

An exploration of factors contributing to patient delay in seeking Tuberculosis care services in the Hhohho region of Eswatini

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KEY WORDS

Tuberculosis (TB);

TB care services;

TB treatment;

Health-seeking behaviour;

Patient delay;

Diagnosis delay;

Health-systems delay;

Treatment delay;

Hhohho Region;

Eswatini.



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Dedication

I dedicate this study mini-thesis to my wife Michelle and my children, Ze'ke and Rio, in appreciation for giving me support and encouragement throughout my studies.



Acknowledgements

I would like to start by expressing my gratitude to my supervisor, Dr. Anam Nyembezi of the University of the Western Cape, for his direction and assistance over the duration of this research work. I want to express my gratitude to the volunteers who agreed to take part in the study. I particularly value the assistance provided by Nurses Vuyani Dlamini and Nkosikhona Shongwe in translating the study tools and equipment into siSwati. Many thanks to Ms. Makhosazana Matsebula, who helped with the data coding.



Declaration

I, Elisha Tinotenda Nyandoro, hereby declare that this study titled “*An exploration of factors that contribute to patient delay in seeking Tuberculosis care services in the Hhohho region of Eswatini*” has not been submitted for a degree assessment here or at any other higher education institution. It is a true reflection of my own study, and all sources that I have utilized or quoted have been mentioned and recognized by way of thorough references.

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Acronyms

BMREC: Bio-Medical Research Council

COVID-19: Corona Virus of 2019

CSO: Central Statistical Organisation

DR-TB: Drug Resistant Tuberculosis

DS-TB: Drug-Sensitive Tuberculosis

EHHRRB: Eswatini Human Health Research Review Board

HCF: Health Care Facility

HCW: Health Care Worker

HICs: High Income Countries

HIV/AIDS: Human Immuno-deficiency Virus/Advanced Immuno-Deficiency Syndrome

LMICs: Low to Medium Income Countries

MDR-TB: Multi Drug Resistant Tuberculosis

NSP: National Strategic Plan

NTCP: National TB Control Program

SOPH: School of Public Health

TB: Tuberculosis

UWC: University of the Western Cape (*South Africa*)

WHO: World Health Organisation

XDR-TB: Extensively Drug Resistant Tuberculosis



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ABSTRACT

Background: Tuberculosis (TB) is one of the top twenty leading causes of death globally and it is the second leading cause of mortality from a single infectious cause after COVID-19 but ahead of HIV/AIDS. In 2020, TB was responsible for ten million disease burden and an estimated 1.5 million deaths world-wide. Africa and South-East Asia account for almost 70% of the global TB burden but HIV/AIDS remains the biggest driver of TB morbidity and mortality in sub-Saharan Africa.

To effectively manage and control TB, public health interventions in areas of high TB prevalence like Eswatini, need to aim at efficiently providing quality TB care services and to improve the treatment-seeking behaviour of the community.

Aim: This study aimed to explore patients' attitudes, perceptions and beliefs that promote or hinder TB care-seeking behaviour at Dvokolwako Health Centre, Hhohho region, Eswatini.

Methodology: This was an explorative qualitative study and the primary data was obtained through semi-structured interviews. A sample of fourteen male and female participants above eighteen years of age were selected from the list of patients enrolled into TB care as late presenters in the period from 1 January 2020 to 30 December 2021. All data collected was audio-recorded, transcribed verbatim and analyzed using the thematic content approach.

Results: The study findings showed multiple factors contributing to the delayed access to TB health services. Inadequate knowledge, beliefs about TB symptoms, stigma associated with TB and lack of access to TB health services were individual factors that were found to contribute to patient delay in seeking TB care services. Lack of decentralized and community-based health education and promotion and negative health care workers' attitudes were the health system-related factors that hindered early TB care-seeking. Persistence of symptoms and family encouragement and support were found to be motivators for eventual presentation into TB care services.

Conclusion: From the findings of this study, a multi-pronged approach targeting the factors hindering early TB care-seeking and strengthening the motivators of health-seeking behaviour is necessary to mitigate the late presentation into TB care services in this and similar settings.

CHAPTER 1: INTRODUCTION

1.1 Background

Tuberculosis (TB) is a disease caused by a fairly ubiquitous bacteria called *Mycobacterium TB* (Greenwood, Slack & Peutherer, 2003). It primarily affects the lungs through the inhalation of infected droplets but it can be disseminated throughout the body (Greenwood *et al.*, 2003). Its typical symptoms include cough, fever, loss of appetite and unintentional weight loss. TB can be treated by chemotherapy whose combination of drugs and duration depends on the strain of the causative bacteria (Longmore, Wilkinson, Turmezei & Cheung, 2007; Caminero, 2013; Lange, van Leth, Mitnick, Dheda & Gunther, 2018). These strains are normally classified into drug sensitive and drug resistant bacteria which cause drug sensitive (DS-TB) and drug resistant TB (MDR-TB and XDR-TB), respectively (Caminero, 2013; Raviglione & Sulis, 2016). Multi-Drug resistant TB (MDR-TB) is caused by a strain of *Mycobacterium TB* that is resistant to at least Rifampicin and Isoniazid, two of the most potent anti-TB drugs. Extensively resistant TB (XDR-TB) is, in addition to being resistant to both Rifampicin and Isoniazid, the causative strains are resistant to fluoroquinolones and any other among Bedaquiline and Linezolid (WHO, 2020).

Despite being a preventable and curable disease, TB still ranks within the top twenty causes of death globally and it is the second leading cause of mortality from a single infectious agent after COVID-19 but ahead of HIV/AIDS (WHO, 2020). In spite of a sustained decline in global incidence of TB of about 2% per year, TB mortality remains substantially high (WHO, 2020). In 2020 alone, TB was responsible for an estimated 1.5 million deaths signaling no significant change when compared to 1.4 million TB deaths recorded in 2011 (WHO, 2018; Abdullahi, Ngari, Sunga & Willetts, 2019).

Africa, together with South-East Asia, account for almost 70% of the global TB burden. However, the drivers of the TB epidemic vary in these world regions (Vesga *et al.*, 2019). In Africa, HIV/AIDS is the main driver whereas in South-East Asia, the burden is underlined by poverty associated factors which hinder access to TB diagnostic and therapeutic services (Vesga *et al.*, 2019).

Eswatini, a land-locked country in southern Africa, is ranked among the top thirty TB/HIV high burden countries in the world (WHO, 2020). Notwithstanding the wide-ranging investments in

programs to lower TB incidence and mortality, target mortality rate (below 5%) has remained out of reach (Verdecchia *et al.*, 2018; WHO, 2020; National TB Control Program [NTCP], 2020). The NTCP annual report noted that late presentation to care was the major driver of the high number of TB deaths (NTCP, 2020). Thus, this study sought to explore factors underpinning the delays in seeking TB care services.

1.2 Problem Statement

In 2016, the government of Eswatini adopted the global plan to end TB in its national strategic plan (NSP) for the four-year period 2016 to 2020 (WHO, 2014; NTCP, 2015). In order to curtail TB spread in the community and the associated morbidity and mortality, one of the plan's primary targets was to reach at least 90% of the population with TB (TB case notification) by end of 2018 (NTCP, 2015). However, the TB case notification has remained stagnant at 65% from 2015 to 2018 (NTCP, 2019). Notably, TB case notification is influenced mainly by the diagnostic capacity of the health care system and patient health-seeking behaviour. Insua, Haumba, Zannat, Matji and Smith-Arthur (2012) noted that the total diagnostic, and therefore notification, delay was approximately 102 days. Of these, patient related delay was about double the health system diagnostic delay. This is further underscored by the 2018 national TB prevalence survey which observed that an estimated 58% of people with symptoms characteristic of TB did not seek care (NTCP, 2018).

The interventions employed in Eswatini, thus far, have been primarily centred on enhancing the diagnostic capacity of the health system through continual TB education of health care workers (HCWs) and acquisition of rapid molecular diagnostic equipment (Verdicchia *et al.*, 2018). This has successfully shortened the health system-related delay but largely ignored patient-related delay, a factor repeatedly blamed for late presentation of patients into TB care services (Insua *et al.*, 2012). Consequently, besides propagating the transmission of TB infection, these undiagnosed TB cases either die or present late with significant morbidity (Sreeramareddy, 2019). This study, therefore, sought to uncover the factors that underlie this trend of poor health seeking behaviour.

1.3 Purpose of the Study

This qualitative study results are meant to provide insights on the factors that hinder good TB care seeking behaviour. The information will benefit the government public health policy and formulation of TB programmatic interventions aimed at improving the accessibility and coverage of TB care services by uncovering key factors hindering positive health-seeking behaviour. The research findings will therefore be disseminated to all relevant stakeholders that include the National TB Control Program (NTCP) under the Ministry of Health, Donors and Implementing Partners, health care workers and the community.



CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

The purpose of this literature review was to introduce the concept of patient delay in the diagnosis and management of tuberculosis. Furthermore, this review of literature aimed to center this study on what has already been revealed in the literature concerning the factors associated with TB diagnosis delay and how their impact on TB health-seeking behavior varies from one setting to another.

The total delay in the diagnosis and treatment of TB is a result of both patient and health system delays (Bogale *et al.*, 2017). Health system delay is when HCWs and the healthcare system take too long to diagnose and treat patients with TB symptoms. Patient delay is when patients wait too long to seek care after developing TB symptoms (WHO, 2006; Bogale *et al.*, 2017). The length of delay was observed to be significantly longer among low and middle income countries than in the developed nations (WHO, 2006; Bogale *et al.*, 2017). In most studies, it was also noted that patient delay was longer than health system delay (Bogale *et al.*, 2017).

