cured. Shunned 'rebellious' young unmarried women who have lost family support and are aged 23 to 31 years may be particularly affected. Findings of this study suggests that women aged 18 to 22 years receive more family succour, but that being between 23 and 31 years-old is correlated with less help, which may place this group at heightened risk of sub-adherence. However, a much older participant, the grandmother of a young woman with MDR-TB shared:

When I first started taking treatment my daughter and her husband were around. We called the children to let them know that I have TB, because they are grown. We told them that there is treatment to be taken by me and told them how I take it. My daughter emphasised to the children because they knew that I don't like pills. My daughter told all my grandchildren about my condition and how they were to take part in my treatment by monitoring how I adhere to the dosages. I used to cry tears when drinking them because it was painful. I ended up crushing the pills and drinking them in yoghurt. TB pills are painful. My main supporters were Anele and Mpilo (grandkids). Sometimes I used to try to convince them to let me skip my dosage. They would refuse and promise to tell the elders if I don't drink them (Susan, grandmother and treatment support for an 18-year-old respondent with MDR-TB).

The quotation above illustrates that it is not all isiZulu-speaking women who lack agency in health behaviour. Findings of this study suggest that women 32 years and older may culturally command greater respect and exercise more agency because they are married, are in recognised unions and/or have older children, translating into better support for this age-group. As discussed in Chapters Four and Seven, children, adolescents and young women in early adulthood are still considered dependents and deserving of care and support during ill-health. Indeed, many participants who were close to completing treatment still lived at home and could name the person, usually a mother, sister or grandmother, who helped them with treatment. Indeed, all household members of women with MDR-TB who participated in this study were relatives (two mothers and a grandmother) of respondents aged 18 to 22 years. Unlike societal arrangements and health belief theories which emphasise self-directed behavioural change at individual level to achieve desired outcomes (Hochbaum 1958; Leclerc-Madlala 2009; Krumeich *et al.* 2001), isiZulu-speaking people prioritise

collaborative family or community approaches to safeguarding the health of members (Haskins *et al.* 2017; Henriques 2013; Bogopa 2010). In these arrangements, health-seeking behaviour is a shared responsibility, as opposed to being predicated on individual decision-making (Haskins *et al.* 2017).

Illustrating these values, a participant was clear that MDR-TB treatment literacy opportunities need to be extended because: 'The importance of communicating with families is two-fold: (i) to ensure that there is prevention of any further transmission, and (ii) to also engage the family to be part of the healing process, so it is more of a partnership in the healing rather than one person who is alone in a corner and having a disease which no one wants to get' (N. Ngomane, Interview, 10 April 2018). This finding partly expatiates respondents' insistence that MDR-TB treatment education and health promotion initiatives should be extended to others within the primary circles of patients, because healing is not an individual concern.

With this understanding, it is clear that withholding of family support is detrimental to the treatment outcomes of vulnerable young women, many of whom already live alone, struggle with childcare and are unemployed as discussed later. Absence of support also implies that patients may not benefit from having traditional rites or cleansing ceremonies performed to rid them of the pollution or 'dirt' believed to underlie their illness (Hutchings 2007). It is believed that when *amadlozi* cause illness in someone, this symbolises their wish for a placatory cow or goat to be sacrificed and offered so they can undo the curse and start the healing process (Krige 1962:288 in Veenstra 2006). Individuals cannot appease *amadlozi* alone; rituals require the leadership of elders and men in the family and involve the entire family or clan. Denial of these rites for patients who believe in them and already doubt the aetiology of MDR-TB may be psychologically damaging and lead to despondency, which may affect treatment-taking. Understanding this is important for determining the content of health communication as efforts are made to merge the traditional and the biomedical without diluting the effectiveness of biomedical treatment for the benefit of members of deeply cultural communities who are also more vulnerable to ill-health.

### ***Contested aetiology of MDR-TB infection and biomedical treatment's competition with an established traditional health system***

This study found that doubts about the cause of MDR-TB and lack of knowledge about its treatment impact how convinced families may be that the biomedical healthcare route is appropriate, potentially reducing commitment to ensuring that patients take all treatment as prescribed. Findings cast light on notable beliefs in the efficacy of

traditional healing practices among participants who contributed to this study. One young woman explained that she tried traditional remedies when she first became unwell.

I've never done the [traditional] consultation *per se*, but I did have a traditional syrup that I fetched from Bab'Bha in Berea which I used when I had chest pains and flu. When I drank it, it would calm the pain but when it was finished, everything came back; the flu and pain. When I went to hospital, I brought my bottle. While the nurses did the pregnancy test, I realised that I was going to get into trouble, so I poured the syrup in a juice bottle. Placing it in the locker was risky because the cleaners at the hospital opened everywhere. I threw the syrup away and that was the end of me and traditional medicines (Makhosi, 31 years, FGD#1, 26 May 2018).

Some participants denied using traditional remedies at all. This evidence should be treated with caution, however, because participants may have been reticent to share intimate information about their cultural practices with an 'outsider' researcher who is not emic to their culture and does not speak their language. It is conceivable that while respondents allowed me glimpses into their cultural beliefs and practices, assumptions that I would not fully understand may have limited discussions. Respondents mixing biomedical MDR-TB treatment and traditional remedies cannot be completely ruled out in the context of this study. Traditional remedies are appealing because traditional health practitioners address the spiritual and physical person, an approach which is diametrical to medical personnel's biomedical theory-inspired focus on the disease, to the exclusion of issues exogenous to patient's bodies. However, because of convictions that MDR-TB is caused by a bacterium, and awareness of the epidemic proportions of the disease in eThekweni and the looming XDR-TB crisis, medical practitioners would be impatient with patients' concomitant use of traditional remedies. Participants complained that healthcare providers were not 'sensitive to patients' situations or to their plights in relation to TB and its treatment' (Zukiswa FGD#1, 22 years, 26 May 2018).

It is worth considering that patients with low MDR-TB treatment literacy may be unclear about whether, or how far they can straddle the line between biomedical treatment for physical symptoms of MDR-TB and the safety of concurrent use of traditional healers for spiritual relief, for instance. Faced with the choice to continue with MDR-TB treatment or put stock in traditional remedies, patients without information about the former may abandon treatment for the familiarity of traditional healing, which also likely has fewer side effects than biomedical treatment. They may return to biomedical treatment when their disease has progressed beyond the point where they can be cured. The information that young women with MDR-TB in

eThekwini Metro consult traditional health practitioners is important to incorporate into the design of health promotion interventions for application in that area.

While attention to the spiritual aspects of illness is fine, the danger is that it is not always clear how MDR-TB drugs and ingested herbal remedies interact in the body and whether or to what extent alternative therapies diminish the efficacy of biomedical treatment. Because it is the ingestion of traditional remedies that is problematic, nurses can probe for this information during consultations and affirm patients' choices to visit traditional health practitioners (and faith communities) for spiritual guidance and emotional support, as long as they continue to take biomedical treatment scrupulously. Health education via interpersonal communication during counselling should clarify safe and unsafe practices when mixing traditional remedies and biomedical treatment. Further, traditional health practitioners can be engaged and trained to educate patients with MDR-TB about the importance of adhering to treatment. This approach has potential to significantly contribute to effective health promotion in eThekwini Metro and reach people with MDR-TB directly with individualised messages. To close the loop, nurses should check with patients whether they are seeking alternative care, record this information in their files and reiterate treatment adherence education with this in mind.

Multidrug-resistant TB treatment knowledge gaps for patients and their support structures alike widen where strong beliefs in the culturally determined roots of illnesses, low knowledge about the aetiology and prevention of MDR-TB, and doubts about the efficacy of biomedical treatment intersect. Refusals by loved ones in young women's families or primary circles to acknowledge the pathogenic aetiology of MDR-TB and its infectiousness may exert social pressure on patients concerning the (non)effectiveness of biomedical treatment, contingently facilitating their sub-optimal adherence. This study found that close male contacts of young women with MDR-TB who contributed to this research were likely to believe in traditional causes of MDR-TB infection and to suggest alternative responses to the biomedical ones indicated. A respondent explained that the support of her brothers was low because:

At home they don't believe that I am sick and that they might also be infected with MDR-TB. They believe this could be something traditional. Even my boyfriend doesn't believe that I am sick. At times he will say 'Doctors will always be doctors; they will always do what they have been taught to do [diagnose diseases] (Nokuthula, 24 years, FGD#1, 26 May 2018).

Nokuthula, who was taking biomedical treatment, repeatedly implied doubts she had MDR-TB at all during the group discussion and attributed these thoughts to men in

her life as expanded later. This is a significant finding to cogitate on, especially if contacts of young women with these divergent views are also opinion leaders in their circles with influence over their attitudes and health-seeking and treatment adherence intentions.

Another novel finding is that fear and unwillingness to admit vulnerability to ill-health is a factor in men's reluctance to accept the diagnosis of primary MDR-TB given to women in their lives. Nokuthula again explained: 'When I vomited blood, we were together with my boyfriend, but he said "No, you're the one who is sick, not me. It's only you"' (Nokuthula, 24 years, FGD#1, 26 May 2018). Men's implied denial of susceptibility to MDR-TB infection finds explanation in hegemonic conceptions of masculinity among the Zulu, where physical strength, ability to earn a living and sexual prowess are revered (Meyer 2017). Multidrug-resistant TB affects the lungs and breathing, it weakens patients and robs them of their virility. Being diagnosed with MDR-TB can, thus, be akin to losing one's manhood, which may account for men's reluctance to seek care because of fears that they may be confirmed as having MDR-TB (Chikovore *et al.* 2016). Men's lesser use of health services and lower participation in care-giving for ill family members suggests that they do not engage with the health systems enough to be as exposed to TB/MDR-TB education and health often, as evidenced by different findings among men who interact with the health system. Lower perception of risk of MDR-TB infection is associated with male partners of respondents who did not disclose that they were co-infected with HIV. Although this study did not seek to establish whether vulnerable young women with MDR-TB were coinfected with HIV or not, it was clear from their responses that some respondents were concomitantly living with HIV.

Findings suggest that male partners of women presumably living with HIV and MDR-TB are more accepting of their partner's diagnosis with MDR-TB and demonstrate more positive health-seeking behaviours, which may translate into better support for their partners. A participant explained:

My boyfriend didn't have a problem [with MDR-TB diagnosis] because he knew that because we already had "this other disease", we were most likely to become infected with other diseases. So, he accepted it, he wasn't shocked. Until today, he regularly goes to be checked for TB (Makhosi, 31 years, FGD#1, 26 May 2018).

Because of regular interactions with health services over years, men living with HIV are familiar with ART and communication practices in HIV care, where PLHIV are educated about opportunistic infections, among them TB and MDR-TB. Indeed, men



living with HIV with partners with HIV and MDR-TB co-infection may be more pragmatic about their susceptibility to infection and the efficacy of biomedical treatment because of patient education strategies that are routinely implemented in HIV care but which, as shown in Chapter Four, are generally lacking in TB treatment. This finding is discussed in more detail later in this chapter.

***‘Phutu and beans is better than phutu alone!’: Absence of social protection for MDR-TB patients***

This study found, similarly to some published literature, that low socioeconomic status is suggestive of experiencing challenges with accessing funds to cover expenses associated with MDR-TB treatment, some of which are ‘catastrophic costs’ for low income families according to the WHO’s definition (Loveday *et al.* 2018; Wingfield *et al.* 2014). Participants explained that:

Patients say they do not have money to come to the clinic. So that is the first challenge we have. We have more defaulters because they skip visits; this is our first challenge. The second one is that patients come from far, and when they come to the facility, we need to make them wait. Patients also say they don’t have food to eat, so they can’t swallow tablets on an empty stomach, this too is a big challenge (Nurse #2, Interview, 7 March 2018).

Others will tell you they didn’t come because they still have medication at home. And when we ask why they still have medication left over they explain that while admitted in the wards, they received food parcels with which to take treatment. Now they are at home they don’t have food with which to take treatment (Nurse #1, Interview, 7 March 2018).

Food insecurity means that patients who manage to collect medication may fail to take all doses as prescribed. Indeed, while hospitals are considered unsanitary and women do not like to be there as explained in the next sub-section, for women who experience food insecurity, hospitalisation is key to their adherence. Asked why vulnerable young women may fail to adhere to treatment, a key participant explained:

Because it’s a lot of tablets for drug-resistant TB. If you don’t have food, unfortunately, taking them on an empty stomach makes the side effects even worse. Patients can identify these things like ‘oh if I do this [take a particular medication] this rash becomes unbearable’. So, people who don’t have food might not take the treatment (J. Ngozo, Interview, 6 March 2018).

I get tired and hungry, only to find that there is no food at home. You can’t have so many pills on an empty stomach. Being told that the pills should be taken before breakfast is also a problem, because they become very heavy in the empty stomach (Enhle, 31 years, FGD#2, 21 July 2018).

People receiving treatment for MDR-TB are counselled to take some medications before they eat and some with food. Failure to secure provisions can result in patients

skipping doses, as illustrated by a participant who said, 'Sometimes I don't have food to eat, and I feel like its suicidal to take medication knowing very well that I don't have food' (Nokuthula, 24 years, FGD#1, 26 May 2018). Beyond the absence of social protections and food security for people with MDR-TB, incidence of sub-optimal adherence among this case study is suggestive of inadequate treatment literacy. The finding that people with MDR-TB would firmly believe that hunger, and not non-adherence to medication, is the more life-limiting challenge illustrates how patients are educated about their treatment; in a generic approach with scant consideration for their specific socioeconomic circumstances. It can also be deduced from this finding that healthcare workers do not adequately discuss counterstrategies to ensure ingestion of all prescribed medications, even as patients experience other challenges like food insecurity. This results in patients believing that there are situations where skipping doses is appropriate.

How anti-MDR-TB drugs interact in empty stomachs to create even more serious side effects than usual must be considered as a significant reason for sub-adherence. When paired with low treatment literacy, uncertain access to food in the continuation phase leads to vulnerable women having to decide between catering for their special dietary and nutritional requirements to adhere to treatment, or prioritising the needs of more people in the family as explained:

I had a problem because there is this treatment that I drink; it requires for me to [take it with] yoghurt or *amasi*.<sup>8</sup> I sometimes do not have the money and when I have the yoghurt, they eat it at home. Because of this, I have to decide not to take the treatment until I have these foods. Sometimes the morning dosage makes me grow an appetite about an hour after drinking it. I have to eat, but I don't want porridge. I want to eat something with meat. All this happens only to find that sometimes I don't even have food at home, so that's when and why I skip my medication at times (Makhosi, 31 years, FGD#3, 29 September 2018).

Insufficient MDR-TB treatment education which only emphasises taking all medication without discussing challenges and counterstrategies to adherence results in some patients unknowingly putting their health at risk as they try to mitigate some negative aspects of treatment, among them the discomfort of swallowing handfuls of tablets on an empty stomach. The need for consistent and standardised social support and employment protections for young women with MDR-TB in eThekweni Metro is substantiated by the finding that unemployment presents significant challenges to young women's adherence to treatment because:

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<sup>8</sup> Traditional fermented milk.

We find that patients do not have money to come [to the hospital] because most of them are not working and they don't have a support system. They've got problems too, they've got kids, and you find that there is no support from home. They don't have anyone to look after their kids, especially when they are supposed to be admitted. They may not come for admission, giving the reason that they can't leave their kids alone because there is no one to look after them (Nurse #3, Interview, 7 March 2018).

While it could be assumed that being employed is protective of individuals' health, this is not the case for vulnerable young women with MDR-TB who contributed to this research because:

It's even worse when they are working, because sometimes it adds to the poverty. If they are single women and single mothers and must work as well to get a source of income, they might opt not to come for their treatment just to make sure that at least they have income. Some of them don't really have decent jobs where they can take sick leave; most of them are domestic workers and if you look at the frequency of time off they need to take to go to the clinic or the hospital [it's not always possible] (J. Ngozo, Interview, 6 March 2018).

Employed women with MDR-TB report difficulties accessing treatment, attributable to being in unskilled and poorly remunerated employment with no protections, including health insurance and paid time off to go to hospital. Young women in this category are also forced to play out some of their illness and recuperation in the public sphere. In the best cases, they negotiate variations in their treatment to fit it around work, as explained by Nontobeko who said:

I have a time set to take my treatment, and a time when I have to arrive at work. The two times clash, because the pills cause nausea and I have to be at work... I drink my treatment at night because I have to go to work. So, I take my whole dosage in the evening around 6pm. I work at a restaurant. I spoke to the nurses and they approved this. I drink 16 tablets in total (Nontobeko 22 years, FGD#2, 21 July 2018).

Some women simply shift treatment to fit their schedules and circumstances without prior discussion with healthcare providers. Women also report skipping doses to keep their energy levels up and avoid drawing the attention of employers and colleagues to themselves for fear of stigma and being made redundant. Even if they do catch up on doses for the day, such behaviour constitutes sub-adherence according to the definition employed in this thesis as established in Chapter Four. Women may feel like they have few alternatives, however, as failure to negotiate time off or experiencing serious side effects often means they need to give up employment to continue with treatment. One participant explained: 'I even stopped working because of the medication. The medication is so strong. Sometimes I feel drowsy; there is no

workplace where they can take a person that can feel drowsy for an hour. So, I can't work until I finish my treatment' (Nothando, 30 years, FGD#3, 29 September 2018).

Being employed also interferes with patients' scheduled monthly visits to a health facility, which is concerning because these are important for monitoring progress, and because this is the only way patients can collect more medication because:

We [TB sector] have just recently joined the CCMDD<sup>9</sup>, which is the central distribution centre for chronic medication. But with drug-resistant TB we still need the patient to come to a facility because we take monthly cultures, we check patients' wellbeing. That can take a bit of time, so on a monthly basis they might need time off to actually come to the facility to make sure that they do all this (J. Ngozo, Interview, 6 March 2018).

Women who miss visits run out of medication but, also importantly, they miss out on being educated about their treatment, common side effects and the importance of adherence at the various stages of treatment they are at. When they do go to facilities, patients complain of long waiting times to access services. Clinic days are Tuesdays and Thursdays only at King Dinuzulu Hospital, which further constricts the days in a month when patients can receive medical services, let alone education about their treatment. Even when patients can get to a facility and have time to wait to receive education, it is not guaranteed that they will receive quality counselling because:

On clinic days, because of the shortage of nurses, we don't do extensive counselling. We only ask patients where they have a problem, and when they tell us, we explain. We remind the patient how to take treatment, and we tell the patient to report each and every side effect, and we tell them to go to the nearest clinic when they have some side effects (Nurse #3, Interview, 7 March 2018).

Money and time constraints discussed earlier preclude the option of patients making separate trips to the hospital for education about treatment and strategies to enhance adherence. Tellingly, none of the participants spoke about being in support groups for people with MDR-TB, whether organised by the hospital or community stakeholders. This gap presents an opportunity to strengthen health education in communities through DOTS supporters as one option. Mass mediated health promotion would also be important for reaching patients and their friends and relatives with information, which would be invaluable for repeating information already shared in healthcare facilities for better understanding and application. This idea is discussed more comprehensively in Chapter Nine. Further, family and friends of MDR-TB patients

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<sup>9</sup> Centralised Chronic Medicines Dispensing and Distribution

who are educated about the importance of treatment can remind patients to take medication as prescribed in-between visits, for the wellbeing of all.

The case study of this research is women at their productive and reproductive peak. As well as being mostly unemployed, only one of the women interviewed reported being married, although many were mothers. This trend is explained by studies that chronicle a decline in marriages among Black South Africans, with the lowest numbers recorded in KwaZulu-Natal (Mkhize and Msomi 2016). While many women reported that their partners were supportive as discussed in Chapter Six, none spoke about male partners caring for children during their treatment. Women who could send their children away to family to be cared for while they were being treated. Respondents to this study framed single mother's caregiving roles as a contributor to sub-optimal adherence because:

A significant number of women at this age are single parents so their first focus, even beyond their own health, would be the wellbeing of their children. Which to them would specifically be about getting well enough to be able to go and work and provide for their children, even if that means in a way sacrificing their own health. So, if they are supposed to stay at home to get an injection from the injection team, they will be out there looking for a job, or doing something that will bring in money so that they themselves can survive and the child they have can survive (N. Ngomane, Interview, 10 April 2018).

They may not come for admission, for the reason that they can't leave their kids alone because there is no one to look after them. There is also no one to take care of their homes and property; most of them are renting homes and live alone with their children. Some are orphans, they are not married, and most of them are single. Those are the problems that we face (Nurse #3, Interview, 7 March 2018).

Some young women's partners abandoned them soon after they were diagnosed with MDR-TB, leaving them with small children to care for alone. These scenarios push, rather than pull, women into the labour market, to work out of economic necessity and to uplift the households they head out of poverty (Mkhize and Msomi 2016). Where these women cannot work due to ill-health, entire families are affected. Makhosi, an internal migrant from neighbouring Eastern Cape province, succinctly explained:

I live on my own since I am here to find a job. Getting food was a problem since I was the breadwinner. My mother has nothing now too since I was supporting her. I am all alone at my shack. Because I am still unemployed, I ask for something from home and they send me about ZAR100. I rely on my child's social grant, but it isn't enough because I still have to pay rent. I also rely on my mother as she is living off her children's support grants too (Makhosi, 31 years, FGD#3, 29 September 2018).

Older female caregivers of young women with MDR-TB who are heads of households also struggle to support families. Household contacts explained that when patients require lengthy treatment for MDR-TB, burdens on household finances can be steep. The grandmother of an MDR-TB patient explained: 'I have four grandchildren; the father of one died. They all need food; they have to dress... When this one was admitted in hospital the social workers didn't give her any food, yet I am the only one working (Susan, Household Contact, Interview, 29 September 2018). While there are several reasons for failures to fully adhere to MDR-TB treatment, pressures on young women (particularly those aged 24 and older) to earn a living and support others, even while receiving treatment, are significant. To ensure their subsistence, vulnerable women abandon treatment prematurely or take it erratically when they start to feel better, so they can return to work or secure employment unencumbered by the need to disclose their MDR-TB diagnosis to employers and colleagues. This study urges for reflection on whether young women would make these choices if they were fully educated and informed about the importance of adherence to halt further transmission of MDR-TB, especially since protecting children and others from infection is raised as a significant motivator of young women's intentions to adhere to treatment in findings presented in Chapter Nine. These findings raise questions about effectiveness of the treatment education approaches utilised with vulnerable young with MDR-TB.

As important as health communication and treatment literacy are to improving adherence, in marginalised communities patients' basic needs must first be catered for if any of the multiple sophisticated responses to the epidemic are to succeed. Biomedical interventions, patient education or other initiatives alone are inadequate in eThekweni Metro and similar contexts; the socioeconomic circumstances of patients must be improved as a prerequisite for successful responses of any nature. The necessity of this is well illustrated in the pithy anecdote shared by a key respondent as follows:

I remember donkey years ago, before Nkosazana Dlamini-Zuma was national Minister of Health, we were at a workshop one day, and I had been [employed in the Department of] Health for one week. I'd read all about the most important components of primary healthcare, I'd read everything I could get my hands on. So, in the workshop we were asked 'what is the most important thing about primary healthcare?'. I should have kept quiet, but I put up my hand and said that I thought education was. This lady [Dlamini-Zuma] took off and she went crazy, and if I think about it now ... she said, 'People will die knowing!'. At the time we didn't know who she was or even that within the next month or two she would become national minister of health. And I would see her on several occasions, and I would always pray that she wouldn't

remember me, because she really exploded that day. It might have been a bad day for her, but she yelled 'People will die knowing! Everyone knows that *phutu*<sup>10</sup> and beans is better than *phutu* alone'. But it's true, people will die knowing. Unless they have the means to improve the situations causing the illness and social ills it's not going to change. We can take education to as many people as we can, and we can urge people to adhere to treatment, but if it's their last ZAR30, will they buy a loaf of bread and milk, or will they use it for taxi fare to go to the clinic? What are they likely to spend it on? (R. Page, Interview, 6 March 2018).

These findings acknowledge what has been tacitly known by policy makers and implementers in South Africa for a while, as well as being explicitly documented in published literature. Even if optimal knowledge levels are reached, and medication dispensed on time by supportive and knowledgeable professionals in well-resourced healthcare facilities, supported patients who are fully integrated into their (marginalised) communities will still struggle to fully adhere to prescribed treatment during the continuation phase. Eradicating poverty and improving lives is the first step to ending the threat of TB to public health. This finding is noted here for its significance to public health communication research in low resource settings, although it remains outside the scope of this study to address.

### ***Dirt and ritual uncleanliness: Avoiding the 'filth' inside and outside***

Linked to poor socioeconomic status and Zulu cultural and health beliefs is the theme of 'dirt', which is considered here in both its literal and allegorical forms. Discussions in this section focus on the poor state of public health facilities and the quality of health services offered to patients from marginalised communities, and bodily pollution caused by the 'filth' of MDR-TB disease. Both reportedly demoralise patients and diminish their dignity, contributing to suboptimal adherence.

Public hospitals with inpatient DR-TB wards in eThekweni Metro are stigmatised as dirty places characterised by infection, disease and death, which ought to be avoided at all cost. Bringing this theme to the fore, one respondent explained simply that 'The day I was diagnosed with MDR-TB and hospitalised, my partner left me. We have a child together' (Nontobeko, 22 years, FGD#2, 21 July 2018). Uncleanliness inside the body, which is discussed below, is mirrored in dirt or filth outside it, both of which are associated with suffering and death. Women reported feeling dejected and negative towards their treatment because of sub-standard healthcare facilities where they receive care. These establishments are described as:

... dirty, no one cleans them. The conditions are bad, the food too. You eat what is there, because that is what is there. The nurses are insensitive and

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<sup>10</sup> A traditional food made of maize.

there is no hygiene. The gowns are dirty and when someone vomits, no one cleans it up. It is hard to see people die in hospital... You find that you will be thinking that you are healing, yet each day people die of MDR-TB in front of you [in hospital]. You just lose hope (Enhle, 31 years, FGD#2, 21 July 2018).

They took a long time to clean up messes, for instance when patients vomited. They took their time to attend to those messes, yet we were breathing that air and looking at it. Imagine that view! (Nontobeko, 22 years, FGD#2, 21 July 2018).

Some respondents admitted missing hospital appointments to avoid the internal and (real and perceived) external stigma attached to engaging with the 'dirty' health system and those in it during the continuation phase of treatment. Aversions to dirt are culturally derived for the Zulu, for whom clean environments and the absence of dirt are a prerequisite for good health and the absence of disease (Henriques 2013), an idea which has parallels in good medical practice. This convergence is worth considering and incorporating into the design of MDR-TB treatment health promotion, so health communication is more culturally proximate and acceptable to patients in KwaZulu-Natal. If vulnerable populations in eThekweni perceive their cultural idioms, normative values and conventions reflected in health promotion disseminated via interpersonal communication and radio and television, they may understand it better and accept it more readily. Health communication designed in this way may be better at influencing audiences' attitudes and health intentions.

Taking this finding a step further, there is symbolism in Zulu culture which links physical filth and 'spiritual dirt'. Participants to this study were very concerned about displaying illness through bringing out 'dirt' via bodily fluids and secretions in public, to the extent that even though they are aware of the importance of strict adherence to treatment, some women skip medications in anticipation of navigating in public spaces. One respondent explained 'The morning treatment caused me to have nausea. So, on the mornings when I had to go to hospital for check-ups, I would skip that medication. Imagine if I threw up in a taxi!' (Enhle, 31 years, FGD#2, 21 July 2018).

Concepts of bodily 'darkness' and 'dirt' are central to Zulu definitions of disease and understanding of infectiousness (Leclerc-Madlala 2009). Besides indicating pathogenic metaphors of ill-health, it is commonly accepted that allegories of darkness and dirt, especially as they pertain to women, are suggestive of either practicing witchcraft or being the target of the ancestors' wrath (Leclerc-Madlala 2009). Ample research from multiple African societies supports this and portrays ideas of women's bodies as dangerous and uniquely capable of harbouring and transmitting diseases (Leclerc-Madlala 2009). Based on these findings, young Zulu women's concerns about



maintaining cleanliness during MDR-TB treatment can be understood both literally and supernaturally, as perceived cleanliness supports their good standing within their families and communities. These ideas can be incorporated into treatment education and counselling provided by healthcare workers, by increasing focus on informing patients about side effects they can anticipate on different drugs and working out individualised plans to follow to assuage these.

Extant literature, some of which was discussed in Chapter Four, establishes that serious side effects of anti-MDR-TB drugs directly cause sub-adherence to treatment. While side effects are discussed in detail in the next section it is important to single out one here, which contributes to perceptions of women with MDR-TB as being unclean. Changing complexions and physical appearance was a prominent thread running through reasons why young women considered or stopped taking treatment as prescribed. Participants explained: 'My body changed after four months, I saw my skin colour changing to being as black as your trousers' (Zukiswa, 22 years, FGD#1, 26 May 2018) and 'I started having pimples on my face and chest, my skin then transitioned to being dark and dry' (Nokuthula, 24 years, FGD#1, 26 May 2018). Bodily pollution, signified by the pustules and attendant secretions that respondent Nokuthula complains about is considered a mystical force that weakens resistance to disease and is strongly suggestive of bad luck and misfortune, called *umnyama*, for sufferers among the Zulu (Hutchinson 2007).

With reference to what is known about their sociocultural context, this study understands young female MDR-TB patients' distress at changes in physical appearances as more than youth- and vanity-propelled hysteria. Indeed, participants emphasised deep feelings of shame about being treated for MDR-TB, but more so for evidence of this being so clearly visible in their appearance:

It was painful. I still feel ashamed too. Even until today, I walk around feeling uncomfortable, hoping that I do not meet any of the people who were my colleagues because they know me as being lighter in complexion. I do not go for my UIF<sup>11</sup> because I am ashamed they'll see me like this (Makhosi, 31 years, FGD#3, 29 September 2018).

Others correlate changes in physical appearance with patients engaging in illicit acts like drug-taking. A respondent described her experiences with treatment as 'painful, because when I got darker people assumed and told me that I was getting darker because I was smoking marijuana' (Zukiswa, 22 years, FGD#1, 26 May 2018). This

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<sup>11</sup> Contribution-based unemployment insurance provided to people who are in between employment in South Africa.

accusation would be especially harmful for women from conservative cultures whose traditions require them to be subservient and obedient, leading them to act to minimise their suffering. A participant explained that ‘The brown one is the pill that made our skin turn black. Yes, it did happen that I would take all my medication but leave out the brown one’ (Zukiswa, 22 years, FGD#1, 26 May 2018). This finding lends impetus to suggestions advanced earlier that communicating side effects of MDR-TB medication is an integral facet of health promotion campaigns which aspire to contribute to enhancing treatment adherence rates. It is likely the drug *Clofazimine* that induces pigmentation changes (Mikhail *et al.* 2018), but the participants to this study did not know this, which highlights gaps in the information provided to patients about the treatment they take.

Further, understanding emotions stimulated in young women by visible side effects of MDR-TB treatment is significant, because ‘emotions and virtues play a part in the physical healing of persons’ and that feelings such as guilt or shame are believed to block physical healing within the body among the Zulu (Henriques 2013:6). As well as negative effects on women’s self-esteem and physical healing, it is important to understand the cultural inferences that prop up the idea of ritual uncleanliness because of pollution by disease (Leclerc-Madlala 2009; Hutchinson 2007) as they relate to physical changes in the appearances of young women. If we understand that conceptions of ritual uncleanliness sign-posted by the physical ‘filth’ expelled from women’s bodies during treatment jeopardise young women’s social standing, we can understand how they may fail to fully adhere to treatment because of fears of being suspected of practising witchcraft or being at odds with *amadlozi*. This is on top of being suspected of having HIV and is helpful for informing the design of health promotion messages.

### **A bitter pill to swallow: Biomedical considerations and environment of treatment**

This study necessarily discusses how modalities of MDR-TB treatment contribute to patient’s sub-adherence, because biomedical treatment is the primary focus of MDR-TB management efforts in South Africa. Findings discussed in this section include patient’s low understanding of biomedical treatment, high pill burdens, treatment fatigue, ‘false cure’, serious side effects, drug interactions with women’s hormones and implications for their reproductive health. Some of these factors were introduced in previous sections but are discussed more comprehensively here. Treatment fatigue translates into women not wanting to hear or speak about their illness and treatment

all the time, as it can be psychologically exhausting. This finding has implications for the effectiveness of health promotion around MDR-TB and urges for careful planning and targeting of interventions and campaigns that consider how, from where and when young women prefer to access information, considerations which are comprehensively addressed in Chapters Nine and Ten.

***‘On any day, I would rather have HIV or cancer’: Drug toxicity, burden and side effects***

A pervasive complaint from respondents to this study concerned the large number of anti-MDR-TB tablets that patients take. Generally, MDR-TB treatment comprises:

Five groups [of drugs] that one needs to take, maybe with an additional two that may be injectable. But now we have *Bedaquiline*. So, you can imagine in these seven groups if you need to take, say three tablets from each group, then it ends up being quite a lot. Again, because most of them have side effects with some you get something upfront to counteract [side effects] like those that affect peripheral neuropathy, which build onto an already heavy pill burden. It’s worse when one has other comorbidities, because some patients are diabetic, as well as having HIV (J. Ngozo, Interview, 6 March 2018).

Copious tablets are physically and psychologically difficult to ingest in the relentless daily cycle over many months that is required in MDR-TB treatment. They are also difficult to take discretely in social situations. MDR-TB treatment is so difficult that some participants to this study revealed that given a choice they would have preferred to have HIV, which is incurable, or cancer over MDR-TB because:

HIV is manageable. You only take one tablet a day. But for MDR-TB you have to take a lot of medications each day. So, I think to me HIV is nothing. It’s just that you have to tell yourself ‘I have to take my medication once a day’. You can carry your medication wherever you go, it’s easy. Unlike with MDR-TB where you have to carry the whole bag, because it’s a lot of medication (Nothando, 30 years, FGD#3, 29 September 2018).

Participants shared their perceptions that ART is more manageable than anti-MDR-TB therapy because treatment for HIV comprises a single tablet with few side effects.

One participant explained:

Look at me. I am dealing with just TB only. Sometimes I even wish that there was another disease that I could substitute with because these pills sometimes do their own thing... like you do get people with diabetes and other diseases, why then is the number of pills taken for TB not decreased to accommodate the other diseases’ medications. You find that the person has to swallow at least 40 pills at a time, because they are treating TB, diabetes, HIV and sometimes hypertension (Nontobeko, 22 years, FGD#2, 27 July 2018).

Treatment even for women without comorbid conditions comprises between 10 and 31 tablets daily, including drugs to counteract side effects of MDR-TB treatment. A

participant who was reticent about contributing to the group discussion at first perked up significantly about halfway through to counter the contribution of another participant that MDR-TB treatment comprised 19 tablets a day. She fervidly explained ingesting 31 tablets a day as follows: ‘... initially 21 [tablets] in the morning before breakfast, then four *Bedaquiline* after breakfast, then six at night. They took some out after three months, that meant 15 in the morning, then two *Bedaquiline*, then three at night’ (Nokulunga, 24 years, FGD#1, 26 May 2018). In an interview, a key participant shared that ‘One patient said, “It just fills my stomach”, [the] medication. Because unfortunately they have to take them with water as well, so they just become full because of the tablets’ (J. Ngozo, Interview, 6 March 2018). The sheer number of tablets in MDR-TB treatment regimens and slow advances in the development of new drugs is cause for complaint among patients, policy makers and practitioners alike. Women also were not knowledgeable about names of the different medications they were taking or their specific purpose in the treatment regimen.

Participants described experiencing incapacitating side effects while simultaneously trying to guess which drugs caused them and alleviate symptoms. To close the gap between the MDR-TB treatment education they receive and their experiences with treatment, women reported experimenting with how, when and whether they take treatment, compromising their adherence. One woman explained: ‘I would take all my medication but leave out the brown one [tablet]. Towards the end of my treatment, I was no longer drinking it. Then they said I was cured’ (Zukiswa, 22 years, FGD#1, 26 May 2018). A respondent from the National Department of Health explained that ‘... clients may feel that they are better once they reach a certain stage of their treatment and then stop their treatment’ (N. Ngomane, Interview, 10 April 2018).

These findings find explanation in insufficient patient education about what each drug in a regimen does to TB bacteria and how all drugs in a regimen interact to kill-off the disease. Gaps in knowledge like these leave patients guessing about the hierarchy of importance of the different medications in their treatment. Patients who are unsure about what strict adherence to treatment is may feel that skipping doses or excluding some medications does not constitute sub-adherence, as long as they keep taking the other drugs and/or catch up on missed doses when they feel better. There is evidence, discussed in more detail in Chapter Nine, that many participants to this study did not know the medications they were prescribed, and that those who did know obtained this information by asking nursing staff to explain their treatment, rather than it being a standard component of information routinely provided.

Women with MDR-TB struggle psychologically with treatment. Taking so many tablets to survive when healthcare workers are accused of selectively informing patients about side effects of treatment may signify to people with MDR-TB and others around them that they are terminally ill. Motivation to adhere may consequently decrease. This finding is linked to discussions later about how, instead of setting people at ease around patients, active treatment for MDR-TB is associated with being infectious and is stigmatised. Despite complaints that they were given insufficient information about treatment, however, respondents were not united in wanting full disclosure about potential severity of side effects prior to commencing treatment. Women concerned about how side effects would interfere with their livelihoods demanded full disclosure, insisting:

‘There are things that they said the tablets do, but the others, they didn’t say what. They didn’t tell me because they suggested that if they tell me, I will be more afraid and then maybe I won’t take my medicine, or maybe it will affect me. I want to know what those things are’ (Zukiswa, 22 years, FGD#1, 26 May 2018).

I wish they were open about all the side effects. I was told that the medication might affect organs such as my kidneys. I was also told that treatment might make me lose my mind. Nobody told me that the treatment will stop me from being able to walk, no one told me that the treatment would change my skin and they didn’t tell me that at times I might have a fast heart rate (Busisiwe, 20 years, FGD#2, 21 May 2018).

When read together with the finding discussed in Chapter Seven that there are no private counselling facilities in the DR-TB Unit at King Dinuzulu Hospital, the challenge of comprehensively educating patients about treatment and its side effects for increasing women’s agency during treatment becomes even more pressing to address. Participants complained that ‘They [nurses] don’t necessarily teach, but they do tell us about the importance of taking treatment well and that the sputum has to be negative for 18 consecutive check-ups... they emphasise taking the treatment as prescribed’ (Zukiswa, 22 years, FGD#1, 26 May 2018). Gaps in ensuring two-way communication between healthcare providers and patients evinces missed opportunities to co-opt patients as partners in biomedical treatment, and to increase patients’ treatment literacy towards ensuring improved adherence. This is particularly important for young women for whom culturally prescribed acquiescence to instructions from elders and authority figures and low educational attainment may result in low capacities to confidently request information about their treatment. Improving standard treatment education and mass mediated health promotion activities would remove the burdens on patients to seek out critical information.

Perceptions that healthcare workers do not respond to young women's complaints about adverse events of treatment with the necessary urgency were also probed. A participant explained: 'When I get to the nurses, they just tell me that it's normal, it's just side effects that will go away in time' (Enhle, 31 years, FGD#2, 26 May 2018). This finding is assessed with reference to claims of 'gender bias', which causes healthcare workers to take women's grievances about pain and discomfort less seriously than those of men and other categories of patients (Samulowitz *et al.* 2018). It urges for greater awareness about how gender norms impact service provision for women and their subsequent experiences in public healthcare facilities. Women like Enhle who feel that their discomfort is dismissed, and who contest attitudes of healthcare professionals and approaches to educating patients about treatment may fail to benefit from counselling if they feel that they cannot ask questions or be treated as equal partners in their own treatment. Indeed, women who are assured that side effects are a prosaic aspect of MDR-TB treatment which cannot be assuaged may feel it is not worthwhile to persevere with physical or psychological discomfort for extended periods, especially if they are unconvinced that treatment will cure them. In the final analysis, because the biomedical MDR-TB treatment programme in eThekweni Metro has competition from an established traditional health belief system and attendant practices as discussed earlier, the requirements and preferences of patients ought to be accorded more consideration if they are to be retained in the healthcare system for the duration of treatment.

### ***Shorter treatment available, but does it help with fatigue?***

When I commenced this research in 2017, standard treatment for MDR-TB was lengthy and sub-optimal adherence due to treatment fatigue, among other factors discussed above, was common. A key respondent from the KwaZulu-Natal Department of Health conceded that '... the period of taking medication is quite long. Even with six months of drug-susceptible TB treatment we have people who are lost to follow-up and not compliant to treatment. So, when you have treatment that is from 24 months to 36 months, the issues become even more complicated' (N. Ngomane, 10 April 2018). Encouragingly, by the time data was collected in the field in 2018, treatment timelines had been shortened as KwaZulu-Natal incorporated *Bedaquiline* for some MDR-TB patients in November 2017 as discussed in Chapter Four.

Inclusion of *Bedaquiline* condenses treatment for MDR-TB to as short as nine months. This study found that shortened treatment comes at a steep cost for patients as side

effects of *Bedaquiline* are considered more debilitating than those of other drugs. This study found evidence of worsening treatment fatigue and non-adherence among some patients, sometimes before they even began taking treatment with *Bedaquiline*. A participant explained:

Around 13 October, I had to start *Bedaquiline*. I knew it as a very dangerous pill; people had told me that it made them crazy, forgetful and all sorts of things. I cried all day when I returned from the doctor, I couldn't eat that day. Do you know of the notorious Simphiwe who is in and out of King Dinuzulu Hospital? He's been there for about two years now because he doesn't adhere to treatment, he doesn't want to take *Bedaquiline* and claims that the injection is too painful. There's this new pill called *Delamanid*, they gave him that and he still doesn't want it because six months is too much for him... When I arrived in the ward, the other patients told me that I'm still enjoying my stay because I haven't started taking *Bedaquiline*. They scared me that I will get what's coming to me when the *Bedaquiline* period comes. I was very active, the injection made me hyperactive and playful. I then started *Bedaquiline* till I completed it, in the end I had no problems (Nokuthula, 24 years, FGD#1, 26 May 2018).

*Bedaquiline* has a bad reputation and some research participants explained how their experiences of taking it exacerbated feelings that MDR-TB treatment is too long and difficult. Additionally, insufficient time for teaching patients about: the tablets in their treatment course, what each medication does and reasons for taking each dose exactly as prescribed, even after they start to feel better and explaining what side effects to expect and how they will be managed also emerged as concerns for participants.

Treatment fatigue, which can be understood by applying the Economics-inspired law of diminishing returns (Mold *et al.* 2010), is a key cause of sub-adherence to MDR-TB treatment. Participant Busisiwe explained that 'a week before I completed my course, I just stopped drinking my pills' (Busisiwe, 20 years, FGD#2, 21 May 2018). The repetition of taking long-term toxic treatment, dealing with side effects that do not abate significantly and no longer feeling unwell may lead to some patients' resolve to adhere to treatment waning, especially if they cannot identify compelling reasons to persevere. This may happen when physical symptoms of illness or effects of treatment are no longer being felt as acutely, or in the case of Busisiwe, patients approach the end of treatment.

This study found that in the absence of education and explanations specific to the stage of treatment that patients are at about why continuing treatment is important, for some the rationale to continue taking medication as prescribed will be missing. It is not enough to summarily instruct patients to adhere to treatment each time they visit a health facility. Ideally healthcare professionals would adopt a motivational

approach with two-way communication when counselling patients and share information pertinent to the patient's stage of treatment and the importance of adherence. Figure 20 in the next chapter is this study's attempt to proffer a practicable counselling plan to contribute to addressing this gap and others discussed in this chapter. A phased approach is adopted to counselling patients, together with their loved ones, on a variety of topics over the entire period of treatment in the hopes that adherence can be enhanced.

### ***Reproductive health, MDR-TB treatment and poor public health service delivery***

Young women (aged 18 to 34 years) receiving treatment for MDR-TB are their reproductive peak and peculiar to them is that they are dually concerned with impacts of treatment on their procreative capacities and intimate relations, including whether pregnancy is contraindicated with anti-MDR-TB treatment. Treatment for MDR-TB disturbs young women's fertility intentions because of its threat to their reproductive abilities. This finding emerged early on during data collection, when a respondent explained that:

Some people are also aware that TB affects other organs, so as a young woman perhaps who has never had children, they would be worried about 'would I be able to get pregnant and have children in future? How does it affect my reproductive capabilities, being affected by MDR-TB? And what happens if I get pregnant whilst I'm taking treatment for MDR-TB? Those are the issues that need to be discussed' (N. Ngomane, Interview, 10 April 2018).

Bearing children to preserve the family name over generations is very important among the Zulu (Lubombo 2015). Harrison and Montgomery (2001:1) emphasise that 'childbearing remains the principal form of self-expression among older Zulu women, with fertility a necessary step toward achieving social status as a woman'. Hanretta (1998:394-395) reveals that women as main characters in stories told to Zulu children 'were almost always exclusively one of three types: the young woman who has reached puberty, the newly-wed bride and the expectant or birthing mother'. These characterisations and narratives of women in Zulu culture passed down through oral tradition and practice necessarily influence how young women with MDR-TB experience their treatment, and how they navigate it to retain their sense of self as Zulu women.

Side effects of the gruelling treatment impact young people's intimate relationships, the conduit through which they will be able to reproduce. Within a cultural framework that privileges conception and motherhood, young women's concerns



around fertility and reproduction are exacerbated by inaccurate and impractical information shared by healthcare providers and worsened by an almost total lack of information on this matter accessible via other mediums. Concerns about fertility and MDR-TB treatment are not unfounded, as TB is a significant cause of menstrual anomalies, loss of pregnancy and infertility (Ghosh *et al.* 2011). Risks of morbidity for both mother and baby where women with TB conceive also increase (Ghosh *et al.* 2011).

This study found that absence of standardised DR-TB counselling guidelines and health education exacerbates chances that inaccurate information will be passed on to patients by healthcare providers. As explained in Chapter Seven, nurses at King Dinuzulu Hospital refer to information in a consent form to counsel patients for approximately twenty minutes prior to initiating them on treatment. Why this is a challenge that needs mitigating is best illustrated by the nurse who admitted that she tells 'the women that they are not supposed to sleep with a man until they complete their treatment. MDR-TB treatment is for two years, but you find that the patient will come pregnant' (Nurse #1, Interview, 7 March 2018). Besides being incorrect, this information fails to consider the emotional, intimacy and reproductive needs of young women in their prime, and whose partners, families and in-laws may have expectations on their reproductive capacities. There is acknowledgment of this dynamic among policy makers and implementers, one of whom explained that:

We always say to the patient 'don't get pregnant, don't get pregnant, but the point is what was the couple's family planning? Were they planning to have a child within one, or two or three years? So how then do we communicate about pregnancy, the impact of being pregnant whilst having MDR-TB? What are her [patients'] thoughts about it? How does that impact the family structure? Because it's not only about her because if it was a plan then there's the husband or the boyfriend. And would that perhaps upset the family structure, if he doesn't get the child at the time that was planned? Even a person who is newlywed, you know in the African culture if you don't have a baby then you are called derogatory names. So those are the issues which need to be looked at (N. Ngomane, Interview, 10 April 2018).