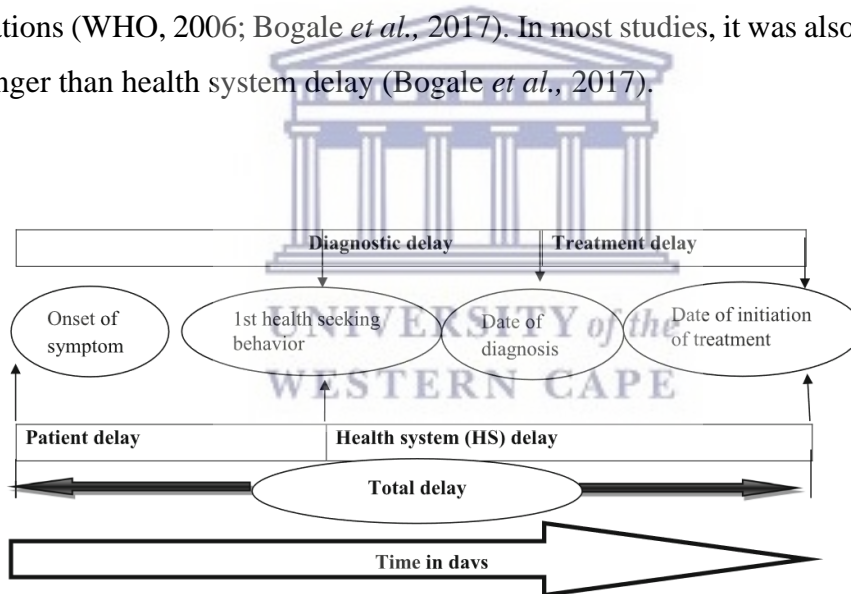


Fig. 1 Flow-chart showing different delay durations contributing to total delay (Source: WHO EMRO, Diagnostic and treatment delay in TB, 2006)

Figure 1: Flow chart showing different delay durations contributing to delay care

2.1 Patient delay in the diagnosis of TB

Patient delay in the diagnosis of TB is defined as the time period between the onset of symptoms characteristic of TB and presentation into care (Getnet *et al.*, 2017). According to Datiko, Jerene, and Suarez (2020), patient delays contributed to approximately 77% of the total delay in TB

diagnosis. A systematic study of the literature revealed that patient delays in both high-income countries (HICs) and low- and middle-income countries (LMICs) were 10 to 15 days or more longer than the generally accepted limit of 2 to 3 weeks (Sreeramareddy *et al.*, 2009). Moreover, this manifestation of poor health seeking behaviour is generally influenced by similar factors in both high and low TB prevalence countries (Christian *et al.*, 2018; Datiko, Jerene and Suarez, 2020). These factors can be divided into three categories namely individual, sociocultural, and health systems-related.

2.2: Individual factors influencing patient delay.

There are a number of personal attributes that affect health-seeking behaviour and consequently patient delay in seeking TB care services. These factors include demographic characteristics such as gender, age and marital status (Fatiregun & Ejeckam, 2010; Getnet *et al.*, 2017; Laohasiriwong *et al.*, 2018). Other factors pertain to how the individuals perceive severity of symptoms, level of knowledge of TB, their degree of literacy, employment status and residential geographical location (Pradhan *et al.*, 2010; Mohamed *et al.*, 2013; Getnet *et al.*, 2017; Kigozi *et al.*, 2017; Christian *et al.*, 2019; Laohasiriwong, *et al.*, 2018).

Culturally assigned gender role places significant influence on care-seeking behaviour (Mbuthia *et al.*, 2018). For male participants in Kenya, the delay was strongly related to their perception of masculinity, whereby seeking care early was associated with being weak (Mbuthia *et al.*, 2018). Furthermore, in settings where males were the sole breadwinners, the fear of loss of employment or inconvenient working hours contributed to delays in seeking health care amongst male patients (Samal, 2016). Female patients in Kenya were delayed due to the need to seek permission or financial support from their partners or their in-laws to enable them to seek TB care services (Mbuthia *et al.*, 2018). This lack of autonomy in accessing care was also seen to extend to their children's health. In addition, research shows that women are more likely to experience social stigma and perceived discrimination due to TB infection, which exacerbates their propensity to seek medical attention (Senbeto *et al.*, 2013).

Patient's age also negatively impacted TB health-seeking behaviour. In Ethiopia, patients aged younger than nineteen years and elderly patients more than forty-five years of age took longer time to seek treatment for their TB associated symptoms (Obsa *et al.*, 2021). Likewise, in Peru, it was

noted that elderly patients aged above forty years and patients younger than nineteen years took longer to visit health facility compared to other age groups (Bonadonna *et al.*, 2017). Gebreegziabher *et al.* (2016) and Asres *et al.* (2017) also found that participants aged forty-five years and above were eight times more likely to delay seeking TB care services compared to younger patients. This could be as a result of younger and older patients depending on others for financial support, including to pay for the costs associated with seeking medical attention (Obsa *et al.*, 2021).

Systematic review of literature and other studies have shown that patient delay is longer when patients perceive their symptoms to be less severe (Pradhan *et al.*, 2010; Getnet *et al.*, 2017). This was underscored by a study conducted in Uganda's peri-urban setting where patient delay was significantly reduced in patients experiencing haemoptysis, chest pains and multiple symptoms (symptoms considered severe) (Sendagire *et al.*, 2010). Apart from symptoms considered severe, Almeida, Skupien and Silva (2015) found that non-specific symptoms of TB were associated with longer delays in seeking treatment and care. In India, the delay in seeking medical care due to the non-specificity of symptoms was further compounded with use of herbal alternatives and self-medicating (Basa & Venkatesh, 2016). Similar trends of delaying TB care-seeking was observed in respondents who believed TB to be more common in their community and so had developed a low TB risk-perception maybe due to a sense of normalization of the illness (Mhalu *et al.*, 2019; Helfinstein *et al.* 2020).

In settings like Free State, South Africa, patient delay in seeking TB treatment was associated to low knowledge and awareness of TB transmission, symptoms and treatment (Kigozi *et al.*, 2017). The findings of the study by Obsa *et al.* (2021) also demonstrated a high correlation between education level and treatment seeking delay, as well as a level of knowledge regarding tuberculosis. Patients with inadequate TB knowledge were more likely than those with adequate TB knowledge to experience lengthier patient delays (Obsa *et al.*, 2021). Additionally, treatment seeking delay was substantially associated with lack of formal education (Obsa *et al.*, 2021). This may be because patients with higher levels of education are more likely to be knowledgeable about TB and seek treatment sooner (Obsa *et al.*, 2021).

In a South African study done in a rural setting, patients with low levels of literacy having only completed primary education, had longer patient delay in seeking TB care services (Christian *et*

al., 2019). Wang *et al.*, (2020) also revealed a similar trend in south-east China where patients who had no to only primary education had significantly longer delays in seeking TB care compared to those who had completed secondary and tertiary education. This may have been a result of the associated inability to interpret information and awareness material aimed at improving TB awareness (Tedla *et al.*, 2020). In contrast, in another South African urban setting, people with higher formal education had longer delays in seeking TB care services which was associated to higher rates of self-medicating and dissatisfaction with service delivery at public health facilities compared to those of lower education (Cramm *et al.*, 2010).

Trends of longer delays in seeking TB care services were also demonstrated in the unemployed population in a study done in Sudan and Nepal (Mohamed *et al.*, 2013; Laohasiriwong, *et al.*, 2018). This is likely due to the accompanying financial constraints that limit their ability to pay for transport, user fees or other associated care-seeking costs as noted from a systematic review of literature by Sullivan *et al.* (2017). Similarly, in Uganda, TB treatment is nominally free but hidden costs associated with accessing TB treatment may have inhibited health-seeking behaviour (Buregyeya *et al.*, 2011). In South India, it was shown that non-workers were more likely to seek medical attention than workers and professionals. (Helfinstein *et al.*, 2020). They contended that this might have been because employed people had less time and convenience than unemployed people, who had a greater time flexibility and were therefore more likely to seek medical attention (Helfinstein *et al.*, 2020).

There is variation in how different places of residence influence patient delay in seeking TB care services (Getnet *et al.*, 2017). In studies conducted in Nigeria and Mozambique, urban residence was associated with longer patient delays (Ukwaja *et al.*, 2013; Saifodine, 2013). This was common in the urban poor and settings close to drug vendors and pharmacies. In North-Western Ethiopia, rural residency had longer patient delay and the participants reported longer distances to the nearest health facility which led most to consult non-formal health providers who were more proximal (Gebeyehu *et al.*, 2014). Delays associated with rural residency is thought to be due to lack of roads and long distance to the nearest HCF (Gebeyehu *et al.*, 2014).

A larger walking distance to an HCF was associated with patient delay, according to researchers in Tanzania (Said *et al.*, 2017). In this study, it was discovered that a significant walking distance between the patient's home and the hospital was a risk factor for delays, with patients who walked

more than five kilometers from the hospital being at an increased risk of delays compared to those who walked less than five kilometers (Said *et al.*, 2021). Other studies discovered that patients were more likely to delay seeking treatment for their TB symptoms if they had to travel at least ten kilometers to the nearest HCF (Santos *et al.*, 2017; Awoke *et al.*, 2019; Obsa *et al.*, 2021).

2.3: Socio-cultural factors influencing patient delay

Socio-cultural beliefs and practices were often associated with use of home remedies, self-medication and consultation of religious and traditional healers particularly in rural communities (Shaikh & Hache, 2005). This was particularly true for patients in a Kenyan study who believed that their symptoms had a spiritual basis and so could only be resolved by traditional healers or herbalists (Mbuthia *et al.*, 2018). Moreover, nearly 37% of TB patients in Malawi who delayed seeking care by at least four weeks had visited a traditional healer first before eventually consulting a health facility (Ngwira *et al.*, 2018). In Peru, the majority of patients diagnosed with TB did not trust the public health system, they only sought care at public health facilities only after exhausting other care options with self-medication as the most reported initial health seeking behaviour (Bonadonna, *et al.*, 2017). In addition to these beliefs, patients in Uganda and Kenya preferred going to traditional healers because they perceived them to be more patient-centred, easily accessible and friendly (Buregyeya *et al.*, 2011).