Vulnerable women with low agency from living in households and communities arranged along patriarchal lines, strong cultural beliefs and traditions and low socioeconomic status that leaves them dependent on men for their livelihoods may be unable to control when they engage in sex or reproduce. Young women in these circumstances may stop taking medication altogether, perhaps once they start to feel better, or skip doses to accommodate intimacy and conception. Women with families that doubt the pathogenic aetiology of MDR-TB and/or have insufficient information

about treatment modalities and the effectiveness of drugs taken consistently may particularly feel pressured to abandon treatment.

The lack of communication and information about treatment and reproductive health is evinced by the consideration that information about TB treatment and pregnancy available in South Africa largely discusses the health of babies during pregnancy and breastfeeding. Little information exists that tackles the subject of whether or how MDR-TB affects fertility, and how treatment affects women prior to conception or after. This study found that communication about women, reproduction and treatment is lacking as healthcare providers almost exclusively focus on preventing pregnancy in young women being treated for MDR-TB:

We try to make sure that patients on treatment for drug-resistant TB are on contraceptives because there are some medications that are contraindicated in pregnancy and lactation. *Bedaquiline* is one drug that we need to be cautious about. Unfortunately, because it's a new drug we don't have much research that has been done on it. But we are very wary to use it in pregnant women (J. Ngozo, Interview, 6 March 2018).

Little is known about how newer drugs, touted as game-changers in MDR-TB treatment, affect women's reproductive capacities and whether they should be contraindicated with pregnancy as intimated above. This issue is linked to intimate partner violence and abuse, which this study finds is an impediment to women's full adherence to treatment. A participant explained that 'It is also important to consider that we know that there are abusive relationships, so in families as well we have to be very careful. We need to find out from the woman [whether we can disclose her MDR-TB status] if she is with a partner who can abuse her verbally or use violence, because of the stigma issues of having MDR-TB' (N. Ngomane, Interview, 10 April 2018).

By linking MDR-TB to HIV positive status (as they commonly are) and considering how both diseases are moralised and associated with irresponsible sexual behaviour as discussed earlier (Leclerc-Madlala 2009; Lubombo 2015), we can appreciate that women with MDR-TB risk being accused of having HIV and of bringing a serious disease home should they disclose. Experiencing violence or the threat of violence is a possibility for female MDR-TB patients. This finding emerged early during fieldwork and influenced the revision of the focus group discussion guide for young women with MDR-TB (see Appendix 3) and the key respondent interview guide for household contacts (Appendix 6) to incorporate questions probing how women's various relationships support or hamper their adherence to MDR-TB treatment, and how health education and treatment literacy can contribute to improvements in this area.

From this line of questioning, women in intimate relationships reported challenges explaining MDR-TB and its treatment to their partners. Asked about their greatest fear about having MDR-TB, the first young woman to respond in one focus group simply said, 'We fear that if we disclose our illness, our partners will leave' (Busisiwe, 20 years, FGD#2, 21 July 2018). Study participants felt that healthcare professionals did not prepare them sufficiently to explain their diagnosis to others and that they did not have the vocabulary to clearly explain their treatment. In these cases, young women conceded that their intentions to strictly adhere to treatment long-term were eroded as a result. This is related to challenges of communicating MDR-TB in pedestrian terms, and difficulties of communicating the long treatment journey in ways that are easily understood by people with low educational attainment and who are not fluent in the English language.

Inadequate knowledge and poor MDR-TB infection and treatment literacy among vulnerable women and their loved ones leads to fears of infection that may result in real or perceived withdrawal of affection and support from young women. Illustrating how MDR-TB treatment is stigmatised and those on treatment discriminated against, a respondent explained that, 'The first day I started taking treatment, my sister left home (Busisiwe, 20 FGD#2, 21 July 2018). Other respondents shared:

My partner ran away as soon as I told him that I was sick. He left, and it makes me want to cry when I think about it. He left with no explanation. He left me with a child and today my child has TB. The baby is now two years old. I just found out last week. Just by telling him that I have been admitted in hospital – that was his cue to leave (Nontobeko, 22 years, FGD#2, 21 July 2018).

There are also issues as to who now will find the patient attractive once they know that they've had MDR-TB. The issues of 'is my information confidential or do other people know'? Because they [young women] are at a very critical stage of looking to impress other people. And also, at the stage where there is courtship, and the person might be in a relationship and whereas females are more accommodating of situations; boyfriends, it could be a factor that he's not going to hang around and wait for a girlfriend who is admitted in hospital (N. Ngomane, Interview, 10 April 2018).

Although treatment protects both patients and contacts by reducing the infectivity of patients and, consequently chances that others may also get infected, a worrying finding of this research is that contrary to the reality, taking MDR-TB treatment is equated with being infectious. Participant N. Ngomane introduced evidence of this phenomenon when she shared that:

If a client is staying with the family and is to be seen taking DR-TB medication, they would rather opt to come [home] and say: 'Actually look I'm better, I'm discharged from hospital', rather than have the family seeing them still taking

medication, which to the family then looks like the person is still infectious (N. Ngomane Interview, 10 April 2018).

This finding urges for treatment education and counselling to be expanded to family members and close contacts of MDR-TB patients, so that they too understand implications of sub-optimal treatment adherence and benefits of full adherence for both patients and families. Without knowledge that loved ones or close contacts have TB, families and friends cannot offer support and without help patients' adherence may be sub-par. Low education, difficulty understanding the too-technical terms used to explain MDR-TB that do not easily translate well into isiZulu, health workers' disregard for the general and specific needs of vulnerable populations, and the consequent low treatment literacy among vulnerable women can be linked back to patients' deprived circumstances. These and other factors discussed below fertilise both young women's susceptibility to MDR-TB infection and low adherence to treatment.

### ***Poor public healthcare service delivery and healthcare worker's attitudes***

This study also found that poor healthcare service provision is a reality of public healthcare, which vulnerable populations in South Africa rely on. A participant made the link between poor services and low adherence by explaining that:

Sometimes people who are already on treatment may stop because they are unable to stomach the treatment that they are getting at facility level and then opt to stop rather than going to face humiliation and maybe being shouted at. Even in the national core standards you find that it was recognised that the attitudes of service providers can hinder access, or clients coming back for treatment (N. Ngomane, Interview, 10 April 2018).

For many participants, MDR-TB treatment involved hospitalisation for between two and six months during the initiation phase. In an extreme case, one woman was treated as an inpatient for 12 months, and still discharged home without being cured due to serious complications. Some participants highlighted that few challenges to treatment occurred in hospital settings, leading to this study finding that many participants experience challenges with adherence during treatment continuation, when they are at home. A timeline for when complications start was given by a respondent who explained: 'We find that at around nine months on the 24-month treatment regimen that's when they default' (J. Ngozo, Interview, 6 March 2018). The fact that patients need to continue and complete treatment in the same environments where they most likely contracted MDR-TB does not augur well for optimal treatment adherence and good treatment outcomes, especially since social

determinants of TB infection are widely acknowledged but not addressed, and treatment adherence education is not readily provided, nor disseminated in a standardised manner.

Some healthcare professionals who live in the same communities as patients reportedly gossip and share confidential medical information about patients with others where they live. Respondents complained that 'There is no confidentiality in healthcare settings. Nurses do not have compassion. They just disclose patients' statuses and diseases without consent in the hospitals' (Susan, caregiver of MDR-TB patient, Interview, FGD#3, 29 September 2018). Following such a breach of trust, some patients seek care at health facilities far from home to prevent neighbours and community members inadvertently learning about their illness and prognosis. The additional challenge inherent in this is that '... clients have to travel distances and they may not have money to travel to the area where they are getting treatment' (N. Ngomane, Interview, 10 April 2018).

Participants described a viscous cycle, where they cannot bear to stay in hospitals long term, including for reasons to do with dirt and uncleanliness discussed earlier, but experience food insecurity and other challenges with treatment when back home, cannot travel to health facilities due to resource and support challenges but then may be forced to avoid receiving treatment near home because of real or perceived experiences of stigma in their communities. Stigma is fear-driven and exacerbated by insufficient knowledge about how MDR-TB is transmitted and treated, and how it can be prevented. This can be related to the low educational and employment opportunities available to vulnerable populations in marginalised and underserved areas, and the knowledge gaps that these factors create between inhabitants of these communities and those of other areas where information is more readily available and accessible, and where the populace can make better use of it towards improving their health.

### ***More than just an MDR-TB patient***

In concluding the discussion of findings about why young women may struggle to fully adhere to treatment in this chapter, it is important to briefly discuss findings of this study which encourage looking beyond implications of sub-optimal MDR-TB treatment adherence in eThekweni on broader public health, to consider how long-term treatment affects patients personally and impacts their lived experiences. Some participants to this study explained that when made to choose between a social life involving alcohol use or adherence to treatment, they take 'treatment holidays' in

attempts to do both. Illustrating the enormous emotional toll that MDR-TB treatment has on patients, one young woman explained candidly: 'I needed one day in the week when I could feel normal, so I didn't take my tablets at all on Saturdays, so I could go out and drink with my friends. On Sundays I would go back to taking my treatment' (Zukiswa, 22 years, FGD#1, 26 May 2018). The high pill burden for MDR-TB treatment, pervasive stigma and assumptions that taking treatment equals being infectious all mean that young women cannot take treatment when they are with 'just anyone' in their social circles. This makes engagement in the public sphere difficult while on treatment. Discussions in Chapter Nine position comprehensive treatment counselling and communication, coupled with broader public health promotion interventions on radio, television, social media and schools has potential to increase knowledge about MDR-TB treatment, so that supportive environments can be built around those taking treatment to reduce impediments to their ability to adhere.

## **Summary**

This chapter theorised causes of vulnerability (Flaskerud and Winslow 1998) and influences of the cultural beliefs and practices of a defined case study of isiZulu-speaking people located in a metropolitan area in eThekweni Metro that result in low adherence to MDR-TB treatment. Findings presented in this chapter expatiated the multifaceted reasons why vulnerable young women receiving some of the most advanced biomedical treatment for MDR-TB in the world at no cost, albeit via overburdened public health facilities, may fail to completely and consistently adhere to treatment. The study found that the clinical management of MDR-TB patients in public health facilities in eThekweni Metro is hampered by poverty, low education and unemployment; considerable structural challenges in healthcare service provision; noteworthy gender and age-based factors; patriarchal and cultural norms that curtail young women's agency and access to healthcare and support; and high levels of stigma. All these factors are exacerbated by low MDR-TB treatment education and knowledge levels among patients and others.

Findings presented in this chapter rationalise why patients falter in adhering to treatment soon after they are discharged home and are in the continuation phase of MDR-TB treatment. Significant to the information presented here is that sub-optimal adherence typically starts at nine-months, three months after patients commence community-centred treatment. This finding was beyond the scope of this study to investigate further. It does, however, present a potential focus for future research to understand what the biomedical, sociocultural or individual reasons for this noted

trend are. Together with the findings presented in Chapter Nine, findings discussed in this chapter are applied to the development of the practicable communication model proffered in Chapter Ten, towards contributing to improvements in vulnerable young women's MDR-TB treatment adherence rates in low socioeconomic contexts.

## CHAPTER NINE

### HOW TO: VULNERABLE YOUNG WOMEN'S ACCESS, PREFERENCES AND USE OF MASS MEDIATED MDR-TB COMMUNICATION

#### Introduction

Discussions in the penultimate chapter of this thesis respond to calls for evidence-based situated strategies to contribute to truncating incidence of primary DR-TB in marginalised communities (Maharaj *et al.* 2016). Findings presented here answer the second and final research questions, which are: (ii) how do young women access information about MDR-TB, and (iii) how can health communication best be relayed and targeted to ensure use of information by vulnerable young women with MDR-TB? The chapter probes treatment knowledge deficiencies among and between people infected and affected by MDR-TB, which ostensibly result from low and peripheral health communication in healthcare facilities, communities and on television and radio stations accessible in eThekweni Metro. Findings were arrived at through analysing treatment literacy and public health communication gaps shared by participants, which were thematically coded and presented in Chapters Seven (outlined in Table 5) and Eight. Gaps that this study attempts to close through the practicable communication model proffered in Chapter Ten are reflected in the last section of Table 5 on page 167.

Chapter Eight presented findings about communication deficiencies in health communication and interpersonal communication for treatment education in healthcare facilities and how these increase, or have potential to positively impact, suboptimal adherence. Discussions in this chapter expand the focus, by probing vulnerable young women's access, preferences and use of mass mediated MDR-TB health communication in eThekweni Metro. Findings presented in Chapter Eight and in this chapter are linked and applied to develop an integrated communication model based on the utilisation of interpersonal communication, television, radio and social media targeted at various audiences to enhance MDR-TB health communication.

This study was conducted during a time when global and national interest in the potential of other interventions to augment the MDR-TB response were gaining momentum, as it became clearer that medicines alone could not end transmission or development of MDR-TB. Indeed, the futility of continuing to heavily invest in biomedical treatment without strengthening follow-up systems and patients'



adherence to treatment is increasingly acknowledged. A participant to this study from the KwaZulu-Natal Provincial Department of Health explained that:

[Adherence to treatment] is vital. I've had long discussions with colleagues about the cost of the new TB drugs, which is huge. I think TB treatment used to be about ZAR70.00 a month per patient. MDR-TB treatment per patient, particularly with *Bedaquiline* and *Linezolid*, costs *thousands* per patient per month. There is no point in spending – I can't tell you the figure and I don't want to make it up – thousands per month per patient for this new special treatment if you don't do huge education around it about adherence and patients end up defaulting on it anyway. – R. Page, Interview, 6 March 2018

With this evidence, the logical next step is to design evidence-based interventions to complement the costly treatment, an area to which this study aims to contribute with the integrated communication model presented in Chapter Ten. Chapter Eight discussed reasons why vulnerable young women may fail to adhere to MDR-TB treatment comprehensively. The next step is to understand more about the case study's media consumption habits, preferences and communication patterns, to support this study's objective of contributing knowledge about how the challenges raised can be addressed through enhanced health promotion. This approach is substantiated by literature that mass media increases impacts of information disseminated via interpersonal communication by repeating it to wider audiences. Indeed, some insist that 'unless and until we find ways of effectively merging mass media messages with interpersonal and group communication, no amount of sophisticated technology or glitzy media presentations will do much to enhance the efficacy of health campaigns' (Katz and Lazarsfeld 1955:133).

The effectiveness of utilising mass media to increase vulnerable populations' knowledge is supported by understanding of target audiences' preferred mediums and channels of communication, type of MDR-TB content they already consume and times when they consume it. It was possible to draw some conclusions about vulnerable young women's access to and preferences in terms of mass mediated TB/MDR-TB content from data collected in the field. It is, however, important to sign-post here that findings presented in this chapter and the next demonstrate how affordability, personal influence and the sociocultural backgrounds of marginalised isiZulu-speaking young women are significant predictors of their media consumption, which must be and are accounted for when determining how best to reach them with health communication about MDR-TB.

## **Imperative to enhance interpersonal communication in healthcare facilities**

Several communication challenges curtail attainment of desired treatment literacy among vulnerable young women in eThekweni as discussed in Chapters Seven and Eight. Moreover, generalised neglect of public health communication over many years means that the first time many people learn about MDR-TB is when they or someone they know is diagnosed. A key participant to this research explained that MDR-TB information deficits result from:

... resource-constraints in the public health sector in KwaZulu-Natal. TB is an older disease, but resources are lacking. Unfortunately, the treatment is so expensive. Just to treat one patient is so expensive. So, because the resources are not so much, we juggle. Do I put so much to prevention, or other areas? We have always been held back by resources. We haven't even marketed or given education that much to ensure that its appealing (J. Ngozo in an interview 6 March 2018).

According to the South African National Tuberculosis Management Guidelines (2014), nurses should be on the frontline of educating patients about MDR-TB and supporting them to adhere to treatment. Nurses who contributed to this study, however, reported being overwhelmed by expectations that they should counsel patients, in addition to providing biomedical MDR-TB services. Further exacerbating the quality of counselling is lack of confidentiality, which was discussed in Chapter Eight. There are no private rooms where patients and their treatment supporters can be counselled about treatment at King Dinuzulu Hospital, which is not indicative of nurses being able to spend a lot of time motivating patients as required. A nurse explained that:

We are supposed to have a space where we can counsel patients. But now we just talk to the patients, as we are sitting here like this. As we are sitting with the patient, we also give them [family members] a chair to sit on, but we let one [between the patient and their relative] sit... I can't say how many minutes it [adherence counselling] takes because we talk to them before they see the doctor and after seeing the doctor when the patient comes for his or her treatment we sit down again and talk to them about how to take the treatment (Nurse #1, Interview 7 March 2018).

As explained in Chapter Five, counselling occurs in the centre of the reception area of the DR-TB Unit, which is prone to interruptions as people pass by to access other rooms and wards. As illustrated in the quotation above, family and treatment supporters are not prioritised for education about how to motivate and monitor patients until they complete treatment. Also, the limited education provided may lack impact anyway, because of how it is given. A respondent explained that:

Counselling is done here in the department, with just the desk and a screen. We also give information to family members. We ask them to come and sit with the patient whilst we are counselling the patient. The information [provided] is the same. We don't give different information to family members. We have some leaflets that we give them. But sometimes we run out of these pamphlets (Nurse #2, Interview, 7 March 2018).

As well as lack of privacy and compromised confidentiality, MDR-TB treatment education is likely compromised by nurses' circumscribed access to approved resources they can use to counsel patients. When asked what materials they refer to during the little time they can dedicate to educating patients a participant explained: 'We use the consent form. We explain what MDR-TB is and how it is treated. The duration of the treatment is also written there. Everything is written there' (Nurse #2, Interview, 7 March 2018). Counselling using the flimsy resource is also by rote, with no reported attempts to tailor content so it better responds to individual patient's motivational counselling and information needs at disparate stages of treatment with their unique challenges.

It is significant that although I observed a copy of the national treatment guidelines in the matron's office, none of the nurses referred to this resource when asked about sources of information they use to counsel patients. Instead, nurses expressed strong sentiments that the expectation that they spend significant amounts of time counselling patients was unreasonable. Considering this, it is conceivable that faced with ill-equipped, overburdened nurses and no privacy, vulnerable younger women may fail to exercise the necessary agency to lobby healthcare professionals to provide more comprehensive treatment education. Also, because young isiZulu-speaking women are culturally required to submit to elders and authority figures and/or because they lack the vocabulary to communicate about MDR-TB, they might be reticent about engaging in exchanges with nurses about their treatment.

The important roles of volunteer health educators in educating patients about MDR-TB at King Dinuzulu Hospital were discussed in Chapter Seven, and this research had been hopeful that this group could play an essential role in the success of the model proffered in this thesis. It, however, turns out that basing any communication model on their involvement would be precarious. At the time of writing this chapter in early 2019 I became aware that the contracts of volunteer health educators working in the DR-TB Unit at King Dinuzulu Hospital had not been renewed at the end of September 2018 due to lack of funds to pay their stipends. It is not inconceivable that their absence widened MDR-TB treatment education gaps. This development did, however,

necessitate adjustments to the envisaged model ultimately proffered in this thesis, to refocus on strengthening nurses' capacities to educate patients about treatment.

Some participants insist that the best way to enhance healthcare professionals' capacities to communicate with patients is by standardising health communication and treatment education and counselling content, similarly to the practice in HIV management programmes where patients are reportedly better able to independently adhere to ART. Generally, participants lacked faith in nurses' capacities to offer empathetic support. In a contribution echoed by others, a participant explained: 'I believe information should be standardised because I wouldn't want healthcare workers to decide what patients should know about MDR-TB... We shouldn't leave it to healthcare workers to decide what should be covered. That's what I mean by standardised. The content must be standardised, how we put it across can be suited to the demographic' (R. Page, Interview, 6 March 2018). These sentiments were likely influenced by realisations that nurses are not sufficiently supported with resources to meet expectations to educate patients. It is important to develop standardised DR-TB counselling and treatment education guidelines or incorporate them into the 'Interim clinical guidelines for the implementation of injection-free regimens for *Rifampicin*-resistant tuberculosis in adults, adolescents and children', which were in draft form in early 2019. This study, however, takes the position that building capacities and improving attitudes of nurses concomitantly needs attention, as efforts are made to corroborate and augment the information they provide to patients through mass mediated communication about MDR-TB, as discussed later in this chapter.

### ***Counselling and treatment education for patients and close contacts***

This study found that it is critical to impress upon patients and contacts the importance of total adherence because, 'If the treatment journey itself can be explained to patients upfront, they can know what should be expected from them, and what is expected of the health facility also' (J. Ngozo, Interview, 6 March 2018). For this approach to work, the appropriateness of the test and treat approach for MDR-TB for patients from low socioeconomic backgrounds must be challenged. Findings presented in this and the previous chapter make clear that some time can be spared to comprehensively educate patients and their contacts about treatment before they are initiated on treatment. This is not to negate the need to swiftly initiate patients on treatment in order to reduce their infectivity and halt transmission, however.

Findings of this study suggest that notwithstanding policy, in practice there are significant lags between diagnosis and treatment initiation anyway. One respondent complained: ‘... the person who told me that I was diagnosed with MDR-TB didn’t explain well. She emphasised that I now have this killer TB. She suggested that I go home, stay indoors and wait for two weeks for an ambulance to be booked for me. I did have suicidal thoughts during this period’ (Makhosi, 31 years old, FGD#1, Interview, 26 May 2018). Periods in-between diagnosis and treatment such as this should be utilised to understand individual patients’ socioeconomic and cultural contexts and prepare each of them to take toxic anti-TB drugs for an extended period in their context. Counselling patients should ideally occur over several sessions while awaiting treatment initiation and include members of their families or households, so they can protect themselves from infection and help others to do the same. Telephone counselling could be employed, as well as pointing patients to social media groups where they can communicate with and learn from other people with MDR-TB while awaiting treatment. It is important to examine consequences of MDR-TB on patients holistically, and not just biomedically, in line with tenets of this study’s health communication approach outlined in Chapter Five.

Because biomedical MDR-TB treatment is the preeminent response in eThekweni Metro, healthcare professionals may over-emphasise dispensing medication and recording large numbers of patients started on treatment, while losing focus of the necessity of ensuring that patients understand why treatment adherence is so important. Results of this study illuminate the importance of communicating treatment in lay person’s terms, considering patient’s socioeconomic and cultural backgrounds, and to trust them enough to fully disclose effects of certain drugs and consequences of non-adherence to them prior to initiation. In this conceptualisation, MDR-TB treatment adherence counselling would cover information on:

... the disease itself, you know, what is this drug-resistant TB? How it can be treated and what each drug does. Maybe not too scientific ... sometimes people can figure out which tablet causes side effects. So, they might just choose not to take that one, because they think this one is the one that causes me this and that. But if they know how important this drug is in the whole cycle – because some kill the actual bacilli, some make it stagnant so it does not grow – if that information is shared in simple language with them, where maybe this drug is eating all the bacilli somewhere, and you know it goes through the whole series, explaining the journey through visuals that maybe in two months after you have religiously taken your treatment, this is how the situation in your lungs becomes. That it’s not the end and you can see that you still have a number of bacilli and that if you don’t take it [medication] for one day or two days, the bacilli multiply and grow. So that they have an idea

of what really happens if they don't adhere to treatment. They can't see it, and they might not feel it immediately in their bodies, but if it's there for them they will think about you know, this is what really happens, and this is why I need this drug, and this is the ultimate drug that kills everything. Because the body at that time [nine months of treatment] feels much, much, better, so they are like, I'm feeling better now why should I even continue with this medication that causes me this and that feeling (J. Ngozo, Interview, 6 March 2018).

Findings of this study suggest that how complicated and lengthy MDR-TB treatment is, and how long patients are hospitalised is extrapolative of how much they know about their treatment. Participant Nontobeko was treated for complicated primary MDR-TB for over 24 months, 12 months of which she was hospitalised. Not all participants who contributed to this research had been hospitalised during the initiation phase of treatment. Generally, participants who were hospitalised had been admitted for less than four months. Nontobeko demonstrated deeper knowledge about MDR-TB treatment modalities and the regime she was prescribed, more than any other participant interviewed for this study. She insisted this was because:

I asked because I need to know what it is that I am drinking. I cannot just drink something that I do not know. If the weight is not increasing, the doctor says that the treatment is not working... I ask. Even when they take my sputum, I enquire about the results. I know that the results take three to four days. The following week when I am there, I ask what the previous result were. I ask (Nontobeko, 22 years, FGD#2, 21 July 2018).

Vulnerable young women who contributed to this study reported becoming more confident about asking questions the more frequently they engaged with healthcare providers and learned more about MDR-TB and its treatment. Because this study limited itself to collecting data from patients being treated for the first time, evidence of this finding was not numerically significant in the analysed data. Thematically, however, it was noteworthy. This finding is strongly suggestive of treatment knowledge gaps existing between patients treated for longer periods and those on shorter regimes, as the latter concomitantly have less access to healthcare professionals and may not be as comfortable with asking questions about their treatment. This urges for communication about MDR-TB treatment to ideally begin prior to treatment initiation and continue at regular and appropriate levels of intensity until completion. Counselling in healthcare facilities would necessary be the starting point, before treatment education is expanded to others, as suggested in the counselling strategy proffered below.

### ***Individual counselling: It starts with the patient***

Participants' accounts suggest that vulnerable women may be more willing to seek support during treatment for MDR-TB than men for instance, and that they can be 'talked' into adhering to treatment. A key participant opined:

I think for women, especially if they are taught well about TB transmission, they will always want to protect their children. If they are taught that if you adhere to your treatment you will be really protecting all the people that you live with. Again, by nature I think women listen better, compared to men. I think they are likely to adhere better than men. For women, I think they speak more easily to other people about their issues, so even getting treatment support from friends or from family members is much easier than how a man will approach that (J. Ngozo, Interview, 6 March 2018).

Challenges arise when considering that vulnerable young women's socioeconomic status, their cultural beliefs, age and gender conspire to reduce their agency in health-seeking. Similarly to other African societies, the health outcomes and life prospects of isiZulu-speaking women within the KwaZulu-Natal enclave, their ancestral home, cannot be considered independently of their children. Therefore, while this study finds that empathetic counselling for individual women at intervals is important, women's relationships with their children should be considered; particularly the impact of impressing upon them that their adherence to treatment helps to protect children in their households from contracting MDR-TB. Evoking the spirit of *ubuntu* or humanity towards others in healthcare, in which the community is more significant than the individual, participants felt that people with MDR-TB have a responsibility to adhere to treatment to protect others, especially children. Here individual counselling could impress upon people with MDR-TB '... that this [non-adherence] is also selfish or dangerous because now the other person will get sick and yet, you know, we can prevent some of these things... because the prevention of others being infected is dependent on this one who knows that they have the infection' (N. Ngomane, Interview, 10 April 2018). This finding demonstrates that counselling for MDR-TB treatment adherence should launch with patients and place primary responsibility for adhering to treatment on them. However, this approach should be predicated on understanding that vulnerability, cultural norms and beliefs may position some young women as lacking in agency around their health until the tools to do so are availed to them. Additionally, incorporating others into young women's treatment is important for increasing their agency, as discussed below.

### ***Couples' counselling at intervals***

As discussed in Chapter Eight, isiZulu-speaking women's sub-optimal adherence to treatment in marginalised communities typified by stigma, patriarchy and strong traditional and cultural beliefs is correlated to unequal power dynamics in intimate relationships between men and women. Treatment for MDR-TB affects sexual health, which may partly account for why women in relationships or marriages stop taking medication, to remain sexually active, in addition to concerns over their reproductive health discussed in Chapter Eight. Participants' contributions indicate that couples' counselling should begin:

Before starting to take treatment. There must be some sort of counselling for both, so that the spouse will understand. Because with this medication sometimes you don't want to have sex. Sometimes it affects [sexual] feelings. So, if you are with someone who doesn't understand, what will happen between the two? The best would be [that] before starting medication the two go and get counselling about these things... I was not told about how medication affects the sexuality. You find that out when you are taking treatment. This month I was asking a friend of mine who is also taking [TB] medication if he experienced the side effects that affect the sex part. He said 'yes', his penis wasn't working. Then he told the nurses that his penis wasn't working, and they explained that it was because of the medication, afterwards it will be fine. Couples should also be counselled about how the patient should take the medication (Nothando, 30 years, Interview, 29 September 2018).

Male partners of some participants were reportedly supportive, which suggests that incorporating men into counselling would be possible and beneficial for them if they are also being treated for MDR-TB. Some women explained how their partners provided for them financially, were physically present and emotionally supportive to help them to adhere to treatment. They explained: 'Mine was supportive. Very supportive. He is my baby's father. He came for visits at the hospital when I was still admitted' (Enhle, 31 years, FGD#2, 21 July 2018) and 'When I had hospital appointments, he gave me money to go because the hospital people told me that I wouldn't be admitted because they were quick to discover my TB' (Zinzile, 34 years, FGD#2, 21 July 2018). Prioritising customised counselling for couples at intervals during the nine to 36 months of treatment and incorporating significant loved ones, some of whom may also have MDR-TB as active treatment supporters and partners in the process is feasible. Additionally, when women are not fearful of losing loved ones because they and their partners have been counselled about implications of MDR-TB treatment and know what to expect, they can concentrate on adhering to treatment.



### ***Family counselling to improve adherence support***

This study suggests the importance of communicating with and counselling others about MDR-TB prevention in households because ‘We need to have a conversation about what it means to have MDR-TB and what is the bearing on the people the person is interacting with’ (N. Ngomane, Interview, 10 April 2018). This approach is also useful for educating individuals who can influence patients’ adherence behaviours, to prevent rising incidence of primary MDR-TB. Counselling patients’ families and household members/treatment supporters is supportive of the (re)integration of patients into their families and communities post-diagnosis and hospitalisation. Family counselling as proposed in this thesis has three objectives: (i) increase health literacy about MDR-TB treatment and prevention among the infected and affected, (ii) reduce stigma attached to MDR-T treatment, and (iii) increase family support for patients until they complete treatment. This is well illustrated by the quotation below from a key participant who explained that communicating with patients is important to:

...ensure that there is prevention of further transmission, and to engage the family to be part of the healing process so it is more of a partnership in the healing rather than one person who is alone in a corner and having a disease which no one wants to get... There are stigma issues as well within the household. Which indicates that as much as we do the counselling of the person who is taking the medication, we also need to think about the people that the patient is staying with. To indicate that the person is no longer infectious and, therefore, needs to integrate as part of the family as best as possible (N. Ngomane, Interview, 10 April 2018).

Targeting influential people around young female MDR-TB patients, particularly older women, male partners and older children to participate in family counselling is essential to enhancing the impact of healthcare services on patients’ attitudes and treatment behaviours. Co-opting respected intermediaries who can continue to motivate patients to adhere to treatment at home complements the family collaborative approach to healthcare observed among isiZulu-speaking people as discussed in Chapter Eight. Applying the lens of the Two-Step-Flow Model to this analysis portends that understanding who to prioritise to participate in family counselling influences messages given to vulnerable young women with MDR-TB to impact their experiences with treatment, as discussed later in this chapter.

Literature reviewed in Chapter Three established that adherence to MDR-TB treatment is most difficult during the continuation phase, but scholars do not elucidate timelines for when problems typically begin or escalate. We do know that adherence becomes more difficult when patients from vulnerable populations are discharged

home, and a few months into the continuation phase. A notable finding of this study, which informs the counselling approach and timelines advanced in the strategy in below, is that there is some understanding of when patients begin to falter in their adherence to MDR-TB treatment in eThekweni, although practitioners were unable to definitively explain *why* this happens then. A key participant explained that: ‘The challenge we find is that around nine months, that’s when they default’ (J. Ngozo (Interview, 6 March 2018), while another shared that:

They are not defaulting in the first four months of the intensive phase of treatment for MDR-TB. People still don’t default then [once stabilised and discharged back home], because the team will come to their house daily for that injection. At that point someone is coming to their house daily; that’s not when they are defaulting. In fact, for MDR (sic) they default in the ninth month. I don’t know what happens in the ninth month (R. Page, Interview, 6 March 2018).

This is an area suited for further research, to determine patterns in the development of sub-optimal adherence among vulnerable populations from low socioeconomic contexts and the causes of these. As more South African MDR-TB patients now receive the injection-free nine-month regimen as the standard, this finding suggests that treatment adherence and success rates among MDR-TB patients who will not have to go past the nine-month mark of treatment will improve. For others on longer regimens or being treated for complicated MDR-TB, however, the challenge still exists. Plotting timelines for MDR-TB sub-adherence among distinct groups in specific contexts, and understanding reasons for dips in treatment adherence observed, for instance at the nine-month mark in eThekweni Metro, presents itself as a viable area for future research.

### ***How to: MDR-TB counselling strategy for vulnerable young women***

This study found that treatment education and adherence counselling at three levels are necessary to contribute to improving vulnerable young women’s adherence to MDR-TB treatment. Counselling for individual patients, couples and family should be motivational and informed by the age, gender, economic and culture-specific challenges that impact adherence among vulnerable young women in eThekweni Metro, as presented in Chapter Eight, and respond to their treatment information needs discussed earlier in this chapter.

Figure 20: MDR-TB treatment adherence patient counselling plan with timelines

<b>Month</b>	<b>Interpersonal communication and counselling intervention</b>
Week 1	<p><b>Intensive pre-treatment initiation training</b></p> <ul style="list-style-type: none"> <li>- Testing and diagnosis</li> <li>- Home assessment to establish the context in which patients will be taking treatment once discharged from hospital</li> <li>- Intensive counselling daily at home for one week prior to treatment initiation for patients and household members preferably by community caregivers or health education volunteers</li> </ul>
Month 1 & 2	<p><b>Treatment initiation counselling for patients and treatment supporters / household contacts</b></p> <ul style="list-style-type: none"> <li>- Understanding socioeconomic and cultural context of treatment</li> <li>- Establishing the aetiology of MDR-TB and prevention of onward transmission</li> <li>- Understanding how drugs act in the body and communicating the importance of adherence</li> <li>- Names of drugs in the treatment regimens</li> <li>- Side effects and their management and managing MDR-TB and co-morbidities</li> <li>- Treatment and reproductive health</li> <li>- MDR-TB treatment, alcohol, cigarettes and drugs</li> <li>- Safely incorporating cultural remedies and rituals in MDR-TB treatment</li> <li>- Signs and symptoms of TB/MDR-TB and importance of contact management</li> </ul> <p><b>Couples' counselling</b></p> <ul style="list-style-type: none"> <li>- Side effects and their management (impact on reproductive health and intimacy)</li> <li>- Ways to support the patient on treatment and personal infection prevention</li> </ul>
Month 3 & 4	<p><b>Counselling for patient and treatment supporters when starting to feel better</b></p> <ul style="list-style-type: none"> <li>- Explaining how drugs work on the MDR-TB bacilli and the risk of mutation without continued treatment</li> <li>- Explaining the efficacy of full adherence to treatment for infection prevention</li> <li>- De-stigmatising treatment</li> <li>- Scheduling follow-up visits to the hospital</li> </ul> <p><b>Couples' counselling</b></p> <ul style="list-style-type: none"> <li>- De-stigmatising MDR-TB treatment</li> <li>- Motivational counselling for partners to support patients to continue treatment at home</li> <li>- Side effects of treatment in relation to women's hormones, moods and sexual and reproductive health</li> </ul>
Month 5	<p><b>Counselling to prepare the patient to continue treatment at home</b></p> <ul style="list-style-type: none"> <li>- Infection prevention at household level</li> <li>- What has happened to the TB bacilli and what will happen if treatment is discontinued</li> <li>- Facilitation of access to a social worker to access food packs or a social grant as appropriate</li> <li>- Education about any changes to drugs</li> <li>- Coping with treatment in the public sphere</li> <li>- Negotiating treatment to fit patients' lifestyles</li> </ul> <p><b>Couples' counselling</b></p> <ul style="list-style-type: none"> <li>- Continued adherence to treatment and infection prevention at household level</li> </ul>
Month 6 & 7	<p><b>Counselling to encourage the patient to stay on treatment</b></p> <ul style="list-style-type: none"> <li>- Starting to feel better and the importance of continued adherence to treatment</li> <li>- Explaining consequences of relapse due to non-adherence to treatment</li> <li>- Continued infection prevention at household level</li> </ul>
Month 8 & 9 (Shorter regimen)	<p><b>Counselling to prepare the patient to discontinue treatment</b></p> <ul style="list-style-type: none"> <li>- Final push to finish all doses of treatment and avoiding relapse and further mutation</li> </ul> <p><b>Family and couples' counselling</b></p> <ul style="list-style-type: none"> <li>- Further infection prevention strategies</li> </ul>

	<ul style="list-style-type: none"> <li>- Signs and symptoms of TB/MDR-TB and importance of being screened for TB at the first suspicion that anyone in the household may have TB or MDR-TB</li> </ul>
10 to 24 months	<p><b>Counselling to encourage the patient to stay on treatment</b></p> <ul style="list-style-type: none"> <li>- Feeling well and the importance of continued adherence to treatment</li> <li>- Mitigating risks of relapse and explaining how much bacilli is left in the body</li> <li>- Consequences of relapse due to non-adherence to treatment (infection of others, pre-XDR-TB, XDR-TB and death)</li> </ul> <p><b>Couples' counselling</b></p> <ul style="list-style-type: none"> <li>- Continued infection prevention and routine screening of partners</li> <li>- Reproductive health and side effects</li> <li>- Importance of continued adherence to treatment and consequences of sub-optimal adherence</li> </ul> <p><b>Family and couples' counselling</b></p> <ul style="list-style-type: none"> <li>- Further infection prevention strategies</li> <li>- Signs and symptoms of TB/MDR-TB and importance of being screened for TB at the first suspicion that anyone in the household may have TB or MDR-TB</li> </ul>

Findings of this study which were discussed earlier are applied to the development of a counselling strategy outlined in Figure 20 above. This plan covers up to 24 months of treatment and relies on healthcare workers providing comprehensive and standardised MDR-TB treatment education and counselling via interpersonal communication in one-on-one and one-to-many interactions. It is one component of the integrated communication model advanced in the next chapter. The strategy below considers that although KwaZulu-Natal began enrolling MDR-TB patients on shorter treatment regimens in late 2017, some patients will still be prescribed longer treatment, especially as rising incidence of primary MDR-TB and XDR-TB increase probabilities of complicated cases needing longer treatment. The shorter regimen, however, means that fewer patients are required to take treatment for more than 24 months. Therefore, a 24-month plan is developed and proffered above, which can be compressed for shorter treatment or expanded to cover longer treatment as needed.

### **Establishing penetration of mass mediated MDR-TB information**

Other mediums of health communication that this study focused on are television and radio. It was important to ascertain what mass media vulnerable young women with MDR-TB have access to, and the channels and programmes they prefer to consume before their potential use for health promotion could be assessed. Literature in Chapter Three established the scant focus on TB/MDR-TB communication on mass media in South Africa. When asked to recall if they had accessed MDR-TB information via television or radio during the 36 months preceding the interview, personnel from the KwaZulu-Natal Department of Health TB Directorate in Pietermaritzburg who participated in this study conceded consuming: 'Nothing, except for the adverts [on

radio]. I know there are those ones by USAID, I've seen a number of those. But they are not specific to drug-resistant TB. The animated ones, the We Beat TB ones. I haven't really seen any others' (J. Ngozo, Interview, 6 March 2018). Another participant explained: 'I've heard some of our very boring radio ones, the KZN Department of Health ones. These are [broadcast] in our allocated month, it's just information in a PSA. But it's the same voice for every topic. We get ours done in March, although I've heard some in February' (R. Page, Interview, 6 March 2018). These findings reiterate the scarcity of mass mediated MDR-TB communication in South Africa as discussed in Chapter Three.

That MDR-TB in eThekweni is a longstanding and significant concern explains the lack of urgency to mount mass media health promotion campaigns. Participants opined that public health communication about MDR-TB only occurs when stakeholders are in crisis mode or pressured to respond to persistent challenges. One participant rued that 'TB isn't taken as seriously as HIV. Even those adverts on 'We Beat TB', they only show them when there has already been a huge outbreak of the disease, when the damage has already been done (Busisiwe, 20 years, FGD#2, 21 July 2018). Also, they only show them during the mornings when everybody is busy, not in the evenings'. These findings connote that rather than being totally absent over the years (2015-2018) reviewed, TB/MDR-TB content discussed in Chapter Four could have been missing on public television and radio stations available to or preferred by vulnerable isiZulu-speaking young women; 'invisible' due to timing and frequency of broadcasting; or overshadowed by the multitude of media channels and programmes accessible to residents of eThekweni. It may also be that the already sparse content is unappealing and fails to resonate with the public, which affects its reception and anticipated impact on audiences' attitudes and health behaviours.

Furthermore, communicating simply and factually, but in ways that encourage patients to adhere to treatment as the only way to be cured can be problematic for MDR-TB treatment. Complications arise when attempting to interpret medical terms and treatment modalities into local languages. This is the case in eThekweni Metro where MDR-TB affects more lowly educated people, for whom information needs to be simplified if it is to be understood and implemented. Participants raised issue with what is communicated about MDR-TB. Some observed that content often obfuscates the fact that the disease is curable, while foregrounding how infectious and dangerous it is. One participant explained:

I think it's also how we communicate, because when we present MDR-TB, we speak about "this type of TB"; in layman's terms we say it's this type of TB that's very difficult to cure, and that many people die of it and only a few people ever get cured of it. So, you talk about it and people see a death sentence. It becomes that if you have it, and people around you know, then it's a very difficult situation (N. Ngomane, Interview, 10 April 2018).

Notwithstanding what is discussed, this study found that MDR-TB is so under-communicated in eThekweni Metro that knowledge largely circulates among the infected and affected, with those on the periphery of these groups unlikely to actively seek or receive information. This helps to prop up the unsupportive communities characterised by stigma where vulnerable young women must receive MDR-TB treatment during the continuation phase of treatment. This finding connotes that mass mediated TB/MDR-TB content in South Africa is insufficient, poorly targeted and/or too complicated or not interesting enough for target audiences to actively consume, as intimated by the reference to 'boring PSAs' presented earlier. This assertion is substantiated by the reality that all four public television stations and many of the radio stations that participants reported accessing and/or preferring broadcast nationally and, therefore, are required to cater to the needs of all South Africans. Communicating nationally would be difficult to do effectively for a disease as complicated as MDR-TB, which has different dimensions and impacts in varied communities.

Viewed within tenets of the Knowledge Gap Theory (Tichenor, Donohue and Olien 1973), these findings demonstrate that media consumers from subordinate socioeconomic, social, racial, gender and age-groups are likely to be less informed than audiences in dominant groups in eThekweni Metro. Furthermore, MDR-TB knowledge gaps were evident between older women, especially unmarried women who are heads of households, and younger women. Some studies discussed in Chapter Five demonstrate knowledge differentials between husband and wives (Katz 1957; Katzman 1974). This study found that women in eThekweni Metro who head their own households may be influenced to consume mass media in order to be sufficiently informed to make decisions to protect their families. This finding connotes that power and authority, not gender, might be more significant predictors of individuals' access to mass mediated information and higher knowledge levels in households in contemporary South African contexts. It also positions older women with MDR-TB who are heads of their own households as potential opinion makers in primary circles of isiZulu-speaking women from low socioeconomic contexts being treated for the disease.

Marginalised women and their treatment supporters generally receive insufficient information as established in Chapter Eight. Because of this, vulnerable young women seeking to become more literate about MDR-TB treatment must actively and persistently ask questions; about the names of drugs they are taking, what each does and explanations of test results, among others. For varied reasons, including distrust of healthcare workers and fear of being ill-treated for being assertive about understanding their treatment, younger women with less agency either keep quiet, or seek information from others who are not healthcare providers. One participant shared:

The lady that I started my treatment with, she was told to come back after every two weeks whereas I was told to come back the following month. I was confused. She completed her injection earlier than me though. When you ask around people will tell you that they take different numbers of pills – some take 16, some take 20. I just want to know why this is so (Busisiwe, 20 years, FGD#2, 21 July 2018).

As well as ascertaining the MDR-TB prevention and treatment knowledge gaps evident between people with MDR-TB and those without, these findings urge for health communication and promotion interventions to also consider information imbalances *within* different categories of patients by age, gender, race, educational qualification, socioeconomic status and cultural context. It is not enough to pronounce on knowledge gaps, without analysing inter-group differences in access to information. Findings of this study signify the imperative to incorporate age-appropriate strategies to the development and dissemination of MDR-TB content, including that targeted at a largely heterogeneous group of women in a strong sociocultural context like eThekweni Metro. Various television and radio channels and programmes appeal to women of different ages, even if they all reside in urban areas and are dealing with the same health challenge. A participant to this study was clear that, ‘You can’t talk to me [via mass media] in the same way you’d talk to a 20-year-old (J. Ngozo, Interview, 6 March 2018)’. Tailoring public health communication to appeal to audiences, particularly younger more connected ones who can flip between channels and communication mediums in search of more appealing content is illustrated by participants’ calls to make MDR-TB information ‘... ‘sexy’, to reach them [young women]. Not like the usual public service announcements from the Department of Health. Content must be young, fun, hip and vibrant to reach them’ (R. Page, Interview, 6 March 2018).

This study found that, predictably, residents of eThekweni who are not personally affected as patients, healthcare workers, close contacts or policy makers and

implementers are even more marginalised in their access to information and as a result may communicate erroneous views in their primary circles. The dearth of accurate and regular public health communication about MDR-TB creates an information vacuum. With the backdrop of subpar communication about MDR-TB treatment in health facilities, failure to saturate the airwaves in marginalised communities with information results in limited dissemination and low analysis and re-circulation of content moderated by opinion makers and information mediators (Lazarsfeld and Katz 1944). This negatively impacts the contribution of health communication to influencing opinions and attitudes towards behaviour change. Absence of conversations about the scant mass mediated MDR-TB content in South Africa means that knowledge about the importance of MDR-TB prevention and treatment adherence will remain the preserve of a few. Understanding how communication should be disseminated and which groups of people to target in low socioeconomic contexts is key to achieving a multiplier effect from mass mediated content. To achieve this, it is necessary to understand vulnerable populations' preferences in terms of receiving information broadcast about MDR-TB, as this study attempts to do below.