In some settings, it has been seen that beliefs and perceptions of TB affect how people seek out healthcare (Mhalu *et al.*, 2019; Helfinstein *et al.*, 2021). This was seen in respondents in South India who believed that using substances such as smoking, caused TB (Helfinstein *et al.*, 2021). Furthermore, some patients in Tanzania delayed getting treatment at a healthcare facility because they believed their coughing was due to smoking and drinking alcohol (Mhalu *et al.*, 2019). In addition, it was believed that exposure to dust and magic were two of the primary causes of TB symptoms (Mhalu *et al.*, 2019).

Stigma associated with TB or its symptoms deterred patients from seeking care early in most LMICs. Cramm *et al.* (2010) and Oluwadare & Ibirinde (2017) assert that despite the degree and manner in which stigma influenced care seeking behaviour varied across different settings, in most African settings as exemplified by South Africa and Nigeria, the association of TB and HIV

hindered patients from seeking care. This was because of the fear of being stigmatized by the community and health care workers (Cramm *et al.*, 2010; Oluwadare & Ibirinde, 2017). The societal tendency to equate the two diseases is thought to be due to Africa's high TB/HIV burden (Ngwira *et al.*, 2018).

2.4 Health-system related factors

In settings where there has not been much investments in TB diagnostics, laboratory support and capacitation of HCWs in primary health care facilities on TB diagnosis, health systems delay is equally significant in delaying the diagnosis of TB (Bogale *et al.*, 2017). In North-West Ethiopia, receiving care from several healthcare providers was linked to health system delays, especially if the initial care was received from primary level health care (PHC) facilities (Bogale *et al.*, 2017). More than 75% of patients had sought formal care before receiving a TB diagnosis, with nearly half having done so more than twice, according to Said *et al.* (2017). This also suggests a low suspicion index and a potential lack of ability to identify TB among healthcare professionals, particularly in PHC (Said *et al.*, 2017).

Apart from purely health-systemic delays, there are health systems related factors that indirectly influence delay in the diagnosis of TB by adversely impacting health-seeking behaviour in patients with TB symptoms (Pardeshi *et al.*, 2017). This is usually in the form of HCW attitude towards TB patients and how they care for them (Pardeshi *et al.*, 2016). Women participants in Tanzania said they felt more at ease receiving treatment from traditional healers as opposed to hospital staff who had a reputation of mistreating patients with TB symptoms (Mhalu *et al.*, 2019). In addition to a client's need for psychological comfort, this could be a sign of abuse and poor quality of care in public health facilities (Bhagyalaxmi *et al.*, 2019). This finding is consistent with studies showing that women in Tanzania and other countries access clinical care facilities in a convoluted manner whereby most patients will only they seek help from health care facilities after exhausting other alternatives (Mavhu *et al.*, 2010; Mhalu *et al.*, 2019).

Lack of decentralized health care services in the community especially TB care services negatively influences patients' access to these services and contributes to lengthening the delay in the

diagnosis and treatment of TB (Dantas *et al.*, 2018). This exacerbates the already alluded to individual factors like distance to the HCF and rural residency (Gebeyehu *et al.*, 2014; Santos *et al.*, 2017). The observation that HIV negative patients had longer delay in seeking TB care and treatment services compared to HIV positive patients further highlights the adverse impact of lack of access to care services on care-seeking behaviour (Bogale *et al.*, 2017). This is because HIV negative patients have less access to health care services especially TB screening, diagnosis and treatment which HIV positive patients get through TB/HIV collaborative activities (Bogale *et al.*, 2017).

2.5 Drivers/motivators for seeking TB care services

The majority of patients with TB-associated symptoms are eventually forced by various circumstances to seek care and according to Mutinda, Kabiru and Mwaniki (2014), these drivers include failure of self-medication, too sick to bear the pains, advice from relatives and friends after worsening conditions.

Initially, self-medication with antibiotics and pain-killers were reported to cause delay in seeking help from HCFs because they were able to mask some of the TB symptoms leading to temporary relief and faux healing (Helfinstein *et al.*, 2020). Individuals were prompted to seek care once the symptoms started to persist in spite of the self-medication as observed by Helfinstein *et al.*, (2020) in South India. The same was observed with failure of treatment and concoction from faith and traditional healers leading to patients experiencing unbearable pains in advanced disease forcing the majority to seek health care in designated TB treatment facilities (Mutinda *et al.*, 2014).

In addition to the persistent and unbearable symptoms, Shatil *et al.*, (2019) observed that the role of family members, relatives and friends played a huge in motivating their sick relatives to seek TB care services and this role became more important when TB patients' health condition deteriorates, became bedridden or too sick to perform any normal activities.

2.6 Conclusion

A review of the literature revealed a myriad of factors that influence health-seeking behavior in TB patients. There were notable inconsistencies highlighted by how one factor caused poor health-seeking behavior in one setting while promoting early care-seeking behaviour in another. Different

genders had different impact on health-seeking behaviour in different studies. Furthermore, in studies lack of knowledge about TB contributed to delays in seeking care but in another setting where TB was common, normalization of the disease led to delay. Another dichotomy emerged between employed and unemployed patients. Nonetheless, the literature reviewed appeared to be consistent in terms of how age affected the health-seeking tendencies of patients with TB symptoms. Moreover, it was also consistent in how the health system's capacity to identify and attract TB patients contributed to health-seeking behavior. In conclusion, it is notable that the majority of the literature reviewed was from studies conducted in East Africa, owing to the fact that most of studies on TB health seeking behavior were conducted in this region and in countries also ranked among top thirty high burden TB/HIV and DR-TB countries in the world (WHO, 2021).



CHAPTER 3: METHODOLOGY

3.1 Aim and Objectives

3.1.1 Aim

To explore participants' beliefs, attitudes and perceptions that promote or hinder TB health seeking behaviour at Dvokolwako health centre in the Hhohho region of Eswatini.

3.1.2 Objectives

- To explore the participants' perceptions and attitudes towards TB care services
- To explore the participants' socio-cultural beliefs that hinder demand for TB care services
- To explore and describe factors that promote TB health-seeking behaviour.

3.2 Study Design

To investigate participant perspectives, perceptions, beliefs, and attitudes underpinning late presentation into TB treatment facilities, an explorative qualitative study technique was used. Participants were free to share their personal lived experiences and the arbitrary meanings they attach to those experiences due to the naturalistic paradigm that underpins qualitative technique (Barbour, 2000 in Jack, 2006). In addition, explorative research design is best suited to provide patient side of the research problem and adds context even to seemingly contradictory behaviours, beliefs, emotions and opinions of individuals from the participants' lived realities (Mack, Woodsong, Macqueen, Guest & Namey, 2005). This is enabled by the effectiveness of qualitative research in uncovering intangible factors such as the social norms, gender roles and religious beliefs and their effect on behaviour (Mack *et al.*, 2005). Moreover, the flexibility of the design gave the researcher the opportunity to forego any preconceived ideas and prejudices thereby allowing the research study to evolve as patterns and themes emerge in tandem with participants' responses (Robson & McCartan, 2016).

3.3 Study Setting

The study was conducted at Dvokolwako Health centre, a rural health facility situated in North-Western Hhohho region of Eswatini (Eswatini Ministry of Natural Resources and Energy, 2018).

The package of TB care services it provides include screening for TB, diagnosis of TB through sample analysis using Gene Expert machine and microscopy and treatment of both drug-sensitive and drug-resistant TB. In addition to TB care services, it also provides care to HIV/AIDS patients, maternity and general outpatients (Kingdom of Swaziland Ministry of Health, 2015). Its catchment area is estimated to be a population of approximately 100 000. This comprises of patients who self-refer and those that are referred from satellite clinics. There are no user fees for TB services, but the facility charges a minimal user fee of about US\$0.15 for all other services (Kingdom of Swaziland Ministry of Health Regional Health Performance Report, 2015). The main economic activity of this catchment area is semi-subsistence farming, however, the government supports the community through grants to the elderly populace above 65 years of age (The Central Statistical Office (CSO), 2019).

3.4 Study Population and Sample

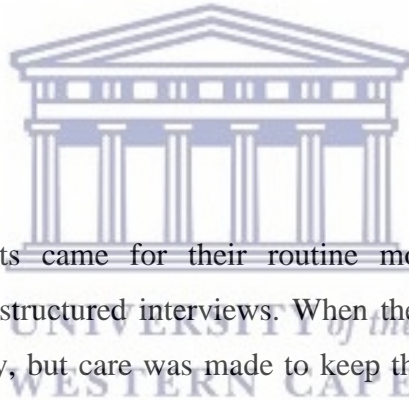
Population studied were TB patients enrolled for TB care services at Dvokolwako health centre in Hhohho region of Eswatini in the period from January 2020 to December 2021. Prior to registration as TB patients, these patients would have been confirmed and notified as TB cases after TB bacteria has been identified in their sputum. The fourteen participants for this study were recruited using a purposeful sampling method. This was informed by TB notification trends from 1 July 2019 to 30 June 2020, when a total of 919 TB cases were notified at the Health Centre in the following age disaggregation: those aged 0 to 19 years were 7.5% (equal distribution of men and women), those aged 20 to 39 years were 54% (male to female ratio was 3:1), those aged 40 to 59 years were 38% (male to female ratio was 2:1), and those aged 60 and up were 2% (male and female in equal proportions) (NTCP Database, 2020). Purposive sampling, according to Alkaabi (2017), is the process of choosing individuals and groups of individuals based on certain criteria related to addressing research study issues. This made it possible for the researcher to concentrate on a certain group of people who have experience with the topic at hand. This sampling strategy was designed to increase the likelihood of obtaining detailed information on patients' perceptions and experiences with the various treatment models (Robson & McCartan, 2016).