### **Preferences for receiving mass mediated information about MDR-TB and contribution of social media**

Many participants who contributed to this study reported being inactive consumers of mass mediated MDR-TB content, who were typically unable to recall information they had consumed. As intimated above, this study found that being personally affected by MDR-TB is correlated with being more likely to actively seek information and retain details. Vulnerable young women with MDR-TB who contributed to this study were more likely to recall content, and to name stations and programmes than other categories of participants, notably nurses. Young women reported preferring to access MDR-TB information via radio. Preferred radio stations include isiZulu language stations like *Izwi Lomzansi FM*, *Gagasi FM*, *Inanda FM*, *Ukhozi FM* and *Nzutuma FM*; East Coast Radio, which is a geographically proximate English language station; and the national station *Lesedi FM*, which broadcasts in Sesotho and is owned by the SABC.

Notwithstanding this, however, participants overwhelmingly recalled TB/MDR-TB information broadcast on television most; especially on news programmes on the national broadcaster's SABC 1. Participant Makhosi (31 years, FGD#1, 26 May 2018) explained: 'On TV, they said the President of South Africa was going overseas to check on this one pill that was said to cure MDR-TB... it was on the news, on SABC 1', while Enhle (31 years, FGD#2, 21 July 2018) added 'There was a time when they spoke



about TB in the news on TV. They were advertising something to do with *Bedaquiline*. They might be adding some pills to the treatment. It was on SABC 1'. This finding finds explanation in Tichenor *et al.*'s (1973) pronouncement that local news programmes close knowledge gaps because local audiences are more invested in and can relate to content broadcast because it directly impacts their lives.

Similarly, advertorials or PSAs broadcast during local television programmes which are culturally proximate (Straubhaar and LaRose 1996) are important formats to reach vulnerable young women with information. Indicating that audiences do retain information from these mediums, a participant explained: 'I saw [TB content] on TV on SABC 1, the advert that's on in the morning in between kids' shows and the soap opera omnibus. This advert is an animated one where they speak about how to use the elbow when coughing, the importance of washing hands... it has that black background' (Zukiswa, 22 years, FGD#1, 26 May 2018). It must be noted, however, that repetition of advertisements to reach more people would be counterproductive, because some viewers switch channels to avoid content they do not want to watch or which they consider overly repetitive. Nokuthula (24 years, FGD#1, 26 May 2018) explained: 'Personally, I don't watch adverts. As soon as there's an advert break, I go to the kitchen to place my plate in the sink'.

As well as the indicated unavailability of TB content on radio, it must be considered that not all vulnerable populations in low socioeconomic contexts in eThekweni Metro have access to the necessary technology via which to access mass mediated public health communication. Residents in marginalised areas, however, likely have better access to radio sets than televisions, as hinted by the participant who explained that MDR-TB content '...should be [broadcast] on both TV and radio because not all of us have a TV and not all of us listen to radio. So, I think it should be everywhere (Nokuthula, 24 years, FGD#1, 26 May 2018). Indeed, the national broadcaster's 18 radio and three television channels, as well as the other community, private, subscription-only and streaming radio and television channels which participants can access suggests that the most effective MDR-TB communication strategy is one which utilises several mediums and channels and is sustained enough to saturate the airwaves with interesting messages over a period of time.

One of the most interesting findings of this study is that including an MDR-TB storyline into a local soap opera or drama has potential to increase reception and conversations about the content in primary circles and online, intensifying information

(re)dissemination and, hopefully, knowledge among vulnerable young women. A key participant suggested that:

There are a lot of the “homebrewed” series that have a very wide audience at prime time. There are lots of conversations about characters in the episodes, so if that can be utilised, and not as a once-off, but maybe over five series, then maybe people in the street will be talking about ‘did you see so and so in the film, let’s say “*Mkubaya*” as an example... on Twitter there will be national conversations about shows. Or people just having conversations, so we need to utilise those platforms. People do a lot of watching of television and they converse a lot about the characters, especially if it’s the main characters (N. Ngomane, Interview, 10 April 2018)

The popularity of soap operas among young women in eThekweni is appropriate (Gibson *et al.* 2019; Tager 2010; Tager 1997), as the genre was first developed with American female housewives as the target audience (Ahmed 2012). A fan of the genre, who recommended the inclusion of MDR-TB information during or between these shows explained:

I don’t do radio, sorry. On TV I watch all the channels, see. At 18:30 I watch *Skeem Sam* on eTV, at 19:00 *Isidingo* on SABC 3, then *Scandal* on eTV at 19:30, *Generations* at 20:00, *Uzalo* at 20:30, then *Muvhango* at 21:00. I watch *iMbewu* on eTV from 21:30 to 22:00. I think the treatment affects my sleep because I barely even sleep, I find myself waking up even at 02:00 am or 03:00 am to watch a movie if there is one (Nokuthula, 24 years, FGD#1, 26 May 2018).

Televised soap operas are a strategic medium to increase public health communication accessible to marginalised communities in eThekweni Metro with entertaining and culturally proximate information that audiences will want to access, discuss and act on. This suggestion is substantiated by discussions of the popularity and effectiveness of edutainment for public health communication in Chapter Four. The Two-Step Flow Theory and Multi-Step Flow Theory are relevant to this study’s examination of how audiences exchange information and opinions about mass mediated content and collectively contribute to establishing and changing prevailing norms in their circles of influence.

An interesting finding in the quotations above and discussed more comprehensively later is the utility of social media and social networking applications in facilitating further dissemination and discussion of MDR-TB treatment and prevention information among geographically and culturally diverse groups, which transcend narrow conceptions of media audience’ primary circles as envisaged by Katz and Lazarsfeld in 1955. This study considers social media for its potential to increase the agency of vulnerable young women resident in enclaved cultures by providing them

with avenues to anonymously solicit information about and share their MDR-TB treatment experiences.

Coming back to television, the soap operas *Uzalo* and *Isibaya*, which are set in KwaZulu-Natal and portray lives of relatable isiZulu-speaking characters, were mentioned frequently as resonating with young women with MDR-TB. A participant suggested:

... [inserting a TB storyline] into soopies like *Uzalo*, *Isibaya* and *The Queen*. *The Queen* is set in Johannesburg, they speak isiZulu and Setswana. On *Isibaya* they speak Setswana and isiZulu. *Uzalo* is in isiZulu. I like it [*The Queen*] because of Connie Ferguson. Because everywhere she acts, she's natural. She doesn't fake, doesn't wear too much make-up. She always wants to protect her family. Use celebrities. People look up to them. They [audiences] like to do the things that they [celebrities] do. People listen to them (Nothando, Interview, 29 September 2018).

The soap opera *Uzalo*, which is set in the marginalised township of KwaMashu in eThekweni Metro and is the most-watched soap opera in South Africa with 10.2 million viewers in 2018 (Zalebs 2019), is of interest to this study. The SABC 1 telenovela sometimes tackles social and health issues in its storylines. In December 2018 for instance, *Uzalo* debuted a plot in which main character Pastor Mdletshe struggles to adjust to being diagnosed with diabetes. Prior to his diagnosis, however, the pastor worries that he might be infected with HIV or TB instead, based on previous sexual behaviour and symptoms experienced. Local soap operas can be important to MDR-TB communication efforts because the more media content reflects the cultures and contexts of audiences, the more confident they can be that remedies communicated are relevant and possible for them to mirror in their contexts (Straubhaar and LaRose 1996). Moreover, as well as accepting mass mediated messages because of her familiarity with the culture and locations portrayed and the language used, participant Nothando suggests that media audiences respond positively to information mediated by celebrity actors or characters they admire, a point which is incorporated into the communication model proffered in Chapter Ten.

Participants to this study indicated that the best television channels for them are the public channels SABC 1, 2, 3 and eTV. Only one participant reported watching *The Lucky Specials*, the only edutainment programme on TB/MDR-TB disseminated on South African television between 2015 and 2018. The participant had, however, not seen the film on television. When asked to name channels or programmes with MDR-TB content, she responded:

I can't think of any, except for *The Lucky Specials* movie that we have been showing, but again it wasn't specific to women. Uptake was good in eThekweni, with just gathering people and showing them that film. We showed the film in the museum... it has been shown in schools, especially high schools and the TVETs<sup>12</sup> as well. It could have been shown in community halls, but I'll have to check with the coordinators because we have given them two DVDs that they are showing around. The Department of Health is rolling out this initiative... We started last year, in the build-up to World AIDS Day, because we get a lot of buy-in from municipalities for World AIDS Day. So, we gave them, and municipalities provided sound for small gatherings. Ever since then we continued, and even now we are using it for the build-up to World TB Day. We started around November [2017] (J. Ngozo, Interview, 6 March 2018).

Broadcasting *The Lucky Specials* on DSTv first, as explained in Chapter Four, clearly illustrates the dividing power of some information dissemination strategies used for critical public health promotion. Channels used to disseminate MDR-TB education contribute to widening existing knowledge gaps between vulnerable populations with low access to media, and those who are not as constrained. Programmes on the national broadcaster's channels are accessible to the majority of South Africans and are critical to vulnerable populations' abilities to access life-saving public health communication. It is critical that these channels are used more for health promotion.

An interesting finding, which ought to have been anticipated during the conceptualisation of this study but was not, is that young women are avid users of new media and that the Internet and social media are significant sources of information for them. A participant who contributed to this study in the early stages was clear that '... people now use their own means to Google "what does having MDR-TB mean? If I am taking this treatment what does it mean?" So even their own ability to have better conversations [about their illness] because of the availability of information on the Internet [improves]. People are much more able to converse from an empowered stance than before' (N. Ngomane, Interview, 10 April 2018). This study had overlooked the utility of this medium to studies aspiring to assess how to respond to a significant public health problem affecting a youthful vulnerable population at the outset. However, as it emerged so strongly in the data gathered, new media is deservedly incorporated in developing the integrated communication strategy proffered in the next chapter.

KwaZulu-Natal Department of Health personnel interviewed for this study were first to promote the practicability of new media to disseminate MDR-TB information to vulnerable young women in eThekweni. One participant urged for its use because

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<sup>12</sup> Technical and Vocational Education and Training institutions.

'There are very few young people who aren't constantly looking at their phones, never listening and never looking up. So, you need to get your messages onto this thing that they're swiping this way and that way' (R. Page, Interview, 6 March 2018). The utility of this finding is supported by indications that there is 93.8 per cent penetration of mobile phone technology in South Africa (Treffry-Goatley 2017). The finding must, however, be tempered by questioning whether young women from low socioeconomic contexts can optimally use new media to increase their treatment literacy. To access the world wide web, users must own or have access to an Internet-capable device and Wi-Fi or be able to afford prohibitively high data costs, which in South Africa are accused of contributing to the digital divide and prejudicing low income and rural populations (Seeth 2018). Secondly, the connexion between educational attainment/literacy and Internet use must be considered, because basic literacy and English language skills are a prerequisite for accessing most content, searching for appropriate information and understanding it enough to be able to apply it (Deen-Swarray 2016). Studies in Africa establish a chasm in Internet use between those who lack or report low reading and writing capabilities and those able to easily read and write, with the widest gap recorded between South Africans on each side of the gulf (Deen-Swarray 2016; Fayoyin 2016)

Although this study did not seek to assess the literacy or English-language competencies of young women with MDR-TB, from observing participants during data collection, all young women could read the informed consent forms and follow instructions to write their names, sign and date the forms, which indicates some literacy. In terms of comfort with communicating in English, however, only a few participants chose to read and sign the informed consent form in English, and all group discussions were undertaken with participants conversing in isiZulu. Applying the lens of the Knowledge Gap Model to this analysis shows how low socioeconomic status, which impacts groups' educational opportunities in developing countries, hinders use of new media and excludes vulnerable populations from accessing life-saving information and resources that are available to others. This finding urges for the development and dissemination of MDR-TB messages in indigenous languages, preferably on mobile websites as most Internet users from low income contexts in Africa access sites via mobile phones (Deen-Swarray 2016).

Notwithstanding potential impediments, because of its wide penetration in South Africa, and eThekwin Metro, the affordability of some sites and its popularity among young people, new media is considered important for public health communication in

contemporary times. As intimated earlier, the Internet and social media expand narrowly defined ideas of primary circles as only occurring in communities. Further, digital primary circles in the form of online communities can support constant interaction and opportunities to influence members. In this conceptualisation, online gatekeepers share and encourage the re-sharing of messages and content on sites and applications (apps) such as Facebook and WhatsApp groups respectively, while opinion makers shape users' ideas and attitudes by sharing and resharing content. Because of the global nature of social media, there are also more opportunities for audiences to be exposed to ideas and interpretations of content that are not in line with the dominant beliefs, norms and traditions of the insular physical communities to which they belong (Habibi *et al.* 2017). This study focuses on these two social networking platforms based on insights from participants that: 'People are using WhatsApp and Facebook. WhatsApp is cheaper. Facebook is eating too much data, but it's OK' (Nothando, 30 years, Interview, 29 September 2018).

The One-Step Flow Model postulates a communication process where media communicates directly to audiences, without messages being filtered by opinion leaders and moderators. This is possible on the Internet, for instance, where users can search for information and choose the sources they will read and accept independently. Additionally, proponents insist that the sizes and number of online communities and the volume of content they generate means that in this medium, opinion leaders, who are prominent in the Two-Step and Three-Step Flow paradigms, are more likely to reinforce and pass on latent opinions than to reframe or significantly influence messages (Bennett 2006). However, even if we concede that opinion leaders' influence is diluted by the now widely available divergent content on the same topics, in deeply traditional communities like those in eThekweni, which privilege family collaborative approaches to healthcare, elders and leaders remain a formidable force mediating accepted norms and standards within their families and communities, including application of health information. Thus, while vulnerable young women's attitudes and health intentions may be influenced by prevailing norms in the online communities they participate in, their behaviours and abilities to act are necessarily influenced by the dominant beliefs and practices in the households and communities where they reside.

These insights urge for the isolation of possible generalised primary groups of young women with MDR-TB in eThekweni, to identify who the opinion leaders and gatekeepers of information in their groups are. Doing this would support efforts to

indicate categories of people other than patients themselves to be targeted with information about MDR-TB and the types of mediums to use to reach them, towards improving vulnerable young women's adherence to treatment in low socioeconomic contexts.

### **Identifying opinion makers and information mediators**

Because personal change ostensibly happens when people who are supportive of patients are involved in the transformation (Michau *et al.* 2014; Mishra *et al.* 2014), it becomes necessary to determine how dissemination of MDR-TB treatment education can be expanded to include others. Michau *et al.* (2014) urge for a community approach to impact individual TB patients towards improving their adherence to treatment. This position is supported by Matebesi and Timmerman (2012:1) who recommend implementing 'enhanced programmes focusing on patients, the community and healthcare providers'. Scholars argue that attitude and behaviour changes do not require a generation if implemented interventions adhere to key principles and that efforts to change people's attitudes and behaviours one at a time have been found to be less successful (Michau *et al.* 2014). This has led researchers to advocate for targeting groups and entire populations for a whole-of-community effect. The importance of focusing on others beyond patients is substantiated by findings that while encouraging specific positive behaviours in TB patients may be effective, without complementary processes that engage others in their social circles, undesirable behaviours and associated challenges may not decline, and in some cases might even increase (Michau *et al.* 2014).

The sections below apply findings of this study to categorise who, or which groups of people were classified as opinion leaders, individuals capable of influencing how vulnerable young women apply MDR-TB treatment literacy education and mass mediated public health communication to enhance their adherence to treatment. It is important to contemplate the communities in which vulnerable young women with MDR-TB live insofar as they impact their treatment practices if the model proffered in this chapter is to contribute to sustained change among the case study of this research.

#### ***Children in schools***

Children of MDR-TB patients are considered outstanding opinion leaders, with perceived high influence over young women's treatment behaviours. Participants suggested that TB/DR-TB prevention and treatment information would be easily accessible and impactful if it is included 'in school subjects like Life Orientation, just

like they include information on HIV' (Makhosi, 31 years, FGD#1, 26 May 2018). Because young women interact with their children's homework chances that they will read about MDR-TB issues in this way are high. Another participant explained:

'I'm a parent so when my child comes with homework, I obviously help him. If it's something that I don't know, I ask mom. If she isn't able to help, I will Google it, in that way the information is shared' (Nokuthula, 24 years, FGD#1, 26 May 2018).

This finding further indicates potential to achieve multi-step flow of MDR-TB communication as many people interact with and discuss a learner's homework, with benefits for multiple household members.

This study finds that communication should not merely focus on patients at the time when they are diagnosed and initiated on treatment, but should be more far-reaching, focusing on children in their formative years, similarly to how HIV education is prioritised in South Africa. Participants explained that MDR-TB treatment is 'overwhelming' for healthcare professionals who are required to provide – and patients and their treatment supporters to receive – a lot of complicated information in a short space of time about the aetiology of MDR-TB and its treatment post-infection. A nurse suggested that: '... the government provide us with school nurses, who will be staying at the schools and telling (students) from young ages about the prevention of TB' (Nurse #3, Interview, 7 March 2018). Teachers and healthcare workers stationed in schools would ostensibly ensure that there is:

... teaching about TB in schools earlier ... so you don't only know about TB because you have contracted the disease, because now you can't even process properly because you've just heard about it. I feel that if we can target information about TB and drug-resistant TB to young people, when they grow up even if it's not only for themselves, but to support others, if they can get the information that would be great. Because I feel that it gets so confusing for them, and it doesn't give them time to really think about this, because they've got the disease they have to start the treatment now (J. Ngozo, Interview, 6 March 2018).

Ideally MDR-TB health communication should not only start when patients are diagnosed with MDR-TB. Further, initiatives can focus on reaching multiple categories of people with information, chief among them children of school-going age who reportedly influence their mothers' health intentions. Because mothers want to keep children in their households safe, they are likely to accept and apply information that children receive from school, mass or social media and pass on to them.



### ***Mothers, grandmothers and intimate partners***

Based on findings discussed in Chapter Eight, this study considers failures to offer customised and confidential education to patients' families a missed opportunity to extend knowledge about MDR-TB beyond patients to members of their primary circles (Lazarsfeld and Katz 1955). These failures can be partly blamed for the fear that surrounds MDR-TB, and for some patients' challenges with fully adhering to treatment when they encounter stigma driven by lack of knowledge. The importance of educating patients and treatment supporters is informed by findings presented in Chapter Eight that for isiZulu-speaking patients, healthcare access is not an individual pursuit, but one in which close family have a say. Educating household members will go a long way to mitigating fears around MDR-TB, which directly lead to stigma. Based on discussions in Chapter Eight, mothers, grandmothers and intimate partners, many of whom are caregivers for young women with MDR-TB are positioned as influential opinion leaders because of their closeness to patients, higher roles in isiZulu family structures and communities and, in the case of women heads of households, demonstrate greater consumption of mass mediated health communication.

### ***Celebrities and personalities***

The aspirational nature of media consumption positions some local celebrities as opinion makers capable of influencing vulnerable young women's MDR-TB treatment behaviours. This has relevance for mass mediated public health messages and social media, where celebrities are often opinion leaders capable of impacting followers' attitudes. Celebrities are viable sources of MDR-TB treatment adherence communication because 'People look up to them. They like to do the things that they do. People listen to them... but they must be all over. It mustn't be a thing that they just do among a certain group of people. It must be a well-known thing' (Noluthando, 30 years old, Interview, 29 September 2018). Some South African celebrities who survived TB, including Miss South Africa 2018 as discussed in Chapter Eight, speak about their experiences of being treated for TB. Hearing from Prince Nhlanguiso Zulu of KwaDlamahlaha, son of Zulu King Goodwill Zwelithini kaBhekuzulu, who is also a TB survivor and health ambassador for KwaZulu-Natal province might be more relevant to isiZulu-speaking communities.

### ***MDR-TB survivors***

As discussed earlier, knowledge about MDR-TB is concentrated among patients and KwaZulu-Natal province healthcare providers and TB management practitioners who, unenviably, are the primary sources of information about the disease and its

treatment. Understandably, household contacts of MDR-TB patients previously treated for TB themselves were more knowledgeable than those with no personal experience of treatment. Communication deficits are worsened by public knowledge that people diagnosed with MDR-TB generally have poor prognoses, as explained by participant N. Ngomane who said: 'We know that it's getting better in terms of getting cured [of MDR-TB], but all the person on the street knows is that it's a disease which is not curable, that very few people get cured' (N. Ngomane, Interview, 10 April 2018). Communication about MDR-TB where there are shortages of accurate and regular information, besides creating missed opportunities to increase public health communication around this disease, is liable to reinforce and intensify the negativity that characterises colloquial discussions about MDR-TB and those infected in eThekweni. This finding positions MDR-TB survivors as an invaluable and trusted category that can be co-opted to educate vulnerable young women about adherence, particularly in peer-to-peer interactions that occur in the communities where patients reside.

### ***DOTS supporters and healthcare providers***

Notwithstanding inadequacies of the KwaZulu-Natal DOTS programme discussed in Chapter Four (Terra and Bertolozzi 2008; Matebesi and Timmerman 2012), this study considers DOTS a potential entryway for nurses, CCGs, and family and friends of TB patients acting as treatment supporters to provide motivational counselling and health education to patients and others during the continuation phase of treatment. There is immense pressure on healthcare professionals in public facilities to educate patients more comprehensively patients. This study finds that treatment education can be strengthened in both healthcare facilities and homes and that DOTS supporters can contribute to this endeavour at community level.

Earlier chapters established the imperative to supplement biomedical MDR-TB treatment with communication to improve treatment literacy if TB management efforts in eThekweni Metro are to succeed. Indeed, as MDR-TB treatment adherence and completion rates remain stubbornly low in South Africa, numbers of people with primary resistance in areas like eThekweni Metro are increasing. Based on communication's listing as a critical enabler of long-term adherence to treatment in documents such as the NSP 2017-2022), this study considers how public health communication, beyond MDR-TB patients alone, can be utilised to better support MDR-TB treatment among a vulnerable population. The model proposed in the next chapter utilises existing communication interventions within healthcare and

community settings for cost-effectiveness. Its successful implementation is predicated on the scale-up of public health communication via mass media and social media, and on impacting the opinion leaders and gatekeepers in young women's households and communities, for maximum impact in terms of reaching audiences.

### **Summary**

This chapter presented findings to support development of a counselling strategy and a model of communication aimed at contributing to efforts to enhance adherence to biomedical treatment among vulnerable populations in low socioeconomic contexts. It argued that repositioning communication in MDR-TB management in eThekweni Metro is necessary to support huge investments made in the biomedical DR-TB programme, not least by protecting the effectiveness of the limited drugs available to treat MDR-TB, by enhancing patients' adherence to treatment and preventing further mutations that would render more drugs ineffective against DR-TB. The integrated model proffered in the next and final chapter of this thesis is based on existing structures and involves lower investment of financial resources than required to improve the material conditions of residents and, therefore, presents a viable contribution to TB management efforts in South Africa.

## CHAPTER TEN

# (RE)POSITIONING COMMUNICATION AT THE CORE OF MDR-TB TREATMENT: PRESENTING AN INTEGRATED MODEL

### Introduction

It is widely accepted that all individuals aspire to good health, and that they would probably take reasonable steps to become or stay healthy, if they know how. Extant literature demonstrates that inadequate and ineffectual health education and communication efforts contribute significantly to patients' poor attitudes towards their disease and treatment (Matebesi and Timmerman 2012). Indeed, scholars link adherence to MDR-TTB treatment to provision of empathetic health communication and counselling by professionals (de Oliveira and Lefèvre 2017; Maswangayi *et al.* 2014) and insist that it is important for TB patients to receive comprehensive treatment education prior to starting treatment (Akeju *et al.* 2017). The paucity of research on how patients' adherence to long-term treatment for serious communicable diseases like MDR-TB in high TB, MDR-TB and HIV syndemic countries can be improved contributes to TB eradication efforts continuing to fail (Atkins 2011; Munro *et al.* 2007; Kagee 2004). This is true for communities like eThekweni Metro, partly because 'adherence as a factor in health management has not been the subject of South African medical research, leaving this area up to social and behavioural scientists to take up' (Kagee 2004:26).

This thesis problematised the relegation of public health communication to the backburner in MDR-TB responses in South Africa, despite global and national policies which emphasise the centrality of information and education to effective TB management. It argued that this shortcoming is exacerbated by non-standardised provision of MDR-TB treatment education and infection prevention information to patients and their contacts in health facilities. Indeed, as well-meaning as they are, the diverse responses to MDR-TB discussed in extant literature and which I was involved in implementing as part of my employment, often fail to consider the disparate socioeconomic, structural, cultural, relational and gender and age-related challenges that contribute to diminishing patients' access to and retention of knowledge about MDR-TB and, after they access it, to act on it.

This research contributes to literature that substantiates the importance of other responses to the MDR-TB epidemic, beyond the biomedical interventions privileged in South Africa's TB management efforts. The importance of this study's contribution

to MDR-TB management efforts is anchored in understanding that improved adherence to prescribed MDR-TB treatment leads to reduced infectivity of patients and MDR-TB transmission rates, to contribute to South Africa's goal of reducing TB by 2022 (SANAC 2015), and the global target of eradicating the disease by 2035 (WHO 2017).

This study responded to identified gaps in research and practice and contributes knowledge to the under-researched topic of non-biomedical responses to sub-optimal adherence to long-term DR-TB medication in the Global South. A broad objective of the study was to address the not-often stated question of 'how' communication strategies can be practically implemented to complement biomedical treatment and contribute to improving vulnerable young women's MDR-TB treatment literacy. Specific objectives of the study were to:

1. Assess the socioeconomic, structural, cultural and gendered issues that drive primary MDR-TB infection and hamper infection prevention efforts and treatment adherence among vulnerable young women in low socioeconomic contexts in eThekweni Metro.
2. Establish forms of mass mediated messages frequently accessed by young women on treatment for MDR-TB and their contacts in eThekweni Metro.
3. Ascertain which people, or groups of people, in contact with vulnerable young women receiving treatment for MDR-TB via public health facilities have the most reported influence in terms of communicating behaviour change and health information.
4. Develop a model that repositions, both epistemologically and practically, mass-mediated and interpersonal communication approaches to MDR-TB in ways that contribute to improvements in the KwaZulu-Natal MDR-TB programme.

This chapter discusses findings of this research which contribute to achievement of Objective 4, by proffering an evidence-based approach to health communication about MDR-TB targeted at a vulnerable population which is derived from primary data. The model advanced relies on MDR-TB communication occurring at (i) intrapersonal, (ii) interpersonal, (iii) group, (iv) organisational and (v) societal levels (Storey *et al.* 2014; Bernhardt 2004; Corcoran 2007; Kreps *et al.* 1998) as discussed in Chapter Four. It is advanced as this study's response to scholars' calls for research that explains *how* communication should be utilised and targeted to practically contribute to TB management efforts.

## **Main findings of the study**

Analysis of findings of this study collected through fieldwork with a case study of young women with MDR-TB and other participant groups resulted in some unique results, which were discussed in Chapters Eight and Nine. Findings suggest that sub-optimal adherence to MDR-TB treatment demonstrated by vulnerable young isiZulu-speaking women from low socioeconomic contexts in eThekweni Metro is exacerbated by patriarchy, high incidence of stigma, and strong cultural beliefs and practices which position them as subordinate to men and elders, and significantly lacking in agency over their health within their families and communities. The findings further suggest that culturally influenced conceptions of ill-health due to MDR-TB infection and traditionally defined family collaborative responses to disease employed by isiZulu-speaking people urge for the incorporation of elders, partners and older children into young female MDR-TB patients' treatment. In this conceptualisation, emphasising biomedical MDR-TB treatment for the individual patient as the denominator of treatment in contexts such as this requires reconsideration. The study finds that other perspectives, including standardised treatment education and health communication, which are incorporated into strategies to reach patients and members of their families with information have relevance.

The study also found that increasing public health communication about MDR-TB through the formal education system and mass media campaigns is crucial, so that when people are diagnosed with MDR-TB, they approach treatment with some knowledge about causes of the disease and its treatment. Interestingly, school-going children, female elders in families and intimate partners emerged as significant information leaders, with perceived influence over the attitudes and health intentions of young women in relation to their MDR-TB treatment. Celebrities and TB survivors were also mentioned as acceptable sources of treatment adherence information that women would be willing to listen to. Further, because of the centrality of traditional beliefs and practices and associated use of traditional health practitioners among the Zulu established in Chapter Eight, this study finds that there is utility in incorporating this group as health promotion partners in TB prevention in eThekweni Metro. Stakeholders working in the TB space can build knowledge and capacities of traditional health practitioners in disseminating MDR-TB prevention information to people who visit them to consult. Further, as part of their spiritual and emotional support roles, they can simultaneously encourage MDR-TB patients to adhere to biomedical treatment until completed.

Analogously to existing literature, findings of this study suggest that there is value in the TB programme borrowing strategies from the HIV management programme, where patients are generally better able to independently adhere to ART. Offering standardised individual, couples' and family counselling at intervals for the duration of MDR-TB treatment was found to have potential to increase vulnerable young women's adherence to treatment for this curable disease. Findings also suggest that patient education to improve MDR-TB treatment literacy using interpersonal communication strategies would be more impactful when bolstered by information disseminated via culturally proximate television and radio programmes (Straubhaar 1991) and social media platforms that allow patients to anonymously request and exchange information with others in expanded and geographically unlimited virtual groups. Counselling families about adherence to treatment becomes especially important because Zulu elders, who are conceived of as cultural gatekeepers of MDR-TB health communication in this study, have influence over whether young women are able to act on it in line with their changed attitudes and health intentions. This study considers that winning the participation of these groups in the treatment of young women is key to getting them to let important information permeate into their primary circles.

Vulnerable young women with MDR-TB require clear communication through succinct and empathetic explanations about each stage of treatment which explains what each drug does and what they should experience at each point. Communication that emphasises benefits of MDR-TB patients' adherence to treatment for children and other household members would be most effective for young women and is an important strategy to prevent new MDR-TB infections and re-infections, and to reduce incidence of the disease in eThekweni Metro. This is also the rationale for including children in the communication process as outlined in Figure 21 below. Further, ensuring that women with MDR-TB are adequately educated about the importance of adhering to treatment has a multiplier effect in terms of protecting children and other immunocompromised members of their households from infection.

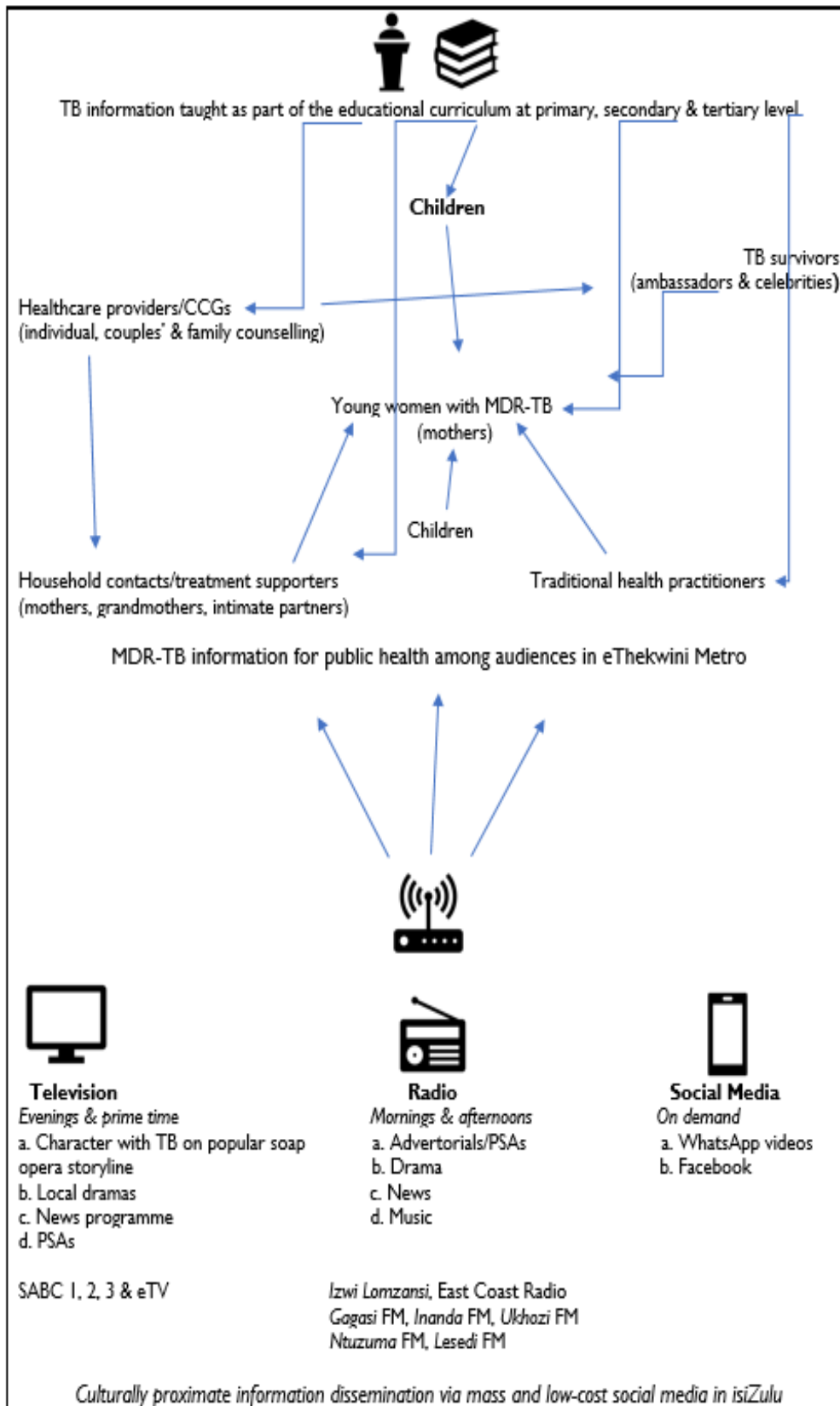
The integrated communication model proffered below foregrounds the primacy of an iterative treatment education and counselling approach implemented in healthcare facilities and homes, as well as public health communication disseminated through mass media and new media targeting residents of low socioeconomic communities with high MDR-TB burdens. The model is based on understanding that 'communication is not a once-off process, because in the first counselling session the

client also goes home and thinks about some things and needs to come back and ask. And it's also about keeping lines of communication open (N. Ngomane, Interview, 10 April 2018). Because of the sociocultural context, it is only by impacting individual patients, their household contacts and communities around them can eThekweni Metro achieve improvements in MDR-TB treatment rates and, consequently, reductions in new infections. This design of the model incorporates these issues.

Figure 2 illustrates the integrated communication model developed from findings presented in Chapters Eight and Nine and the summary of main findings above. Varied health communication strategies and mediums are applied to the development of model, which utilises one-way and two-way communication approaches in a multi-pronged integrated strategy that aims to reach diverse audiences with pertinent MDR-TB information. This study found it necessary to incorporate multiple mediums of communication for greater impacts. The necessity of applying four mediums and emphasising the repetition of communication at various levels is informed by the health communication approach (Cross *et al.* 2017) illustrated through the linked VPCM, Knowledge Gap Model, Two-Step, Multi-Step and One-Step Flow theories, as well as select social and behaviour change theory respectively. The proffered model further aims to encourage bottom-up communication processes where audiences actively interpret meanings in messages and make informed choices about their health from a point of empowerment, which is the point of health communication (Cross *et al.* 2017).



Figure 21: Integrated communication model to improve MDR-TB patients' treatment literacy and adherence



The integrated MDR-TB treatment adherence communication model illustrated in Figure 21 above advances an evidence-based practicable approach to public health communication that optimally integrates interpersonal communication and counselling in healthcare settings, and hard news and edutainment programming mainly via television, radio and social media targeted at the specific MDR-TB treatment needs of vulnerable young women. The model avoids pitfalls outlined by Cross *et al.* (2017) in health promotion research approaches. Firstly, it focuses on the family and others around MDR-TB patients and not individual patients in isolation. Secondly, lay perspectives from research participants presented in Chapters Seven, Eight and Nine directly informed the development of the model. Finally, information flows in multiple ways through communication between various groups using multiple mediums of communication.

The integrated communication model proffered urges for the use of integrated interpersonal communication and mass media to disseminate critical public health communication about MDR-TB in South Africa, and social media to spark and carry forward conversations about disseminated content. Three big mass media health promotion trials from the 1970s which established the efficacy of mass media in disseminating behaviour change communication affirm the model advanced above. The United States of America Stanford studies, the North Karelia Project in Finland and North Coast Health Lifestyle Programme in Australia compared the effectiveness of integrated community and mass media communication, and mass media-only interventions in impacting changes in behaviour (Donovan and Carter 2003). The consensus finding of these studies is that optimal behaviour change is best achieved through *combined* mass media and community-focused interventions (Donovan and Carter 2003). This study advances this idea and enhances it by suggesting the incorporation of formal education through schools' curricula, integration of traditional health practitioners in health communication initiatives in deeply cultural low socioeconomic contexts as appropriate and use of new media to achieve more pronounced results that respond to the MDR-TB treatment adherence challenge in contemporary times, particularly for the benefit of young people.

It is important to establish at the outset that success of the proffered model relies on the SABC fully carrying out its public health communication mandate to proactively inform and educate the nation about diseases such as MDR-TB. It is also based on assumptions that media institutions and practitioner have or can acquire the skills necessary to identify MDR-TB stories and report them. Success of the model further

relies on the forging of sustainable partnerships between radio and television content developers, media stations and stakeholders, including clinicians working on TB management in South Africa, to ensure accuracy of information shared. The model insists on the use of multiple channels to disseminate information all year, and not only when there is a spike in TB or MDR-TB incidence in an area, or during commemorations of World TB Day annually. Every woman, man and child in South Africa should be able to recite the symptoms of TB/DR-TB, know how to protect themselves from infection, and understand that MDR-TB is curable if all treatment is taken faithfully.

It is important to elucidate that the integrated communication model advanced in this thesis is not a one-size-fits all approach, nor is it transferable to other environments without adjustment. Successful application in other ecologies is dependent on the identified vulnerable populations sharing similar characteristics to the case study of this investigation, and on parallels existing between cultural and socioeconomic circumstances and availability of free access to MDR-TB treatment and services. Literature discussed in Chapter Three, and findings presented in Chapter Eight point to there being scope for theoretically substantiated communication strategies to improve treatment adherence rates among vulnerable young women in resource-constrained communities with strong cultures.

It is important to clarify that this study focused on enhanced communication as one of many multisectoral and programmatic interventions that must be implemented in tandem if stakeholders in South Africa are to achieve targets set in policy documents such as the NSP (2017-2021), the SGDs and End TB Strategy, including implementing social protections for MDR-TB patients and improving their socioeconomic status. The thesis demonstrated that there is support for complementary initiatives to the biomedical ones in wide use. Indeed, national public health policies that informed this research encourage incorporating social and behaviour change communication strategies in TB education and communication. Specifically, South Africa's NSP (2017-2021) asserts that '[T]o be effective, social and behaviour change communication (SBCC) approaches must be of quality, achieve high coverage of the target population and include measures to reinforce messages through multiple channels' (SANAC 2017:52). Effective approaches are defined as those that are 'theory-based, client/community centred, participatory, oriented around the benefits of key behaviours, and linked to services' (SANAC 2017:52). The integrated communication model communication advanced in this chapter does this by suggesting the

dissemination of targeted MDR-TB information via mediums that include interpersonal communication in healthcare and community settings and mass media and social media for maximum reach and impact on audiences' attitudes and behaviours in relation to complete adherence to treatment for MDR-TB.

## **Conclusion**

This thesis was arranged in ten linked chapters which were cultivated to explicate the three research questions and achieve the four research objectives set. Earlier chapters served to contextualise the history of the MDR-TB challenge, location of the study and research questions to lay the foundation on which they are addressed in later chapters. Chapter One contextualised the study by discussing my professional and academic interest in the research problem of sub-optimal adherence to MDR-TB treatment in syndemic countries which can afford some of the most sophisticated biomedical treatment in the world. I ruminated on how South Africa underemphasises the necessity of implementing complementary social approaches to support the financial investments made to make treatment available and protect the continued effectiveness of the limited drugs offered to treat DR-TB.

Literature was reviewed in Chapters Three and Four. Chapter Three discussed available literature on the availability and effectiveness of extant health communication interventions in health facilities and via mass media in South Africa. These were assessed as they comprise the contribution of communication to MDR-TB prevention and treatment adherence in support of biomedical responses to the mounting epidemic. This chapter established the validity of research such as this one, which argued for the prioritisation of health communication and health promotion in MDR-TB management responses in low socioeconomic contexts.

Chapter Four attempted to demonstrate the centrality of adherence to MDR-TB treatment. It discussed the specific challenges that hamper vulnerable young women's adherence to MDR-TB treatment in marginalised communities in eThekweni Metro, and the potential of communication to improve patient's treatment literacy towards enhanced adherence long-term. Challenges to adherence documented in the literature presented include structural, socioeconomic and cultural factors, among them poverty, unemployment, inequalities at various levels, inadequate access to education and decent housing and amenities, poor nutritional status, gender inequality, migration and alcohol and drug use, all of which increase poor people's vulnerabilities to TB.

Discussions in Chapter One were critical to the development of the conceptual framework presented in Chapter Five, which linked my professional experience and academic interest in contributing to MDR-TB management efforts to cogent literature and the health communication, nursing and mass media theories utilised in this study to emerge with a created framework within which to undertake the research. Indeed, discussions in Chapter Two about the contested aetiology of TB, historical efforts to eradicate it over millennia and successes in the Global North, as well as the contemporary challenge of MDR-TB in eThekweni Metro contextualised investigation of the distinct variables of young women's motivations to not adhere to treatment in-context. They touched on shortcoming of health education in facilities and mass mediated public health communities, and opportunities to enhance contributions of health communication strategies to improve public health in the literature on the topics presented in Chapters Three and Four.

Chapter Six explained the research methodology utilised for this study, which aimed to produce culturally, and historically specific knowledge constructed through the researcher's interactions with carefully selected participants and which can only be understood with reference to participant's socioeconomic and cultural contexts, as established in Chapters Two and Three. The chapter discusses the qualitative research design and multiple methods of data collection applied, the physical location of the study and the multipronged purposive sampling strategy used to select 20 participants from five categories to contribute to the study.

Data collected through the process explained in Chapter Six was comprehensively analysed in Chapter Seven, where the process culminated in the identification of significant broad clusters to explain reasons for MDR-TB patient's suboptimal adherence to treatment. Broad themes, which were presented and discussed in detail in Chapter Eight, the first of two findings chapters in this thesis, included cultural beliefs and practices, environment and socioeconomic status, biomedical and structural considerations, and intrapersonal and relational factors.

Discussions in Chapter Eight aimed to address research question number one, by explaining why vulnerable young women with MDR-TB resident in low socioeconomic communities like eThekweni Metro may fail to fully adhere to treatment long-term. Findings presented aimed to identify opportunities to improve the treatment education provided to vulnerable populations, their families and residents of high MDR-TB burdened areas. Participants explained that the clinical management of MDR-TB in public health facilities in eThekweni Metro is affected by patients' poverty, low

education and employment and overcrowded living conditions; considerable structural challenges in health service provision; noteworthy gender, age-based, patriarchal and cultural norms that mediate women's agency and access to healthcare and support; high levels of stigma; and low MDR-TB treatment literacy and prevention knowledge.

Chapter Nine aimed to address the study's second and third research questions and to consolidate the findings from both findings chapters to develop and proffer an integrated communication strategy in Chapter Ten. The model advances practicable approaches to contribute to improving MDR-TB treatment literacy among patients and increase the flow of information to the public in eThekweni Metro, KwaZulu-Natal, South Africa, so supportive environments with reduced stigma can be built around patients and their families.

### **Generalisability of research findings and limitations of the study**

While the idea that findings of this study are generalisable and transferable to similar contexts cannot be completely discounted, it must be conceded that they would only apply in limited and well-defined contexts. Findings of this study are applicable to experiences of a narrow group of marginalised young women with MDR-TB patients from eThekweni Metro, KwaZulu-Natal, South Africa. However, it cannot be ruled out that conclusions drawn could be applicable to similar cases located in comparable socioeconomic and cultural contexts, and where TB, MDR-TB and HIV are at epidemic levels. Detailed descriptions of the context of the study presented in Chapter Three, the conceptual framework explicated in Chapter Five, the methodological approach explained in Chapter Six and the data analysis process discussed in Chapter Seven all provide thick enough description of the setting and process of this study to allow for similar studies to be undertaken elsewhere. Indeed, while the findings may not be generalisable to other contexts, it is possible that the research methodology and approach is fully transferable.

This study could have emerged with different findings if, for instance, the age range of women with MDR-TB had been expanded to include women 35 years and older, or the number of participants increased to collect information from doctors and pharmacists at the DR-TB Unit at King Dinuzulu Hospital about patients' challenges with adhering to MDR-TB treatment, their roles in educating patients about treatment and possible solutions to the research problem. A limitation of the study which is linked to this consideration is that I did not visit communities where young women with MDR-TB reside, or the DR-TB Unit on visiting days to observe MDR-TB

treatment in action and to assess roles of healthcare workers and CCGs in the provision of treatment education and health communication. For this study, these shortcomings were partly occasioned by financial and resource challenges, as well as fears for the safety of the research team going into unfamiliar communities in eThekweni. Better resourced studies can transcend this limitation to explore these issues for a more full-bodied ethnographic approach, among other areas for further research as suggested below.

### **Scope for future research**

While this study was comprehensive, it nonetheless opened up a few potential areas for further inquiry. The study posed important questions regarding the validity of efforts to (re)position communication to reinforcement biomedical responses to the MDR-TB epidemic for the benefit of a case study in eThekweni Metro. This study's location within the specific context of eThekweni Metro and the demographics of the groups most affected by TB raised important issues concerning cultural implications for young women of having MDR-TB in low resource urban areas where cultural beliefs and traditions significantly impact health beliefs and practices. A specific smaller study could more deeply engage with young women and their contacts on this theme, which was unfortunately outside of the scope of this research to discuss comprehensively. Further research could adopt a micro approach which examines this thematic issue alone, to obtain deeper insights into how gender, age, low socioeconomic status and culture impact health access and outcomes among specific groups in African countries.