3.4.1 Inclusion criteria

The sample was drawn from this population by purposively selecting TB patients who presented for TB care services with at least two weeks history of TB symptoms as recorded in their chronic care files and TB register. The sample consisted of five female and two male participants in the age group 20 to 39 years; two female and two male participants aged 40 to 59 years and three male participants in the age band above 60 years. TB nurses in the TB department assisted in the identification of suitable participants using the aforementioned chronic care files and TB register.

3.4.2 Exclusion criteria

Patients aged nineteen and below were excluded from participating in the study (to align with Eswatini TB register nineteen-year-age range notation namely 0-19; 20-39; 40-59 and 60 years and above). Furthermore, patients with extra-pulmonary tuberculosis, mental health diseases, and elderly participants with dementia who were unable to provide informed consent were excluded from the study..



3.5 Data Collection

When the sampled TB patients came for their routine monthly TB reviews, data was collected through in-depth semi-structured interviews. When they came for their reviews, they were each interviewed separately, but care was made to keep them away from their consulting clinicians to minimize any bias that might have arisen from being interviewed in a potentially intimidating environment. Interviews were conducted by Expert clients attached to the TB department and were held in the participants' preferred language which was either siSwati or English. Patients' responses were audiotaped in an open but private space in the TB department where privacy was ensured. COVID-19 regulations were adhered to by ensuring that both the interviewer and interviewee were properly wearing their face masks, sanitizing their hands and observing social distance in an open environment.

The rationale of using interview for data collection is that it offers a flexible way of illuminating the reasons underlying poor demand for TB care services, despite increased coverage and access. The findings may potentially highlight why the current programs and care services are failing to

address these gaps. Being semi-structured, the interview guide permits the interviewer to modify the wording and line of inquiry but not the meaning of the questions. Furthermore, face-to-face interviews has the additional advantage of non-verbal cues which, if captured, deepens the understanding of verbal responses (Legard *et al.*, 2003).

3.6 Data Analysis

A Thematic Content (coding) Analysis (TCA) approach was used to analyse data in my research project. My qualitative research problem was premised on the exploration of the underlying issues that contribute to patients' poor demand for and consequent late presentation to TB care services. The research design was explorative in nature and there were no pre-determined categories of factors, thus, key concepts and phenomenon were extracted from the data collected through an inductive process.

The first phase of this approach entailed familiarization with the data collected, which implied a deeper understanding of the data gathered (Robson & McCartan, 2016). In my research, I immersed myself in the data starting from the transcription process of the audio-taped interviews. Here, after transcribing a session, I made a copy of the transcription which I went through with a highlighter pen highlighting and noting down any emerging ideas together with a brief note explaining my thought process. Since this was an iterative process (Robson & McCartan, 2016), starting earlier on in the study enabled a deeper grasp of the data from the outset in a piecemeal fashion which was easy to manage. This stage culminated into a statement summarizing key issues arising from the data gathered to aid subsequent analysis.

Following familiarization, the initial coding of the data was conducted. As defined by Robson and McCartan (2016), codes were constructed from key ideas or concepts extracted from information gathered from interviewing the participants. In this research inquiry, coding was done manually and an overlap between familiarization and coding was anticipated as coding also entailed a thorough understanding of the data gathered to uncover ideas of interest, a process which started during the transcription process. Similarly, key impressions were highlighted and linked to an annotated code on the margin of the transcription sheet. Initially, I put as many codes as appropriate which I refined iteratively. By the end of this phase I compiled a list of codes juxtaposed to excerpts

from the transcript with identifiers to ease the process of locating where the data was desegregated from the text.

This repetitive process of refining the codes ushered in the third stage which entailed the identification of themes. Themes are the over-arching categories formed from clustering of similar or contiguous codes (Robson & McCartan, 2016). Some of the themes may arise from topics that keep recurring in the data, or terminology that the participants use which maybe metaphors employed to describe concepts, meanings or events (Robson & McCartan, 2016). This phase was also repetitive until there was satisfaction that most of the key concepts had been coded and the codes had been clustered into broader categories.

The constructed themes were then reviewed in the fourth phase. The themes were tested on further codes and data by an iterative process of constant comparison to check for contiguity (Robson & McCartan, 2016). In this stage, some themes were discarded which did not fit with the data and some were disconfirmed using negative cases (Pope, Ziebland & Mays, 2000). Other related themes were combined to form one broader descriptor. The association between these themes was also assessed thereby linking them to even broader organizing themes and consequently a global theme which ties all these concepts. These codes, themes, organizing themes and global themes were woven into a thematic map with the primary goal of answering the original research question (Pope *et al.*, 2000; Qualitative Research Methods (QRM) Module guide, 2020).

3.7 Rigour

To ensure scientific rigour, this qualitative study was conducted in a methodology that ensured the qualities of scientific rigour are met by employing the strategies discussed below.

3.7.1 Saturation

Saturation was achieved through starting data review from the onset and through-out data collection. Thus, the saturation point was reached when no new additional insights or ideas were emerging as the participants were interviewed (Woodsang *et al.*, 2005).

3.7.2 Credibility

Credibility was achieved through conducting the research methodically and coherently in clear and transparent steps (Malterud, 2001). Furthermore, by interrogating the findings and interpretation

and by displaying and discussing how data was analyzed and processed, level of internal validity and credibility was improved (Malterud, 2001).

3.7.3 Thick description

Secondly, a rich description of the research setting and population demographics and general socio-economic characteristics were detailed, particularly when using the lens of the participants so that their social realities are portrayed as perceived by them (Creswell & Miller, 2000). It is also important for external reviewers and stakeholders to have a vivid picture of the social phenomenon being interrogated.

3.7.4 Reflexivity

Reflexivity was used to objectively examine for coherence in the design steps (Malterud, 2001). Subsequently, it was also employed to assess if data coded into themes made sense and is a true reflection of what had been communicated by the participants. This enhanced credibility of the study by minimizing researcher bias as well as allowing social patterns to emerge unpolluted by the researcher's preconceptions or prejudices (Malterud, 2001).

3.7.5 Confirmability

Confirmability was achieved by having an audit trail in the form of audio recordings of the in-depth interviews complemented by notes where feasible (Robson & McCartan, 2016).

3.7.6 Transferability

Transferability equated to external validity by Malterud (2001) was achieved in this research through ensuring a rich comprehensive description of the geographic setting, population and the sample that participated in the study. The findings of this study were used to formulate solutions pertinent to this population, however, transferability enabled approximate conclusions to be made pertaining to populations of a similar nature.

3.8 Ethical Considerations

Ethical approval was granted by the UWC Biomedical Research and Ethics Committee (BMREC) and also by the Eswatini Health Human Research Board (EHRRB) and the Management team at Dvokolwako Health Centre.

Respondents' participation in this study was voluntary. An information sheet was used to provide a clear explanation of the study's methodology and goal. To participate in the study, participants had to give their consent. The study's participants' identities and confidentiality were upheld at all times. Respondents were advised that they could opt to stop participating in the study at any time, without having to give a reason, and that doing so would not put them at risk of losing out on anything. The identities of patients were not necessary nor used in the review due to the sensitivity of the data that needed to be gathered. Hard copy data generated in this study was kept in a secure cabinet in the Senior Medical Officer's office, and electronic data was stored in secure computer files on the University School of Public Health data repository. This data will be destroyed after five years.

3.9 Payment and Compensation

Study participants did not benefit personally through payments, compensation or incentives during the study apart from the normal TB treatment and care services provided at the health centre.



CHAPTER 4: RESULTS

The findings of this research investigation are described in this chapter. It begins by outlining the general characteristics of the study participants before moving on to the findings about how the participants perceived the factors underlying their late presentation into TB care services. The factor are discussed under the key themes that emerged from the data namely individual and health system issues. Lastly, the research respondents went on to give further insights on factors that motivated their eventual engagement with health care facilities for TB treatment and care services.

4.1 Participants' profile

A total of fourteen participants were interviewed in this study. This comprised of seven female and seven male participants. Their ages ranged from twenty to seventy-seven years. As illustrated in **Table 1**, all male participants had at least one child and five of them were staying with their partners as married or stay-in couples. The majority of the female participants (six out of seven) were single, and all had children except for two participants.

While most of the participants attained at least primary school education, two male participants had no formal education. Two male participants were retired miners and the rest of the respondents had no formal employment and their sources of income ranged from semi-subsistence farming and short-term contractual employment.

Table 1: Socio-Demographic Description of Study Participants

Variable	Category	Gender		Participants (n)
		Male	Female	
Age	20 - 30	1	5	6
	31 - 40	1	0	1
	41 - 50	1	1	2
	51 - 60	1	1	2
	>60	3	0	3
Marital Status and Children	Single with no children	0	2	2
	Single with children	2	4	6

	Married with children	4	1	5
	Stay-in-couple with children	1	0	1
Level of Education				
	No Formal Education	2	0	2
	Primary Education	1	1	2
	Secondary Education	4	6	10
Employment	Retired	2	0	2

Four participants were diagnosed with TB after experiencing TB symptoms for more than a year and of these, three were male participants. Again, four participants were diagnosed between six months and a year’s duration of illness. Six participants were diagnosed between 2 weeks and 6 months since onset of symptoms.

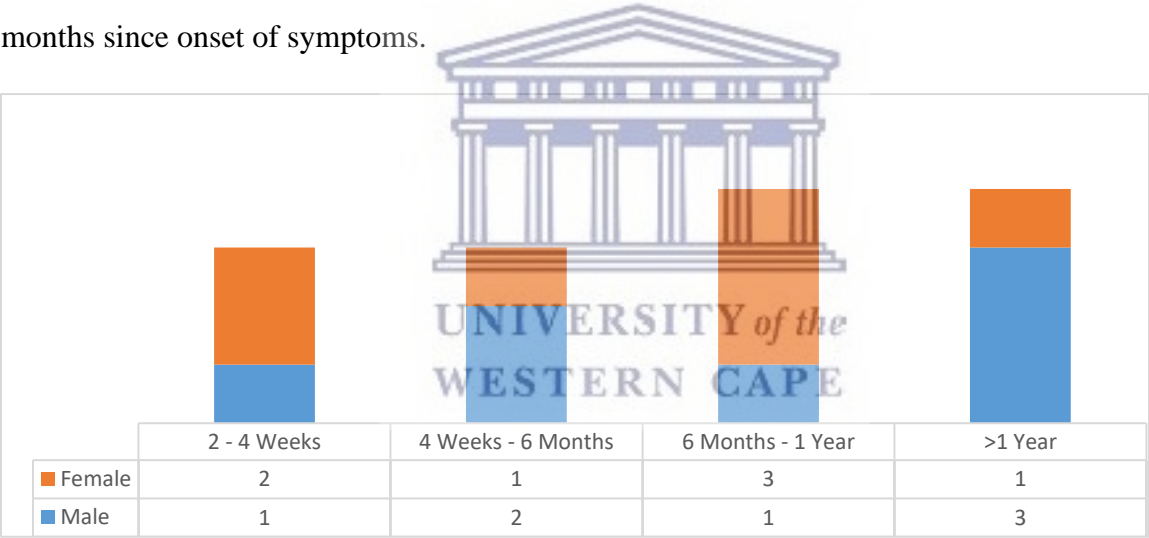


Figure 2: Duration of Symptoms before TB diagnosis

4.2 Themes and Sub-Themes

The responses from the research participants were categorized into three main themes that described factors underlying their late presentation into TB care services and motivations

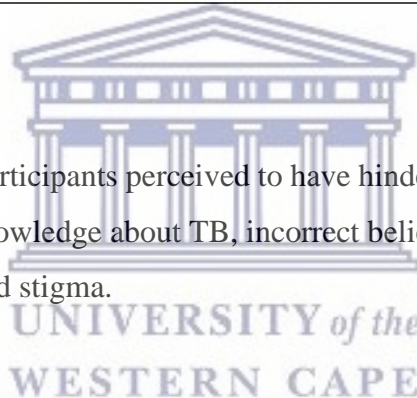
underlying their eventual presentation to TB care services. These themes were individual, health system-related and motivating factors as summarized in **Table 2** below.

Table 2: Themes and Sub-themes

Main Theme	Sub-theme
Individual factors	<ul style="list-style-type: none"> • Level of knowledge about TB • Beliefs about TB symptoms • Access to Health Care services • Stigma
Health System-related Factors	<ul style="list-style-type: none"> • Lack of Community Health Education and Promotion • Health care workers' attitudes
Motivating Factors	<ul style="list-style-type: none"> • Persistence of Symptoms • Family-driven motivating factors

4.2.1. Individual Factors

The individual factors that the participants perceived to have hindered them from presenting early into TB care were inadequate knowledge about TB, incorrect beliefs about TB symptoms, lack of access to Health care services and stigma.



4.2.1.1. Level of knowledge about TB

i. No TB knowledge

Among the participants interviewed, six out of fourteen said they delayed seeking care because they had no prior knowledge on anything about TB disease before their encounter with the health care facility. These were four female and two male participants.

“I knew nothing about TB, in fact, I thought I was just having a minor flu which will go away on its own.” [Male, 25 years].

“I did not have any information at all about TB prior to coming to the hospital I only knew about traditional medicines which I learnt from my grandmother.” [Female, 51 years].

The participants who had some level of knowledge about TB delayed seeking medical care because they lacked knowledge regarding symptoms characteristic of TB disease.

“...the delay in coming here was because TB is not the first thing one would think of judging from the symptoms I was experiencing at the time.” [Male, 41 years].

“... I just knew that TB is like a flu but the symptoms confused me because in the first diagnosis, I did not have the symptoms I had now” [Male, 63 years].

Others delayed seeking care because they did not know about the treatment and care services available to them.

“...I did not know the kind of help available to me even if I was to be diagnosed of TB disease” [Male, 25 years].

The other respondents mentioned that they did not know the cause of their symptoms, therefore, they delayed seeking care because they attributed their symptoms to other causes.

“...we all thought that the cough was being caused by the dust when it was actually TB. That’s why it took me long to come to the hospital.” [Female, 30 years].

“I thought the symptoms were a result of a different type of flu, only stronger, that is why I continued to take flu medication from our local chemist...” [Female, 20 years].

ii. Low level of knowledge about TB

From the responses to the interview questions, some participants actually knew about some aspects of TB disease as illustrated in the quotes below:

Some participants knew how TB infection is transmitted from one person to another.

“I knew that TB is transmitted when someone coughs without closing one’s mouth...” [Male, 41 years].

“... the little knowledge I had was on how one can gets TB, I got this information from my first diagnosis when I was working at the mines. [Male, 63 years].

Other respondents knew some of the symptoms associated with TB disease.

“I was coughing and I knew that TB causes coughing...” [Male, 25 years].

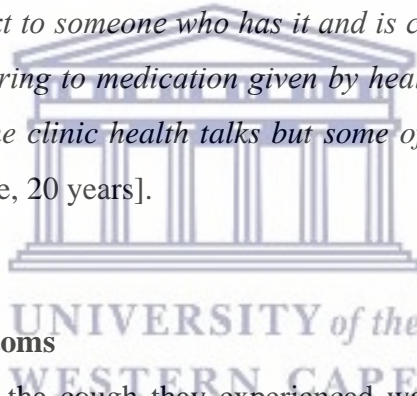
iii. High level of knowledge about TB

Some even demonstrated high level knowledge on most aspects of TB disease.

“I knew that TB is spread when you breathe in air contaminated with TB and some of the common symptoms are coughing with phlegm and a lot of sweating. I knew about this from health education talks done at the clinics... I also knew that TB is best treated at health facilities...” [Female, 27 years].

“... I know that TB is transmitted from one person to another through the air and that it causes coughing, so much tiredness, fever and over-sweating. This is taught at the mines during routine health talks...” [Male, 62 years].

“... you can get TB if you sit next to someone who has it and is coughing. I also knew that there are different types of TB... adhering to medication given by health care workers helps. Most of this information, I got it from the clinic health talks but some of it from newspapers and other people I interact with...” [Female, 20 years].



4.2.1.2. Beliefs about TB symptoms

Some participants believed that the cough they experienced was a result of being bewitched, therefore, they sought alternative remedies for bewitchment first before seeking care from health facilities.

Some of these participants consulted faith healers first when flu medication had failed to resolve their symptoms.

“...because I had been sick for some time and have been using flu medication with no success... I was taken to a man of God who confirmed my earlier belief that I had been bewitched...” [Female, 27 years].

Other participants decided to consult traditional healers first.

“The problem is that the TB symptoms are similar to the symptoms you have when you have been bewitched, that is why we always start by seeking help from traditional doctors first because we know the effects of witchcraft are quick to kill you and hospitals cannot help. Only when the traditional healer failed to treat my painful cough and sweating at night, is when I went to the clinic...” [Female, 20 years].

One participant who was a traditional healer tried self-medicating with traditional medicines first.

“... my traditional medicines usually cure most things including coughing but this time around I continued to cough a lot and I developed a lump on my neck which was not going away” [Female, 51 years]

4.2.1.3. Access to the Health Care Facility

Some participants mentioned that the unavailability of money for bus fare also contributed in delaying them from visiting health facilities earlier.

“...even though I had suspected TB, because I was once treated for TB in the mines, I stay very far in Nsingweni where I have to catch two buses to get here... the distance itself is not a problem for me, my issue is the money for bus fare...” [Male, 63 years].

“... I stay a bit far and I do not always have money for bus fare to visit the hospital so I usually walk. Because of this I only go to the health facility if the symptoms are worse... it's about an hour's walk which can be a problem if one is too sick.” [Male, 52 years].

4.2.1.4. Stigma

Even when the participants had started to suspect that their symptoms could be due to TB disease, they further delayed seeking care because they feared the stigma attached to a diagnosis of TB from the community.

“I was uncomfortable because there is just a negative perception on TB that made me uncomfortable to seek help... I was generally scared to confirm it because I thought people will give me an attitude as a sickly person.” [Female, 20 years].

Other participants feared that if TB is diagnosed, they will be stigmatized by their close family members.

“...they told me that ‘if you have TB, we cannot eat with you...’ [Female, 30 year].

4.2.2 Health System Factors

Some participants perceived that the health care system was also a deterrent to early care-seeking. They blamed the lack of community health education and promotion and negative health care workers’ attitudes.

4.2.2.1. Lack of Community-Based Health Education and Promotion

Some participants felt that, as a community, they were not well educated on matters pertaining to TB and they also had no time to go to health care centres where such TB information and care services were available.

“...it would be best to have people go around communities to teach about TB symptoms, transmission and treatment. This will benefit street vendors, like us, who do not have time to go to the clinics” [Male, 38 years].

4.2.2.2. Health Care Worker Attitudes

Some participants delayed going to the health care centres because they were anxious about the health care worker attitudes because they did not know what to expect.

“Sometimes you fear going to the clinic because nurses will shout at you asking why you delayed and yet you delayed because you were still coming to terms with your sickness... and you will also be fearing the worst.” [Female, 20 years].

“I am just scared of the hospitals and I just thought it was a minor flu which will resolve on its own hence the delay” [Male, 25 years].