Tuberculosis has been the leading cause of natural mortality of men in South Africa, who are documented as having poor health-seeking behaviours. Another potential area for further research could aim to understand the topic of this thesis from the perspective of young men with MDR-TB in eThekweni Metro. It can be argued that research in this area is urgently needed. Investigations could test whether some conclusions presented in this study find parallels with the experiences of young isiZulu-speaking men, and whether gender-based differences in MDR-TB treatment are as significant as found in this research. Finally, research into differences between experiences of young or older men and young women with MDR-TB treatment in low resource settings would be as significant to public health communication literature in Africa as this study may turn out to be.

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## APPENDICES

### Appendix I: Guidelines to aid identification of potential research participants receiving treatment for MDR-TB by KDH nursing staff



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#### GUIDELINES TO AID IDENTIFICATION OF POTENTIAL

#### RESEARCH PARTICIPANTS ON TREATMENT FOR MDR-TB BY

#### KDH NURSING STAFF

#### What the study is about

My name is Petronella Mugoni (Ms). I seek the participation of women aged 18 to 34 years who have been on treatment for multidrug-resistant TB (MDR-TB) for more than six months to take part in focus group discussions for a PhD study that I am conducting under the auspices of the Centre for Communication, Media and Society (CCMS) at the University of KwaZulu-Natal, Howard Campus, Durban.

The Hospital Manager at King Dinuzulu Hospital has given written permission for me to recruit research participants via the MDR-TB Unit at the hospital (letter attached). The Nursing Manager has also consented to me recruiting potential participants through you, in your role as nursing staff in the King Dinuzulu Hospital Drug-Resistant TB Unit (find letter attached). I request your support with recruiting for this study.

The study has been cleared by the University of KwaZulu-Natal Biomedical Ethics Research Committee and assigned the ethical clearance number BE379/17. I have also been authorised to conduct research in KwaZulu-Natal Province by the Provincial Department of Health (NHRD Ref: KZ\_201711\_047). Copies of both letters are attached to this form.

#### Purpose of the research

The research aims to better understand reasons for high incidence of primary MDR-TB and low adherence to treatment among young women from low socio-economic communities receiving treatment via public health facilities, and how these can be improved through better use of integrated communication strategies.

It aims to understand why young women on treatment for MDR-TB at times fail to take all their treatment in the correct doses and at the correct times until treatment is complete. It will also examine how communication can be used to better inform and educate MDR-TB patients and members of their households on the importance of sticking to their treatment regimens to prevent new MDR-TB cases.

### **Who can participate?**

The study seeks to recruit young women aged 18 to 34 years old currently receiving treatment for MDR-TB from King Dinuzulu Hospital. This must be the first instance the women are receiving treatment for any form of TB. Potential participants must not have: ‘

- i. been treated for TB 30 or more days before they were diagnosed with MDR-TB;
- ii. a recorded medical history of treatment for TB before the diagnosis of MDR-TB; and
- iii. a medical record indicating 10 or more days of treatment using anti-TB drugs for conditions other than TB, or any previous results of drug-susceptibility testing showing resistance to the drugs *Isoniazid* and *Rifampicin*.

### **Further, women sought for inclusion must:**

have been on MDR-TB treatment for more than six months  
no longer be infectious, as evidenced by a culture negative sputum test, and must be in the maintenance phase of their treatment

### **Recruitment process**

Based on information in patient charts, the researcher requests that nursing staff assist with recruitment to the study by handing over recruitment flyers to suitable potential research participants when they visit the facility for consultations.

As outlined in the recruitment flyers, women interested in taking part in the research are invited to send an SMS to Petronella C. Mugoni on 079 386 1250 indicating their first name and age. I will call them back with information on when the next group discussion will be held and to arrange for their participation.

### **What form the research takes**

Focus group discussions will be done with between four and six young women who will all get an opportunity to speak about the issue that interests the researcher. Each participant will take part in only one group discussion. Discussions will be conducted in isiZulu and English and will last 1 hour and 15 minutes in total. Interpreters will be part of the research team.

Nothing said during the interviews will be used for anything other than the research, and all contributions will be treated with confidentiality. Information and personal details will not be shared outside of the research.

### **Venue for focus group discussions**

Focus group discussions will be held at the Durban Mission Church near South Beach, Durban, in the morning or afternoon during weekdays and weekends from March to July 2018.

### **Benefits of participating in the study**

No financial rewards will be gained from your participation. However, refreshments will be available before the focus group discussions begin.

Reimbursements will also be provided to cover for costs of public transport (bus or minibus taxi) incurred by participants who travel to take part in the study, up to a maximum of R100 per person.

### **Risks of participating in the study**

The risk in the study is that participants may share personal or confidential information by accident, or that they may feel uncomfortable responding to some questions. As I do not wish for this to happen, participants will not have to answer any question or take part in the interview or focus group discussion if they feel any question(s) are too personal or if talking about some issues makes them uncomfortable. Participants will have the right to withdraw from the study at any point.

**Who else to contact**

If there are some questions that the researcher cannot answer, you can also contact my research supervisor, Dr Musara Lubombo (031 260 1813, [apmlubombo@gmail.com](mailto:apmlubombo@gmail.com) / [LubomboMI@ukzn.ac.za](mailto:LubomboMI@ukzn.ac.za)).

If you wish to find out more about this study, please contact the Biomedical Research Ethics Committee at University of KwaZulu-Natal on 031 260 4769 or [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)).



## Appendix 2: Informed consent form for women with MDR-TB (English)



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INYUVESI  
YAKWAZULU-NATALI

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### INFORMED CONSENT FORM

#### [Informed Consent Form for

\_\_\_\_\_  
(PRINT NAME)

#### This form has three parts:

- i. Information sheet (presenting information about the study)
- ii. Certificate of Consent to Participate in the Study (for your signature if you consent to participate)
- iii. Certificate of Consent for Photographs to be taken during focus group discussions (for signature if consent is provided)

**You will be given a copy of the full Informed Consent Form you sign.**

#### Part I: Information sheet

##### Introduction

I invite you to contribute to research entitled ***(Re)Positioning communication for enhanced multi drug-resistant tuberculosis treatment adherence in KwaZulu-Natal: Towards an integrated model of communication***. You may choose to participate in or not participate in this research. You may also seek the advice of someone you feel comfortable talking to before you decide to participate, or not to. If there are any words or terms that you do not understand, I am happy to explain them to you before you make your decision.

##### Purpose of the research

The research aims to better understand the reasons for high incidence of primary MDR-TB infections and low adherence to treatment among young women from low socio-economic communities receiving treatment via public health facilities, and how these can be improved through better use of integrated communication strategies.

##### Type of research intervention

Your participation will be in the form of a Focus Group Discussion or Key Informant Interview. Focus Group Discussions – in which between three and five other people will also take part at the same time – will take an hour and fifteen minutes in total. In-depth Interviews will take 40 minutes.

##### Reasons for selecting you as a participant

- i. You have been selected to participate in this study because I believe you will provide unique and rich information of value to the study, as well as for one of the reasons below:

- ii. You are a woman aged 18 to 34 years who has never had any form of TB and is now on treatment for MDR-TB as an outpatient at King Dinuzulu Hospital, eThekweni Metro.
- iii. You are a close contact of (you live in or have lived in the same household as) a young woman who has been or is currently on treatment for MDR-TB.
- iv. You are a healthcare provider working in the MDR-TB Unit at King Dinuzulu Hospital.
- v. You work for the KwaZulu-Natal Provincial Department of Health in a capacity that allows you to make programmatic and administrative decisions about interventions.

### **Voluntary participation**

Your participation in this research is entirely voluntary and you have full control over whether to participate or not. There will be no consequences if you chose not to contribute to this study. Should you feel the need to leave the focus group discussion or stop the interview, you are free to do so at any point. If you do not wish to answer any of the questions during the interview or focus group discussion, you do not have to.

### **Research process**

Only the research team – the researcher and an interpreter – will be present during the interviews, unless you would like someone else to be there. Focus group discussions will involve the research team, you and between three and seven other participants. With your consent, entire interviews or focus group discussions will be tape-recorded, but no-one will be identified on the tape. I will store the tape and will destroy it as soon as the research has been assessed. All information recorded will be kept strictly confidential. Outside of the research team, only my supervisors will have access to the information. I will store the tapes in a secure place and destroy them as soon as the research has been assessed.

### **Audio recording and pictures**

I request your permission to audio record the focus group discussion or key respondent interview you will take part in. Written notes will also be taken as part of the data gathering process. Pictures taken will not be included in the final thesis but will be used as an additional way of assessing and documenting non-verbal communication and group dynamics.

### **Duration**

The research takes place over three years in total (2017 to 2019). During that time, I might ask to speak to you more than once, depending on the information gathered during the research and whether I need more details. It is also possible that there might be no need for follow-up discussions. Should you wish or need to contact me or my research supervisors to add more information or retract information previously given, you can reach us using the contact details provided below.

### **Risks**

There is a risk that you may share personal or confidential information by accident, or that you may feel uncomfortable responding to some questions. As I do not wish for this to happen, you do not have to answer any question or take part in the interview or focus group discussion if you feel the question(s) are too personal or if talking about some issues makes you uncomfortable.

**Benefits**

There will be no direct benefit to you, but your participation will help me to understand the challenges experienced by patients around MDR-TB treatment adherence, and possible opportunities for strengthening integrated communication strategies to increase treatment adherence among young women with MDR-TB.

**Incentives**

Please note that no incentives are offered for taking part in this research. Refreshments will be provided during focus group discussions, and minibus taxi fares will be reimbursed for participants who travel to participate in focus group discussions or key informant interviews.

**Confidentiality**

The study may draw the attention of observers, healthcare providers, family and community members who may ask about the research. I assure you that I, the interpreters/research assistants and those assessing the study will not share information about you with anyone else. Information collected for this research project will be kept private. Any information about you will have a number and pseudonym on it instead of your name. Only I and the interpreters/research assistants will know what your number/pseudonym is. I will personally take all necessary steps to ensure that the information is stored in a secure location. This information will not be shared with anyone and will be destroyed at the end of the research.

**Sharing the results**

Nothing you tell me will be shared with anyone else outside the research team, and nothing will be attributed to you by name. The knowledge that I get from this research will be shared with you before it is made widely available to the public. I may then publish the results so that other interested people may learn from the research.

**Right to refuse or withdraw**

As indicated earlier, you do not have to take part in this research if you do not wish to do so and choosing not to participate will not have any consequences on you or your ability to access health services at King Dinuzulu Hospital. If you wish to, you will have the opportunity to review your remarks at the end of the focus group discussion or key respondent interview. You are free to modify or remove portions of any remarks you are not comfortable sharing, or if you do not agree with my notes, or if I did not understand you correctly, or for any reason whatsoever.

**Who to contact**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me

This proposal has been reviewed and approved by the Biomedical Research Ethics Committee at University of KwaZulu-Natal. If you wish to find out more about this study, please contact 031 260 4769 or BREC@ukzn.ac.za).

You may ask me questions about any part of the research study if you wish to. Do you have any questions?

## **Part II: Certificate of Consent to Participate in the Study**

**(This section is mandatory)**

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

**Print name of participant**

\_\_\_\_\_

**Signature of participant**

\_\_\_\_\_

**Phone number of participant**

\_\_\_\_\_

**Date** \_\_\_\_\_  
**Day/month/year**

I have witnessed the accurate reading of the consent form by or to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

**Print name of witness** \_\_\_\_\_

**Signature of witness**

\_\_\_\_\_

**Date** \_\_\_\_\_  
**Day/month/year**

## **Part III: Certificate of Consent for Photographs of Me to Be Taken During the Study**

**(This section is mandatory)**

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I asked have been answered to my satisfaction. I give my CONSENT/DO NOT GIVE MY CONSENT for photographs of me to be taken during the study (**circle** the correct option)

**Print name of participant**

\_\_\_\_\_

**Signature of participant**

\_\_\_\_\_

**Phone number of participant**

\_\_\_\_\_

**Date** \_\_\_\_\_  
**Day/month/year**

**Statement by the researcher/person taking consent**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what will be done.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

**A copy of this form has been provided to the participant. Yes**

**No**

**Print name of researcher/person taking the consent** \_\_\_\_\_

**Signature of researcher /person taking the consent**

\_\_\_\_\_

**Date** \_\_\_\_\_

**End**

## Appendix 3: Focus group discussion guide (young women aged 18 to 34 years)



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### TOOL 1: FOCUS GROUP DISCUSSION GUIDE

### WOMEN 18 TO 34 YEARS CURRENTLY ON TREATMENT FOR

### MDR-TB

**Total focus group time:**

1 hour + 15 minutes

**Project title:** *(Re)Positioning communication for enhanced multidrug-resistant tuberculosis treatment adherence in KwaZulu-Natal: Towards an integrated model of communication*

The study seeks to understand the experiences of young women receiving treatment for primary multidrug-resistant TB (MDR-TB) via the outpatient facility of the Drug-Resistant TB Unit at King Dinuzulu Hospital. It aims to explore how mass media and interpersonal communication and counselling in healthcare and community settings can contribute to improving treatment adherence among young women aged 18 to 34 years from eThekweni Metro.

#### Overview

The study hopes to elicit responses that will help answer the following questions:

1. What are some of the challenges that result in young women receiving treatment for MDR-TB failing to take all their medication as prescribed, and to finish their courses?
2. How do young women receiving treatment feel health providers can give them information in ways that would result in them better adhering to treatment?
3. Are young women receiving treatment interested in learning more about MDR-TB disease and its treatment outside the hospital setting?
4. What mediums of communicating information about MDR-TB treatment and prevention do young women with MDR-TB think would be most relevant for their needs?
5. From who, in their communities and social groups, would young women like to hear more information about MDR-TB treatment and prevention?

#### Introduction (15 minutes)

- The researcher welcomes participants and introduces herself, the research assistant/ interpreter and describes their respective roles.
- Explain the purpose of the discussion broadly, outlining why participants were selected.
- Discuss the purpose and process of focus groups and explain that the discussion will last approximately one hour.

- Explain the presence and purpose of audio and video recording equipment and cameras.
- Go over ground rules and discussion guidelines, such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to ensure that there is time to cover all questions.
- Address the issue of confidentiality, inform the group that information discussed will be reviewed, and that names will not be used in any analysis of the discussion or in the thesis.
- Go through the informed consent form and ask participants to complete and sign the form indicating their informed consent to participate in the study, for discussions to be audio and video recorded, and for photographs to be taken.

### **Discussion questions (60 minutes)**

- Ask participants to introduce themselves using their first names and ages, and community where they live, and begin the focus group discussion.
  - Ask participants to indicate their highest educational qualification and employment status.
  - Ask each participant to indicate how long they have been receiving treatment for MDR-TB.
  - Ask each participant to mention who they live with in their households.
1. In what ways have your lives changed since being diagnosed with MDR-TB?
  2. Have you ever stopped taking your treatment without discussing it with your healthcare provider?
    - How long had you been on treatment by the time you stopped taking it?
    - For how long did you stay without treatment?
    - What are some of the reasons you had to stop taking treatment?
  3. How have your relationships with other people changed since you started taking treatment for MDR-TB?
    - If you are mother, in what ways does having children affect your ability to adhere to treatment for MDR-TB?
    - In what ways does being in an intimate relationship with a man make it easier or harder for you to adhere to MDR-TB treatment?
  4. In what ways do you think your experiences of having MDR-TB differ from those of older women? Or men's?
  5. What would you like healthcare providers to know about why you sometimes struggle to take all your treatment as prescribed?
  6. What sort of information do you receive during your visits to King Dinuzulu Hospital for your check-ups?
  7. Now that you are being treated, what are some questions that you still have about MDR-TB disease and its treatment?
  8. What do you wish other people could know about MDR-TB disease and its treatment?
  9. What sort of information could be useful for helping young with MDR-TB to stay on treatment?
  10. Where and from who do you think it would be best for young women to receive this information? (Probe for responses such as from (i) a doctor or nurse at King Dinuzulu Hospital, (ii) a DOT provider or community carer at home, (iii) the radio or television (iv) social media (v) other sources (ask participants to name them)?)
    - Why is this so?

11. In the past six months, have you watched or listened to any radio or television programmes or content about MDR-TB available here in eThekweni?
  - If so, can you name the programme and/or station?
  - If not, which stations or programmes do you feel would be good for sharing information about MDR-TB prevention and treatment?
12. In what ways could the Internet be a good source of information about MDR-TB treatment for young women such as you?
13. What about social media? If yes, which platforms would be best?
14. Who at the health facility, in your family, household or your community would you be MOST likely to listen to if they shared information about MDR-TB and the importance of adhering to your treatment regimen? Why is this so?
15. Who at the health facility, in your household or in your community would you be LEAST likely to listen to if they shared information about MDR-TB and the importance of adhering to your treatment regimen? Why is this so?
16. What are some hopes you have for when you complete your treatment?
17. Is there anything I have not asked about that you would like to share?



## Appendix 4: Key respondent interview guide – KwaZulu-Natal Provincial Department of Health staff



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Durban, 4000

### TOOL 3: KEY RESPONDENT INTERVIEW GUIDE

### KWAZULU-NATAL ACSM MANAGER AND TB PROGRAMME

### MANAGER

**Total interview time:** 30 minutes + 10 minutes  
(introductions)

**Project title:** *(Re)Positioning communication for enhanced multi drug-resistant tuberculosis treatment adherence in KwaZulu-Natal: Towards an integrated model of communication*

This is a confidential interview that seeks to explore how mass mediated messages and patient counselling can be used to improve treatment adherence among young women from eThekweni aged 18 to 34 years receiving treatment for multidrug-resistant TB (MDR-TB) through the outpatient facility of the King Dinuzulu Hospital Drug-Resistant TB Unit.

#### Introduction (10 minutes)

- Welcome respondent and introduce myself.
- Explain the purpose of the discussion broadly, outlining why the respondent was recruited into the study.
- Discuss the purpose and process of key respondent interviews and explain that the interview will last approximately thirty minutes.
- Explain the presence and purpose of audio and video recording equipment.
- Go over ground rules and discussion guidelines, such as being prepared for the researcher to interrupt to ensure that there is time to cover all questions.
- Address the issue of confidentiality, inform the respondent that information discussed will be reviewed as a whole, and that names will not be used in any analysis of the discussion or in the thesis.
- Go through the informed consent form and ask the respondent to complete and sign the form indicating their informed consent to participate in the interview and for discussions to be audio and video recorded.
- Ask the respondent to introduce themselves using their first name and designation and begin the interview.

**Key respondent interview questions – KwaZulu-Natal Advocacy, Communication and Social Mobilisation Manager and TB Programme Manager (30 minutes)**

- A. *Successes in the management of MDR-TB*
1. Can you briefly explain your role in the management of TB in KwaZulu-Natal Province?
  2. What are some notable successes in the management of MDR-TB patients recorded in eThekweni district in terms of improving treatment adherence rates?
- B. *Challenges and the management of MDR-TB in eThekweni Metro*
3. MDR-TB is a significant and growing health challenge in eThekweni. What would you say are the main impediments to halting new infections in the metro?
  4. Low adherence to treatment (loss to follow-up) has been identified as a particular challenge to MDR-TB management efforts in eThekweni. What are some of the main challenges that you feel contribute to young women with MDR-TB in particular not adhering to their treatment?
- C. *Provision of information about MDR-TB and its treatment inside the hospital setting.*
5. What key information do you feel should be communicated to support young women in eThekweni Metro to adhere to their MDR-TB treatment until completion?
  6. How (via what medium) do you feel this information would be best disseminated? Why is this so?
- D. *Suggested media for communicating MDR-TB treatment and prevention to young women*
7. Let's discuss different sources of information or communication about MDR-TB and the importance of adhering to treatment that are available to patients.
    - a. Are you aware of any television or radio programmes or channels disseminating information about MDR-TB that people in eThekweni Metro have had access to in the past three months? If so, please name these.
- E. *Suggested sources of information about MDR-TB treatment and prevention*
8. Which other people in the primary circles of young women with MDR-TB do you think should be provided with information on treatment adherence in the hopes that when they speak, the messages will be better accepted and acted upon by MDR-TB patients?
  9. Is there anything that I haven't asked about that you would like to share?

**End**

## Appendix 5: Key respondent interview guide – health workers at King Dinuzulu Hospital



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### TOOL 4: INTERVIEW GUIDE

### HEALTH WORKERS AT KING DINUZULU HOSPITAL

**Total interview time:** 30 minutes + 10 minutes  
(introductions)

**Project title:** *(Re)Positioning communication for enhanced multi drug-resistant tuberculosis treatment adherence in KwaZulu-Natal: Towards an integrated model of communication*

This is a confidential interview that seeks to explore how mass mediated messages and patient counselling can be used to improve treatment adherence among young women from eThekweni aged 18 to 34 years receiving treatment for multidrug-resistant TB (MDR-TB) through the outpatient facility of the King Dinuzulu Hospital Drug-Resistant TB Unit.

#### Introduction (10 minutes)

- Welcome respondent and introduce myself.
- Explain the purpose of the discussion broadly, outlining why the respondent was recruited into the study.
- Discuss the purpose and process of key respondent interviews and explain that the interview will last approximately thirty minutes.
- Explain the presence and purpose of audio and video recording equipment.
- Go over ground rules and discussion guidelines, such as being prepared for the researcher to interrupt to ensure that there is time to cover all questions.
- Address the issue of confidentiality, inform the respondent that information discussed will be reviewed as a whole, and that names will not be used in any analysis of the discussion or in the thesis.
- Go through the informed consent form and ask the respondent to complete and sign the form indicating their informed consent to participate in the interview, and for discussions to be audio and video recorded.
- Ask the respondent to introduce themselves using their name and designation and begin the interview.

#### Key respondent interview questions – health workers in the Drug-Resistant Unit at King Dinuzulu Hospital

- I. MDR-TB is a significant and growing health challenge in eThekweni. What would you say are the main impediments to halting new infections in the metro?

2. How big is the loss to follow-up rate among female patients being treated for MDR-TB at King Dinuzulu Hospital?
  3. What sort of challenges do you feel contribute to young women in particular with MDR-TB being treated at King Dinuzulu Hospital not adhering to their TB treatment?
  4. What are some notable successes recorded in the DR-TB Unit at King Dinuzulu Hospital in terms of improving treatment adherence rates?
  5. The South Africa National TB Guidelines highlight the importance of providing information, including spending a significant amount of time counselling patients, to support treatment adherence. How is this implemented at King Dinuzulu Hospital?
    - And do you feel that the requirements in the guidelines are practical, given the DR-TB disease burden being handled at the hospital?
  6. Could you describe how doctors and nursing staff would conduct a standard visit with a patient who has just been diagnosed with MDR-TB? What information is given to them during this visit? And in subsequent visits?
    - What mediums are used to disseminate this information?
  7. What sort of information, if any, is given to family and household members of MDR-TB patients on preventing new MDR-TB infections in their households?
  8. Let's discuss different sources of information or communication about MDR-TB and the importance of adhering to MDR-TB treatment that are available to patients.
    - b. Are you aware of any television or radio programmes or channels disseminating information about MDR-TB that reaches people in eThekweni in the past three months? If yes, please name these.
  9. Who in the communities where these young women live do you think should be provided with information on treatment adherence in the hopes that when they speak, the messages will be better accepted and acted upon by MDR-TB patients?
10. Is there anything that I haven't asked about that you would like to share?