4.2.3. Motivating Factors

In addition to the factors contributing to delays stated above, participants also highlighted some of the factors that motivated their eventual presentation to health care facilities to seek help.

4.2.3.1. Persistent TB Symptoms

Some respondents eventually decided to go to the health facilities because of the persistence of their symptoms.

“I came to get help because I have been sick for quite some time now...” [Female, 20 years].

Others were motivated by the fear of death when they started suspecting that they might have TB,

“...once I began suspecting that I could be having TB, I resolved to seek help from the clinic because I had started to perceive TB to be a ticket to death” [Female, 51 years].

The other participants feared being stigmatized because their body image and health continued to deteriorate as the symptoms persisted.

“...because of the persistent loss of weight, I became uncomfortable around people as I seemed to be attracting more attention and negative comments from people from my neighbourhood who knew my normal body size, that is why I decided to step up and seek help...” [Female, 20 years].

“...some of my family members told me that if I have TB they will not eat with me, this later forced me to seek help because I yearned to belong to the family again...” [Female, 30 years].

4.2.3.2. Family-driven factors

Family factors also contributed towards motivating some participants to seek care for their symptoms.

For some participants, family members directly encouraged them to go and have their symptoms assessed at a health facility.

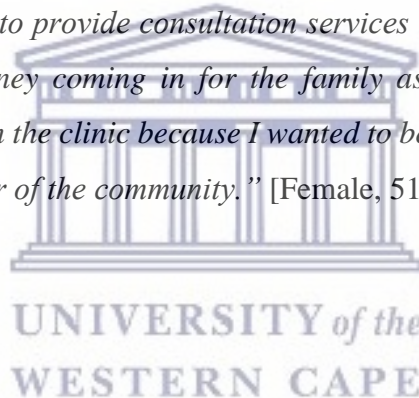
“After seeing my persistent weight loss, my relative who is a nurse persuaded me to go get my symptoms checked and she assured me that I will be well taken care of at the hospital” [Male, 41 years].

Other participants were motivated by the desire to protect their families from contracting TB disease

“Most diseases nowadays are easily transmissible, so I decided to quickly seek help to protect my family from contracting the disease too” [Male, 52 years].

Some participants were eventually driven to seek care by the need to get well again so that they are able to provide financial support to their family dependents.

“...when I am sick, I am unable to provide consultation services to my clients because I struggle to kneel down. This affects money coming in for the family as I am the bread winner...so I eventually went to seek help from the clinic because I wanted to be cured so that I can support my family and be a valuable member of the community.” [Female, 51 years].



4. 3 Summary of Findings

The findings of this research study show that individual participant-associated factors and health-system associated factors contributed to TB patient delay in seeking treatment and care. Among individual factors, the key issues were inadequate TB knowledge and incorrect beliefs about TB symptoms which they attributed mostly to witchcraft. The delay was, therefore, due to the consulting of traditional or faith healers before a health care facility. Stigma associated with TB and distance from HCFs also hindered early access to TB care services. Beyond the individual factors, lack of decentralized health education and promotion and negative HCW attitudes worsened the poor health-seeking behaviour amongst the TB patients. Nonetheless, the worsening TB symptoms and family encouragement were the main drivers that compelled the participants to

eventually seek care. The next chapter goes further to explore how these findings relate to and are validated by available literature.



CHAPTER 5: DISCUSSION

5.1 Introduction

This research study aimed to explore factors that hindered patients from seeking TB care services early despite experiencing symptoms. It also sought to explore factors that motivated participants to eventually seek TB care and treatment services from health facilities. This chapter will discuss the findings from this research enquiry and how these findings relate to available literature. The themes that will be discussed are individual and health-system-related factors that participants perceived to have hindered them from presenting early into TB care services and factors that promoted their eventual presentation into care. Lastly, the chapter concludes by discussing the strengths and limitations of the study.

5.2 Individual Factors

5.2.1 Level of knowledge

From this research enquiry, lack of adequate knowledge about TB contributed as a barrier to early presentation into care. This was noted in respondents who had no knowledge about TB and those who lacked knowledge about the causes, symptoms, transmission of TB and available TB treatment services. The results of this study are similar to findings of (Basa and Venkatesh, 2016) done in India, which also noted that poor knowledge about TB was the most self-reported reason for delay in seeking TB care services. In addition, Marahatta *et al.*, (2020) noted that one of the significant causes of delay was that though participants had knowledge about TB, they lacked knowledge regarding prominent symptoms of TB in a study done in a similar rural setting in Nepal.

Nonetheless, some participants had high knowledge about TB but still delayed seeking care. This shows that having good knowledge about TB might not be sufficient to improve TB health-seeking behaviour. This is supported by the findings of Almeida, Skupien and Silva (2015) who failed to see the association between patients delay in seeking TB care and lack of knowledge about TB. Furthermore, in a systematic review on research assessing factors associated with health seeking delay, some studies which included some done in Ethiopia, reported high levels of knowledge about TB among participants who had significant delays in seeking TB care (Samal, 2016).

It is interesting to note that a review of Demographic Health Surveys (DHS) in fifteen countries, including eight from Africa, found that knowledge about TB curability took precedence over knowledge about TB transmission in curtailing patient delay in seeking TB care services because it was perceived that an increase in the knowledge about TB transmission was counterintuitive as it seemed to increase TB associated stigma and the consequent poor TB care seeking tendencies (Rood *et al.*, 2017). This seems to contrast the findings of this enquiry which had participants with good knowledge about TB curability but still delayed in seeking care. This supports the notion that other multi-factorial determinants are necessary to effectively influence TB health-seeking behaviour apart from the patients' level or type of knowledge about TB.

5.2.2 Beliefs about TB symptoms

Some respondents delayed seeking TB treatment services because they believed that their symptoms were a result of witchcraft. These participants, thus, consulted traditional and faith healers first depending on one's beliefs. This is consistent with other studies done in similar African settings for instance, in North Ethiopia, Alema *et al.*, (2019) found that TB patients who first sought treatment from religious healers or from traditional healers were at a significant risk of longer health seeking delay. Similarly, a study that assessed factors associated with delay in East Africa (Tanzania, Kenya and Uganda) noted that beliefs linked the causality and transmission for TB to witchcraft or curses resulted in most patients resorting to seeking remedy from traditional healers before going to a formal healthcare centre (Msoka *et al.*, 2021).

This reason may be that traditional and faith healers are still highly respected and influential in both urban and rural communities of southern Africa (Edward, 2012). In addition, Eswatini has one traditional or faith healer for every one hundred and ten people making them about eight times more than doctors trained in western medicine (Edward, 2012). Ultimately, about 85% of the population in Eswatini, both educated and non-educated consult a traditional or faith healer first before a health facility for any illness (Nann, 2021).

To further highlight how strong and entrenched these beliefs linking TB to witchcraft are, Matakanye *et al.*, (2021) in a study done in South Africa, found that about 76% of respondents visited traditional or faith healers even after the diagnosis of TB had been confirmed. In contrast, some studies like Nann (2021) argue that it is not solely about beliefs but more of lack of access

to health care facilities that causes patients to end up resorting to faith or traditional healers who are easily accessible in their communities.

5.2.3 Access to the Health Facility

The unavailability of funds to cover transport costs was a barrier for some participants who stayed far away from the nearest health facility. This was so even for participants who suspected their symptoms to be due to TB. This is similar to what was noted by Santos *et al.*, (2017) in a quantitative study in Angola where they found that patients staying outside the ten kilometre radius of the nearest health care facility, had longer delay in seeking TB care services. Another quantitative study done in a population consisting of newly diagnosed TB patients in Ethiopia, Seid and Metaferia (2018) also found that patients who needed to walk more than thirty minutes to the nearest health facility significantly delayed seeking TB treatment services compared to those who walked for less time.

5.2.4 Stigma

The stigma attached to TB disease made some participants more inclined to keeping their illness a secret due to fear of being isolated by their families and their communities. This stigma was perceived to be arising from the association people make between TB and being unhygienic or contagious. This is consistent with the findings of a study done in Hohoe Municipality in Ghana Osei, Akweongo and Binka (2015) where they found that the perceived infectiousness of TB and its association with poverty were major causes of stigmatization affecting health seeking behaviour among suspected TB patients.

Eswatini being among top thirty TB/HIV high burden countries globally, the strong association between TB and HIV may also have exacerbated the stigma experienced by those who were diagnosed of TB as they were automatically perceived to be HIV co-infected (WHO, 2021). This agrees with what Msoka *et al.*, (2021) found in their study in East Africa. Similarly, Khan *et al.* (2021) discovered that stigma was a significant barrier to accessing TB care services for the participants because of the fear of being isolated by their communities in Pakistan.

5.3 Health System Factors

5.3.1 Lack of Community-Based Health Education and Promotion

Some respondents felt that TB care services including health education were centralized at health care centres away from their communities. This greatly limited access to the information on TB more specifically for community members who could not find time to visit health facilities. This may have aggravated the impact of the lack of adequate knowledge about TB thereby leading to sub-optimal utilization of TB health services. This paucity of decentralized health education and promotion has also been noted in the general population of Ethiopia in a study done among TB patients who had delayed seeking care (Datiko *et al.*, 2019). In this study, they found that close relatives were the main sources of TB information, implying that if none of the family members had encountered TB, the TB patients were unlikely to have known much about TB to promote early presentation into care (Datiko *et al.*, 2019). This also concurs with the findings of a study done in Myanmar by Htun *et al.*, (2018) where TB patients who delayed seeking care services ascribed their late presentation to the lack of access to health information.

In this study, some participants had low awareness concerning the severity and consequences of TB and others did not know about the TB care services available. This aligns with the findings of a study done in Nepal which noted a significant patient delay in seeking TB treatment because of the low awareness on the available TB care services and the national free TB treatment policy (Marahatta *et al.*, 2020).

5.3.3 Health Care Worker Attitudes

Many studies from diverse settings agree with the notion that the way patients experience the health care system as a result of health care worker – patient interaction has a direct influence on the health-seeking behaviour of those patients and their communities (Phetlhu & Watson, 2011; Hu *et al.*, 2012; Pardeshi *et al.*, 2016). This has also been evident in this study where some respondents, even if they might have wanted to visit a health facility sooner than they did, they delayed because they were anxious about how they would be treated by health care workers (HCWs). Participants were hesitant to seek care because of the anticipated unprofessional and rude conduct from HCWs like being shouted at even when one was evidently sick. Other respondents opted to endure the symptoms hoping they would resolve on their own than approach a health

facility. The adverse impact of similar HCW attitudes and conduct on TB health-seeking behaviour was also documented in the qualitative studies done in Zimbabwe (Mavhu *et al.*, 2010) and Malawi (Kumwenda *et al.*, 2016). HCWs who were part of the study by Kumwenda *et al.*, (2016) in Malawi even acknowledged these concerns from the communities they served but they blamed this to the frustrations they experienced from working in resource-strained environments and poor remuneration. Although this enquiry did not have HCWs participants, the setting is comparable to rural Malawi. In India, the majority of the surveyed HCWs lacked compassion and tended to avoid TB patients (Pardeshi *et al.*, 2017). Most of these HCWs either knew of a colleague who had had TB or they had not undergone a training program on TB (Pardeshi *et al.*, 2017).

The other reason respondents were reluctant to seek care from health facilities in this study probably emanated from bad previous experiences as some had been treated of TB before. This phenomenon was also noticed in patients previously treated for DR-TB who delayed seeking care because they lacked confidence in health care workers attitude due to their previous encounters (Bonadonna *et al.*, 2017; Bhagyalaxmi *et al.*, 2019). As a result, participants opted to exhaust other available treatment options first before they decided to present to a health care facility (Bhagyalaxmi *et al.*, 2019).

5.4 Motivators For The Eventual Presentation To TB Care Services

In spite of the delays, the participants eventually sought care from the health care facilities. The main facilitators were the persistent TB symptoms and encouragement from close relatives and family.

5.4.1 Persistent TB Symptoms

For most participants, symptoms remained unresolved after trying different remedies ranging from self-medication and services from traditional or faith healers. At some point the symptoms became unbearable physically as they worsened, and psychosocially as a result of the stigma attached to deteriorating body image. Similarly, in Kenya, Mutinda, Kabiru & Mwaniki (2014) also found that the majority of participants who had delayed seeking TB care services eventually sought help when they became too sick to bear the pains and when they realised that self-medication was not working.

According to Helfinstein *et al.*, (2020), having fever for a week or more and unintended weight loss significantly increased the odds of care-seeking implying that having symptoms for longer and the type of symptoms experienced prompted affected individuals to seek care.

5.4.2 Family-driven factors

In settings with no effective community health education and promotion as also reported by some participants in this study, most people got most of the health-related information from their close relatives and family members as also noted elsewhere (Datiko *et al.*, 2019).

In this enquiry, family motivation to seek care ranged from family members directly encouraging their sick relatives, participants' desire to protect their close relatives from contracting the disease to the need to regain fitness to be able to earn a living to support their family dependents. Shatil *et al.* (2019) in their qualitative study, also found that the opinions of family members and relatives were key determinants for health-seeking behaviour among patients with TB symptoms.

These studies, however, did not explain how the role of family members influence health-seeking behaviour but it might be that family support and encouragement countered factors that negatively impacted TB health-seeking behaviour like stigma, wrong beliefs and inadequate knowledge about TB.

In contrast, other studies by Senbeto *et al.*, (2013) and Seid & Metaferia, (2018) assert that larger family size was associated with longer patient delay in seeking TB care services and they argued that the reason was the huge financial responsibilities that hindered their ability to afford costs associated with accessing health care even if there might have been a higher likelihood of having a family member with knowledge about TB in a larger family.

5.5 Limitations and Strengths of The Study

5.5.1 Limitations

The findings of this research study came from a sample size of fourteen participants who were already enrolled on TB treatment and therefore their views might not be transferable to the entire rural population of Eswatini because, for instance, perspectives of patients with TB who did not seek care services were not included. Furthermore, the study might be limited by the reliance on participants' ability to recall events and time duration of symptoms which risks introducing

inaccuracies by way of recall bias. The study would have been further strengthened if HCWs were involved as key informants so that their perspectives were also considered to enrich the findings.

5.5.2 Strengths

The findings of this study are voices of real people describing their lived experiences in their own words. In addition, participants voluntarily spoke about factors that motivated them to seek care, thereby providing balanced and rich accounts of their experiences. The interviews were conducted in the participants' language of comfort to ensure that only their voices were captured.



CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

This chapter presents the conclusion of this study that sought to uncover factors that contribute towards patient delay in seeking TB care services in a region of Eswatini. It also provides recommendations to optimize TB health seeking behaviour in line with the findings of this research study.

6.1 Conclusion

This study found that inadequate knowledge about TB is one of the key factors that hinder TB patients from seeking care services early. This might be lack of knowledge about the causality, transmission, symptoms of TB and the available services, thus, making it hard for patients to make a connection between their experience and need to seek appropriate care.

Nonetheless, having good knowledge about TB was not sufficient for early care seeking because there were participants with high level knowledge about TB. Beliefs linking TB symptoms to witchcraft and curses caused some patients to seek help from traditional and faith healers first causing delays in seeking needed TB treatment from health care facilities.

Lack of access to health care services primarily because of lack of funds to cover transport costs also had an impact on the duration of time patients took to eventually seek care. A study done in Eswatini by Nann (2021) also made a connection between lack of access to care and consulting traditional or faith healers first potentially worsening the delay in seeking the needed care.

Stigma attached to TB and the associated fear of being isolated was another key factor that caused some participants to hide their illness thereby contributing towards delays in seeking care. The stigma arose from the perceived connections between TB and infectiveness and also the perception that being diagnosed of TB automatically means one is co-infected with HIV.

Lack of community-based health education and promotion meant that patients had no requisite information and awareness about TB to motivate health-seeking whenever one had symptoms associated with TB. This contributed to the lack of knowledge about TB.

Negative HCWs attitudes made TB patients reticent to seek care because of the anticipated unprofessional and rude conduct from HCWs. This anxiety was also reported by participants who had prior negative experiences.

6.2 Recommendations

From this research enquiry, most of the factors impeding TB health-seeking behaviour are interrelated and therefore require a multi-pronged approach to mitigate the poor care-seeking behaviour. In line of these findings of this research enquiry, this section highlights the recommendations aimed at improving TB health-seeking behaviour amongst undiagnosed TB patients:

1. Decentralization of health education and promotion into communities, especially those that are likely to have less access to health care services with emphasis on early treatment seeking. This is primarily aimed at supplanting lack of knowledge and awareness about TB in these communities.
2. Use of peer educators to drive community-based health education and promotion is anticipated to help mitigate stigma associated with TB.
3. Health education should also emphasize on the curability of TB and feasibility of treatment and not just on symptoms associated with TB and transmission. This is likely to have a positive impact on stigma reduction and correcting incorrect beliefs on TB.
4. Engagement and collaboration with traditional and faith healers as partners in identifying cases and facilitating linkage to effective TB treatment may help reduce patient delays to TB care services.
5. Further research at a larger scale is needed to better understand social drivers of health-seeking behaviour to optimize interventions designed to improve care-seeking behaviour.

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APPENDICES

Appendix 1: Participants' Information Sheet (English Version)



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

INFORMATION SHEET

Project Title:

An exploration of factors that underlie late presentation of patients into TB care services in the Hhohho region of the Kingdom of Eswatini.

What is this study about?

This is a research project being conducted by Elisha Nyandoro, a student at the University of the Western Cape. We are inviting you to participate in this research project because you have been classified among late presenters and so we believe you have information important for the research. The purpose of this research project is find out information that will help develop interventions that will help patients seek Tuberculosis Care services early.

What will you be asked to do if you agree to participate:

You will be asked to answer interview questions. The questions will be asked in a language you understand and are designed to understand reasons that may have caused you to seek TB care services late. This interview is estimated to take about one hour of your time. . The interview session will be audiotaped.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not appear on the audiotapes but you will be accorded a code which will be used as an identifier. .

To ensure your confidentiality, the data collected will contain participant identifier codes and will be stored on password-protected audio files on the computer. The identification key and additional interview notes will be locked in cupboard housed in the Senior Medical Officer's office and the researcher will be the sole custodian of the key.

If we write a report or article about this research project, your identity will be protected.

The risks of this research:

All human interactions and talking about self or others carry some amount of risks. These may include embarrassment or discomfort as a result of some questions during the interview session. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. If required, a chaperone of your choosing will be present during any stage of the interview session. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. In addition, the participant maybe at risk of contracting Covid-19 disease, however, this risk will be mitigated by ensuring that both participant and interviewer are correctly wearing their face masks, sanitize their hands and observe social distancing according to the Kingdom of Eswatini Covid-19 regulations.

The benefits of this research:

This research is not designed to help you personally, but the results may help the investigator learn more about how TB disease and the associated barriers to TB care are perceived in the community. We hope that, in the future, other people might benefit from this study through improved understanding of these perceptions and barriers to TB care services.

The research findings will help policy makers to develop better strategies to enable potential TB patients to seek care services early before they get too sick and to prevent death from TB disease.

Do you have to be in this research and may you stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if you have questions?