**End**

## Appendix 6: Key informant interview guide – household contacts of MDR-TB patients previously or currently on treatment



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### TOOL 2: KEY INFORMANT INTERVIEW GUIDE

### CONTACTS (HOUSEHOLD MEMBERS) OF MDR-TB

### PATIENTS PREVIOUSLY OR CURRENTLY ON TREATMENT

**Total focus group time:** 30 minutes + 10 minutes

**Project title:** *(Re)Positioning communication for enhanced multidrug-resistant tuberculosis treatment adherence in KwaZulu-Natal: Towards an integrated model of communication*

This research seeks to explore how mass media and interpersonal communication and counselling in healthcare settings can be used to improve treatment adherence among young women aged 18 to 34 years from eThekweni Metro receiving treatment for primary multidrug-resistant TB (MDR-TB) through the outpatient facility of the Drug-Resistant TB Unit at King Dinuzulu Hospital.

#### Overview

The study hopes to elicit responses that will help answer the following questions:

1. What are some of the challenges that result in young women receiving treatment for MDR-TB failing to take all their medication as prescribed, and to finish the courses?
2. How do young women receiving treatment feel health providers can give them information in ways that would result in them better adhering to treatment?
3. Are young women receiving treatment interested in learning more about MDR-TB disease and its treatment outside the hospital setting?
4. What mediums of communicating information about MDR-TB treatment and prevention do young women with MDR-TB think would be most relevant for their needs?
5. From who, in their communities and social groups, would young women like to hear more information about MDR-TB treatment and prevention?

#### Introduction (10 minutes)

- Welcome respondent and introduce myself, the research assistant/interpreter and explain our respective roles.
- Explain the purpose of the discussion broadly, outlining why the respondent was recruited into the study.

- Discuss the purpose and process of key respondent interviews and explain that the interview will last approximately thirty minutes, and an additional 10 minutes to explain the informed consent form and research process.
- Explain the presence and purpose of video and audio recording equipment.
- Go over ground rules and discussion guidelines, such as being prepared for the researcher to interrupt to ensure that there is time to cover all questions.
- Address the issue of confidentiality, inform the respondent that information discussed will be reviewed as a whole, and that names will not be used in any analysis of the discussion or in the thesis.
- Go through the informed consent form and ask the respondent to complete and sign the form indicating their informed consent to participate in the interview, for discussions to be video and audio recorded, and for photographs to be taken.
- Ask the respondent to introduce themselves using their first name and age, and community where they live, and begin the interview.

### **Key informant interview questions (60 minutes)**

1. How are you related to the young woman being treated for MDR-TB at home?
2. In your opinion, in what ways do you think young women experience having MDR-TB differently from older women? Or men?
3. What could you say are some challenges that may cause young women in your community to stop taking their MDR-TB treatment before the doctor or nurse advises them that they can stop?
4. In your opinion, does being in an intimate relationship with, or married to, a man make it easier or harder for young women with MDR-TB to adhere to their treatment?
5. What sort of information have you ever received about ways in which you can support your household member or loved one to take all their medication at the prescribed times and for the recommended duration until they complete the course?
  - From who or which sources did you receive this information?
6. What questions do you still have about MDR-TB treatment that you think would help you to support your household member or loved one to stay on treatment if they are answered?
7. Where and from who do you think it would be best for young women to receive more information about MDR-TB treatment?
8. Do you think young women receiving treatment are interested in learning more about MDR-TB disease and its treatment during visiting days at the hospital, or at home?
  - If so, what sort of information do you think would be important to share?
9. What do you wish other people could know about MDR-TB disease and its treatment as it affects young women in your community?
10. In the past six months, have you watched or listened to any radio or television programmes or content about MDR-TB available here in eThekweni?
  - If so, can you name the programme and/or station?
  - If not, which stations or programmes do you feel would be good for sharing information about MDR-TB prevention and treatment?
11. Could the Internet be a good source of information about MDR-TB treatment for young women with MDR-TB?

12. What about social media? If yes, which platforms would be best for the age-group 18 to 34?
13. Who at the health facility, in your household or in your community do you think young women would be MOST likely to listen to if they shared information about preventing the spread of MDR-TB and supporting others to adhere to their treatment? Why is this so?
14. Who at the health facility, in your household or in your community do you think young women in your community would be LEAST likely to listen to if they shared information about preventing the spread of MDR-TB and supporting others to adhere to their treatment? Why is this so?
15. Is there anything I have not asked about that you would like to share?
16. Do you have any questions for me?

**End**

## Appendix 7: Research Assistant/Interpreter confidentiality agreement



UNIVERSITY OF  
KWAZULU-NATAL  
INYUVESI  
YAKWAZULU-NATALI

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### RESEARCH ASSISTANT/INTERPRETER CONFIDENTIALITY

#### AGREEMENT

I, \_\_\_\_\_ [print name of research assistant/interpreter], agree to work as a research assistant for Petronella C. Mugoni (the primary investigator). Duties under this assignment will include assisting with recruitment of participants to the study, logistics to arrange the venue, interpreting the content of focus group discussions and key information interviews from isiZulu to English and vice versa, recording data collection sessions, transcribing and proofreading.

- I agree to maintain full confidentiality when performing these tasks, particularly to:
- i. keep all research information shared with me confidential and not discuss or share information I gain as a result of participation in the research in any form or format (e.g. email, flash sticks, CDs, tapes, transcripts etc.) with anyone other than the primary investigator
  - ii. hold in strictest confidence the identification of any individual that may be revealed during the course of performing the research assignment
  - iii. not make copies of any raw data in any form or format (e.g. CDs, flash sticks, tapes, transcripts etc.) unless I am expressly requested to do so by the primary investigator
  - iv. keep all raw data that contains identifying information in any form or format secure while it is in my possession. This includes:
    - v. keeping all digitised raw data in computer password-protected files and other raw data in a locked file
    - vi. closing any computer programmes and documents of the raw data when temporarily away from the computer
    - vii. permanently deleting any e-mail communication containing the data, and
    - viii. using closed headphones when transcribing recordings
  - ix. give, all raw data in any form or format to the primary investigator when I have completed the research assignment
  - x. destroy all research information not returnable to the primary investigator (e.g. information stored on my computer hard drive) upon completion of the research assignment.

**Name of research assistant:** \_\_\_\_\_

Signature of research assistant \_\_\_\_\_ Date \_\_\_\_\_

**Day/month/year**



**Address:**

\_\_\_\_\_

**Mobile number:** \_\_\_\_\_

Printed name of primary  
investigator \_\_\_\_\_

Signature of primary investigator \_\_\_\_\_ Date \_\_\_\_\_

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## **Appendix 8: Biomedical Ethics Research Committee ethical clearance letter (Ref BE379/17)**



BREC Authorisation -  
BE379.17.pdf

## **Appendix 9: KwaZulu-Natal Department of Health approval for research to be conducted at King Dinuzulu Hospital (Ref. KZ\_201711\_047)**



Annex 13 - DoH  
approval -PMugoni.pc

## **Appendix 10: Gatekeeper letter 1: King Dinuzulu Hospital – Medical Manager**



Gatekeeper Letter -  
PMugoni (217077622

## **Appendix 11: Gatekeeper letter 2: King Dinuzulu Hospital – Nursing Manager**



Annex 12 -  
Gatekeeper letter from

## Appendix 12: Initial coding for themes

<p><b>Theme:</b> Structural, cultural and gendered issues that drive transmission of MDR-TB in eThekweni and hamper infection prevention efforts and treatment adherence</p>	<p><b>Theme:</b> Forms of mass media and mass mediated messages frequently accessed by young women on treatment for MDR-TB and their contacts</p>	<p><b>Theme:</b> People or groups with most reported influence in terms of communicating behaviour change and health information to young women with MDR-TB</p>
<p><b>Codes</b></p> <p>Failing at sputum-taking          “There is so much”          Hungry for knowledge          Long uncomfortable journey          High cost of new MDR-TB drugs          ‘Like HIV counselling’          Can’t make patients wait to start treatment          Throw resources at          Hectic protocol in government          No budget for ACSM          All TB budget goes to treatment          Outbuilding          No schooling          Find a job          Poverty impacts where people live          Can’t read          Lots of young women with MDR-TB          Quite a lot of old men          Intergenerational relationships          Catching it from someone else          Not just from defaulting now          Lots of young men          Ages of people in homes          Lots of reasons          We know the reasons          Out of DOH control          Socioeconomic backgrounds          Where, how, with whom people live          ‘People will die knowing’</p>	<p><b>Codes</b></p> <p>High literacy rate          TB is a hidden something          eThekweni has most media in KZN          Community radio &amp; newspapers          People listen to community radio          Radio &amp; TV          Gagasi &amp; Metro FM          Five FM or East Coast Radio          Age is a big thing          Music is a biggie          Social media          DVD in hospital waiting area          Captive audience          Edutainment          One-on-one          English and isiZulu of everything          Both languages          Standardised messages to suit (groups)          Gvt offices and dpts waiting areas (SARS, Home Affairs)          Etv          SABC 2          Facebook          March          February          Take over the airwaves – repeated          Need to move faster with TB          Taxi branding &amp; transit TV          Events are useless for communication</p>	<p><b>Codes</b></p> <p>Can’t be sure exactly what works          Cover everything          Churches          In bars, pubs and shebeens          Hear something 3 times for it to stick, so 3 things          Standardised to suit (demographics)          Health workers shouldn’t decide what information patients get          Teaching TB in schools          Ambassadors          Role models – ask the young people          ‘Nothing for is without us’          Millennials want to be entertained          Top artists          Ongoing quality counselling          Counselling patient, and people she stays with          Wellbeing of children          Someone who makes an effort          Understand patient          Strangers don’t judge          Healthcare worker          Tailor-make          Community caregivers          Engage family as part of healing process</p>

<p><i>Phutu &amp; beans better than phutu alone</i></p> <p>Improve situation causing illness</p> <p>No food, poor nutrition</p> <p>Government resources not communicated</p> <p>Sleeping in one room/ventilation</p> <p>No ribbon for TB</p> <p>Not many know what TB is</p> <p>24 to 36 months of treatment</p> <p>Hospitalisation to be stabilised</p> <p>Daily injections</p> <p>In it for the long haul</p> <p>Not defaulting in 1<sup>st</sup> four months</p> <p>Default @ nine months</p> <p>Emotional support &amp; observation</p> <p>On their own/live alone</p> <p>Remember to take meds</p> <p>Feeling fine/better</p> <p>No standardised health education</p> <p>40 minutes one-on-one with patient</p> <p>Forgot to ask</p> <p>Shock at diagnosis</p> <p>Hearing loss, cold feet, nausea</p> <p>Take knowledge for granted</p> <p>Unprofessional health workers' attitudes</p> <p>Lecture/talk down to young people</p> <p>Gossip about patients</p> <p>Stigma kills people, not TB &amp; HIV</p> <p>Clinic far from home</p> <p>Time and money</p> <p>Secrets</p> <p>No confidentiality in health facility</p> <p>First interaction is make-or-break</p> <p>Just handed pills</p> <p>Opportunity to ask questions</p> <p>Missing out on school</p>	<p>World TB Day/Month is hijacked</p> <p>Communication with feedback</p> <p>Individual patient focus</p> <p>Internet</p> <p>Mixed approach</p> <p>Individualised content</p> <p>'Homebrewed' television</p> <p>Prime time</p> <p>Discussion of characters in episodes (main)</p> <p>People in streets talking</p> <p>Twitter national conversations</p> <p>WhatsApp</p> <p>People don't read</p> <p>Tendency not to listen to adverts</p> <p>Appropriate language</p> <p>Storylines on radio or TV</p> <p>Full information with background</p> <p>MDR-TB too serious to communicate in 2 sentences</p> <p>Lost in interpretation</p> <p>Facts and figures</p> <p>Won't work in eThekweni</p> <p>'Africans love stories'</p> <p>Cell phone application</p> <p>No time to read</p> <p>Lots of house chores, bite sized information</p> <p>Lots of buy-in from municipalities for World AIDS Day – community gathering</p> <p>MDR-TB communication before diagnosis</p> <p>So little &amp; not really familiar</p> <p>SABC 1 NEWS</p> <p>Beat TB adverts</p> <p>Should be everywhere</p> <p>I don't watch adverts</p> <p>Adverts between soap operas</p> <p>Broadcast TB adverts all the time</p> <p>Soap opera surfing</p> <p>Skeem Sam, Etv (18:30)</p> <p>Isidingo SABC 3 (19:00)</p> <p>Scandal Etv (19:30)</p>	<p>Careful not to alienate</p> <p>Children educate parents</p> <p>Young people</p> <p>Females of same age range</p> <p>Husband/partner</p> <p>Cured MDR-TB survivor</p> <p>Small support groups</p> <p>Rich person in community</p> <p>Leader</p> <p>Healthcare worker MDR-TB survivor</p> <p>Treatment supporters</p> <p>Appropriately capacitated</p> <p>Don't give wrong information</p> <p>Support groups</p> <p>Nurses</p> <p>Pastors in churches</p> <p>Counsellors</p> <p>Other MDR-TB patients</p> <p>School curriculum – via children's homework</p> <p>Church</p> <p>Partners</p> <p>Hospitals/clinics – in all wards</p> <p>TB commemorative day</p> <p>Mothers of women with MDR-TB</p> <p>Community meetings</p> <p>Counselling couples about impact of medication on relationship</p> <p>Counselling couples on how the patient should take medication</p> <p>People look up to celebrities</p>
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Clients themselves not compliant	Generations (20:00)	
Health worker skills to treat	Uzalo (20:30)	
Poor attitudes	Muvhango (21:00)	
Client humiliation	IMbewu (21:30)	
Shouted at	Ukhozi FM	
Taking treatment viewed as = to being infectious	Gagasi FM	
Communication with feedback	Izwi Lomzansi	
First counselling session	Lesedi FM	
Depression – psychological aspect	Metro FM	
Physical attractiveness	Local radio stations	
Courtship	Something short	
Single parents	Don't want to be bored	
Provision – well enough to work	Characters on soap operas	
Reproductive and productive capacities	Have heard enough MDR-TB infor	
Serious side effects explained	WhatsApp	
Serious side effects not explained	Might be people who would read	
Guessing which drugs cause side effects	The Lucky Specials movie	
Google symptoms	Beat TB campaign	
Injection team visits stigmatise	Government PSAs	
'Announcing MDR-TB status' to neighbourhood	Held back by resources	
Self-stigma	Radio interview on reduced number of MDR-TB pills/regime	
MDR-TB in layman's terms	Introduction of Bedaquiline	
Death sentence	Izwi loMzansi	
Bewitched	Ntuzuma FM	
Supportive family	Facebook page – Ladies House	
Prime of lives	Evening is ideal	
Drug-to-drug interactions	Prime time	
Family planning	Testing during roadshows	
Sexual relationships	Do more pamphlets	
Pregnancy	WhatsApp is cheaper	
Affect reproductive capabilities	Facebooks takes too much data, but it's OK	
Don't get pregnant	I change the channel when adverts are on	
Impact on family structure		
African culture	<b>Theme:</b> Media programmes/content/messages identified	
What did I do to get this?		
Alone in a corner	<b>Codes</b>	
Abusive relationships	TB can be cured	
Partner himself is afraid	Signs and symptoms of TB	

<p>Consequences of disclosure</p> <p>All the person on the street knows is it's a disease that is not curable</p> <p>Migrant workers</p> <p>Daughter-in-law</p> <p>TB/HIV coinfection of 65% in KZN</p> <p>Other co-morbidities</p> <p>MDR-TB/HIV coinfection 75% in KZN</p> <p>Inadequate education prior to treatment initiation</p> <p>High workload among healthcare workers</p> <p>60% already on ARVs</p> <p>400 informal settlements in the metro</p> <p>Ventilation is an issue</p> <p>Empty stomach</p> <p>Main five group of meds</p> <p>Injectable medicine for 4 months</p> <p>'Pills just fill my stomach'</p> <p>Child-bearing age</p> <p>No decent jobs, no sick leave</p> <p>Some meds contraindicated in pregnancy</p> <p>Negotiating sexual activity difficult</p> <p>Dependent on a man</p> <p>By nature, women listen better</p> <p>Terizidone causes psychosis</p> <p>Women and their hormones</p> <p>Feeling horrible all the time</p> <p>TB is an old disease</p> <p>TB information is 'boring'</p> <p>Disability grant</p> <p>Skip visits</p> <p>24 months of treatment</p> <p>Left medication at home when visiting partner (mobility)</p> <p>Boyfriend said 'leave your tablets'</p> <p>Contraceptives</p>	<p>Early presentation saves lives</p> <p>Treatment adherence is the 1st way to prevent TB</p> <p>MDR-TB diagnosis disclosure plan</p> <p>Explain expected treatment journey upfront</p> <p>Basics of MDR-TB</p> <p>Prevention and cure</p> <p>What each drug in the regimen does</p> <p>Simple language</p> <p>Visual journey of TB infection and treatment on a timeline</p> <p>Communicating by stages</p> <p>Names of specific TB drugs</p> <p>Side effect management</p> <p>Benefits of treatment</p> <p>Practical ways of identifying hearing loss</p> <p>Common side effects</p> <p>First interaction with patients is 'make or break'</p> <p>MDR-TB can be passed on</p> <p>How MDR-TB is transmitted</p> <p>What is TB, MDR-TB &amp; XDR-TB</p> <p>Why after years of treatment one may not be cured</p> <p>Culture and blood sample reports</p> <p>Why and how treatment differs</p> <p>Expectations of treatment</p> <p>Why the slow advancements in TB treatment, when HIV has one drug</p> <p>Co-morbid conditions TB, HIV, diabetes, hypertension</p> <p>Can only be treated in the hospital</p> <p>Infection prevention on public transport</p> <p>Take treatment on time to reduce infection inside</p>	
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<p>Screening contacts/lack of disclosure</p> <p>Counselling in corridor</p> <p>Group counselling</p> <p>Same information for patients &amp; family</p> <p>Run out of pamphlets</p> <p>Strict times to take medication</p> <p>Patients don't follow instruction</p> <p>I was in jail</p> <p>Still have left over medication</p> <p>'We tell women they are not to sleep with men until their treatment is complete'</p> <p>Patient will come pregnant</p> <p>Have own plate, spoon &amp; cup</p> <p>Relative listen to what doctor says to patients</p> <p>Cried when diagnosed</p> <p>Pills made me lose my mind</p> <p>Didn't know who I was</p> <p>Body changed</p> <p>Skin colour changed to black/darker @ 4 months</p> <p>Diagnosis wasn't explained well</p> <p>'Killer TB'</p> <p>Waiting for an ambulance</p> <p>Suicidal thoughts</p> <p>I was dying</p> <p>Wrong (DS-TB) medicine initially</p> <p>Hope I was going to live</p> <p>Told I would die</p> <p>Breadwinner</p> <p>Dark skin blamed on marijuana use</p> <p>Ashamed</p> <p>UIF</p> <p>Vomiting blood all week</p> <p>Relieved to find out what was making me sick</p> <p>Looked forward to starting treatment</p> <p>Pimples on face and neck</p>	<p>TB kills it's not like HIV or diabetes</p> <p>Sending yourself to an early grave</p>	
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<p>Never stopped completely</p> <p>Skip morning medication</p> <p>Nausea from taking meds on empty stomach</p> <p>Evening dose not as problematic</p> <p>With yoghurt or <i>maas</i></p> <p>Medicine increases appetite</p> <p>Don't want porridge, want meat</p> <p>On Saturdays didn't drink tablets</p> <p>Needed a break</p> <p>Injection daily for 6 months</p> <p>Couldn't sit on buttocks every day</p> <p>Pain was too much</p> <p>Suicidal to take medicine without food</p> <p>Difficulties at work after hospitalisation</p> <p>Can't provide for self</p> <p>Here to job hunt</p> <p>My shack</p> <p>Looking for work</p> <p>Rely on child's social grant</p> <p>Social grant for MDR-TB (6 months)</p> <p>Family of 12, nine adults</p> <p>Nobody is working</p> <p>Oily food</p> <p>Not alone in treatment</p> <p>Family insult and isolate</p> <p>Brothers understand I'm unwell</p> <p>Look after child</p> <p>Boyfriend doesn't believe I'm sick</p> <p>This 'other disease'</p> <p>Goes for check-ups</p> <p>Traditional curses &amp; witchcraft</p> <p>Herbal syrup</p> <p>Chest pains and flu</p> <p>Calm the pain</p> <p>Pregnancy testing</p> <p>Didn't deny it</p> <p>If I die</p> <p>Child asks if I've taken treatment</p>		
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Protecting children Hospitalisation Ambulance Getting food Swollen feet Weak and restless Side effects after 3 months Encourage Staggered treatment intake times Personal IPC Masks Didn't tell me some side effects Scare me Complexion Knowledge of side effects will "scare you Reputation of medicines as 'dangerous' Hearsay Better not to know Rather not know Other patients scared me with stories Want to know some side effects – not the very serious ones 19 tablets 31 tablets Brown tablet smells bad Brown pill made me turn black in complexion Patients had to sign for brown pill Treatment education only on brown pill Drink all but not brown tablet Brown pill speeds up healing Better not to know names of treatment Low knowledge of names of meds 'If we are lucky' they tell us names and uses of meds MDR-TB is deadly		
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<p>No discrimination and isolation</p> <p>Relapse</p> <p>Doctor-prescribed treatment break</p> <p>Lifestyle changes</p> <p>Need to be near your medication</p> <p>Medication cannot be discretely taken among other</p> <p>Affects intimate relationships</p> <p>Partner left as soon as I was diagnosed</p> <p>Can't drink alcohol or go to clubs</p> <p>Morning treatment causes nausea</p> <p>Afraid to throw up in a taxi</p> <p>Negotiated to take all meds in the afternoon</p> <p>Skip doses to eat favourite meals</p> <p>Throw away brown pill</p> <p>Changes in complexion</p> <p>Loss of self esteem</p> <p>Stopped at 8,5 months once nurses told me I would soon complete treatment</p> <p>Treatment clashes with work responsibilities</p> <p>Fatigue impacts work</p> <p>Have to work</p> <p>Can't be around 'just anyone' when taking MDR-TB treatment</p> <p>Fired from work</p> <p>Discrimination at work</p> <p>Hard to see people die in hospital</p> <p>Coughing and stomach pains</p> <p>Kidney problems</p> <p>Side effects</p> <p>Focus on treatment</p> <p>Alcohol</p> <p>I couldn't eat</p> <p>Change my lifestyle</p> <p>Away from people</p>		
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<p>Some other chronic disease</p> <p>Treatment from people not good</p> <p>Badmouthing me</p> <p>TB always comes with HIV</p> <p>He ran away as soon as I told him I was sick</p> <p>My child has TB</p> <p>Hospitalised for almost a year</p> <p>Time for treatment awaits</p> <p>Push people away</p> <p>Brothers are supportive</p> <p>Fight to stay alive</p> <p>I have someone to live for</p> <p>He will never have a mother again</p> <p>Medication is not enjoyable</p> <p>Drugs are too many</p> <p>Medication makes me dizzy</p> <p>Loss of appetite</p> <p>Whole body painful ‘</p> <p>Treatment is not child’s play</p> <p>More than 10 tablets</p> <p>Medication affects sex life</p> <p>I’m darker now</p> <p>Side effects are temporary, like pregnancy side effects</p> <p>Medication makes you feel like you are pregnant</p> <p>It changes your mood</p> <p>Support is everything</p> <p>Have to carry a lot of medication wherever you go</p>		
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