If you have any questions about the research study itself, please contact Elisha Nyandoro at **telephone number** +268 7831 9686 and **email:** 3918032@myuwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Utah Lehmann
SOPH Director/ Coordinator
School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
South Africa
Tel: +27 822023189
ulehmann@uwc.ac.za

Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za



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WESTERN CAPE

Appendix 2 : Participants' Information Sheet (siSwati Version)



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

INFORMATION SHEET: (siSwati Version) LIKHASI LWELWATI

Sihloko salalucwaningo:

Kutfola kabanti tizatfu letibangela bantfu kutsi baphute kufuna lusito mayelana nesifo sesifuba sengati esifundzeni sakaHhohho eveni laseSwatini.

Lwani lolucwaningo?

Lolucwaningo lutawube luchutjwa nguElisha Nyandoro longumfundzi wase University of the Western Cape. Bewucelwa kutsi ube yincenye yalolucwaningo njengobe utfolakele ungolomunye walabaphutle kufinyelela emfolamphilo kutewufuna lusito loluphatselene nesifuba sengati, ngako siyetsemba utawuba nelwati lolwanele lolungasita kulolucwaningo. Inhloso yalolucwaningo kutfola lwati lolwanele lolungasita kutfola tindlela tekukhutsata banftu kutsi basheshe batfole lusito nekwelashwa kwesifuba sengati.

Yini lokubhekwe kutsi ukwente uma uvuma kuba yincenye yalolucwaningo?:

Utawucelwa kutsi uphendvule luhla lolutsite lwemibuto. Lemibito itawubutwa ngelulwimi lowutawuluva kahle futsi ibhalwe ngendlela letawenta ukhone kuchaza kabanti ngetizatfu letikubangele kutsi uphute kufuna lusito ngesifuba sengati. Lengcoco ilinganiselwa kutsi ingatsatsa sikhatsi lesingaba mizuzu lengemashumi lasitfupha, pheceleti 'one hour'. . Lengcoco itawentiwa ngesitfwebula mavi.

Kutawugcinwa kuyimfihlo yini kungenela kwami lolucwaningo?

Labachuba lolucwaningo batawugcina imininingwane yakho ifihlakele, kutawubate lokuhlanganisa timphendvulo takho kanye nemininingwane yakho. . Leyo nombolo itawuwatiwa ngulophetse lolucwaningo kuphela kutsi yabani.

Letingcoco letitfwetjuliwe titawugcinwa kungcondvomshina losezingeni lelisetulu ngetekuphepha. Imininingwane letawube ihlanganisa libito lakho kanye nenombolo yakho yalucwaningo itawugcinwa iphephile ikhiyelwe ekhabetheni ehhovisini lalophetse lomtfolamphilo, ngulophetse lolucwaningo kuphela lonalesikhiya futsi lovumelekile kuvula lelikhabethe.

Uma khubhalwa ngalokutfolakele noma sekushicilelwa ngalolucwaningo, imininingwane yakho angeke ivetwe.

Bungoti lobungahle bube khona ekungeneleni lolucwaningo:

Njalo uma kunetingcoco letiphatselene nemuntfu lucobo lwakhe nomelomunye, kuba khona litfutjana lebungoti tsine kuloko kucocisana. Loku kungafaka ekhatsi kutiva uhlazeka nobe kungakhululeki ngalokwanele ngenca yaleminye yalemibuto lebutwako. Kepha ke, siyetsembisa kukwesekela ngako konkhe lokusemandleni etfu kutsi utivele ukhululekile futsi uphephile sisachua lolucwaningo. Makunesidzingo kungaba nemuntfu lometsembako masisachubeka sibuta imibuto. Uma kuvela kutsi udzinga lusito kubochwephesha tsite, sitawukubhalela incwadzi letawukuchumanisa nabo kute utfole lolusito lolufanele.

Lusita ngani noma kanjani lolucwaningo:

Lolucwaningo ulakahlosi kusita wena wedvwa kepha imiphumela yalo itawusita lona loluholako kutsi ati kabanti ngetimvimba letibangela bantfu bangalufuni lusito kusenesikhatsi kanye nekutsi iTB ibukeka kanjani emimangweni lesiphila kuyo. Siyetsemba kutsi ekuhambeni kwesikhatsi baningi bantfu labatawusitakala emuveni sekubuketwe kabanti tinkinga netimvimba letikhona letibanga kutsi bantfu baphute kufuna lusito ngeTB.

Lolucwaningo lutawuphindze lusite tishayamtsetfo telive kutsi takhe tinhlelo letibukele bantfu labasolakala kutsi banaso lesifo seTB kutsi batfole lusito masinyane kute bavikeleke ematfubeni ekutsi babulawe ngulesifo seTB.

Kufanele yini kutsi ube yincenye yalolucwaningo futsi uyakhona yini kuphuma kulo?

Kungenela nobe kuba yincenye yalolucwaningo kuselungelweni lakho leliphelile kutsi utikhetsela ngaphandle kwekuphococelelwa ngumuntfu. Uvumelekile kutsi wale sanhlobo kuba yincenye yalolucwaningo. Uma uvuma kuba yincenyenye yalolucwaningo, uvumelekile kulushiya nobe ngusiphi sikhatsi noma sigaba. Uma ungavumi kuba yincenye yalolucwaningo moma ukhetsa kuphuma esigabeni tsite, ngeke ujeziswe ngaleso sincumo futsi kute lokutakulahlekela.

Uma unemibuto ngalolucwaningo?

Uma unemibuto mayelana nalolucwaningo ungachumana na Elisha Nyandoro enombolweni yamahlalekhikhini letsi +268 7831 9686 **noma likheli labongcondvomshina:**
3918032@myuwc.ac.za

Uma ikhona leminywe imibuto lonayo mayelana nalolucwaningo nemalungelo lonawo ngengenceye yebantfu labalungenele nob eke ufisa kuveta indlela lophatseke ngayo nobe indlela loluchubeke ngalo lolucwaningo, ungachumana nalalabalanzelako:

Prof Utah Lehmann
SOPH Director/ Coordinator
School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
South Africa
Tel: +27 822023189
ulehmann@uwc.ac.za



Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za
Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville 7535

Tel: 021 959 4111

E-mail: research-ethics@uwc.ac.za



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Appendix 3 : Interview Guide (English Version)

1. Can you tell me about yourself?

Prompts

- Age
- Gender/sex
- Marital status
- Number of children
- Level of education
- How far do you stay from the Center?

2. Can you tell me about your TB diagnosis?

Prompts

- When were you diagnosed (Month and year)?
- Where were you diagnosed (facility name)?
- What made you to seek TB diagnosis?

3. Can you tell me what you knew about TB before diagnosis?

How TB is transmitted

- Which symptoms of TB you knew before you were diagnosed?
 - Where did you hear about them (Media, health care facility, family, friends)?
- Which TB care services you knew before you were diagnosed?
- What TB treatment you knew before you were diagnosed?
 - Where did you get the information about TB treatment (Media, health care facility, family, and friends)?

4. Explain to me why it took you long to seek care despite feeling unwell for some time?

Prompts

- Please share some personal challenges that made you to take so long to seek care
 - What were your beliefs about TB care services
 - What were your attitudes towards TB care services

- What were your perceptions about TB care services
- Is there stigma associated with TB in your family and community
- What are the myths and misconceptions about TB in your family and community
- What are family constrains to TB care services
- What are community constrains to TB care services
- What are religious constrains to TB care services
- What are health facility constrains to TB care services
 - Do you think the health care facility is far?
 - Did you expect bad services from the health professionals?

5. What motivated you to seek TB care services?

Prompts

- What are the personal factors
- What are the family factors
- What are the community factors
- What are the health care facility/personnel factors



Appendix 4: Interview Guide (siSwati Version)

LUHLELO LWEMIBUTO: Longenele lucwaningo

6. Ngicela ungitjele kafishane ngawe?

Tinsita

- Ligana mesibongo
- Iminyaka
- Bulili
- Sigaba sekutsafwa
- Inombolo yebantwana lonabo
- Sigaba lesisetulu lofike kuso ngemfundvo
- Uhlala khashane kanganani nalomtfolamphilo?

7. Ngicela ungitjele ngendlela lowatfola ngayo kutsi unalesifo seTB?

Tinsita

- Watfola nini kutsi unalesifo (Inyanga nemnyaka)?
- Watfolakala kuwuphi umtfolamphilo (Ligama lemtfolamphilo)?
- Yini lokwabanga kutsi ute ufune kuyopopola iTB?

8. Ngicela ungichazele kutsi lobokwati ngeTB ngaphambi kwekube utfolakale kutsi unayo?

Ngingabekisa ngekutsi itselelwana kanjani

- Ngutimphi timphawu teTB bewutati ngaphambi kwekube utfolakale unayo?
 - Ngabe weva kuphi ngaletimphawu (Tinhlelo tetindzaba ngekwelulukana kwato, emtfolamphilo, ekhaya, kubangani)?
- Nguluphi lusito lweTB bewulati ngaphambi kwekube utfolakale unayo?
- Nguyiphi indlela yekwelapha iTB bewuyati ngaphambi kwekube utfolakale unayo?
 - Walutfolaphi lwati ngekwelashwa kweTB (Tinhlelo tetindzaba ngekwelulukana kwato, emtfolamphilo, ekhaya, kubangani)?

9. Ngitawucela ungichazele kutsi yini lekwentse kutsi utsatse sikhatsi lesidze kufuna lusito ekubeni besewuvene utiva ubutsakatsaka emtimbeni?

Tinsita

- Ngingacela kutsi uchaze kabanti ngalokuphatselene nawe lebekukuvimba kutsi angafuni lusito masinyane
 - Yini inkholelo yakho mayelana nelusito lweTB
 - Bewutitsatsa nome ulemukela kanjani lusito lolukhona ngeTB
 - Wena uyibuka ngaluphi luhlangotsi iTB
- Ingabe ekhaya nome emangweni wangakini kukhona yini kucwaya lokukhona mayelana neTB
- Ngabe yini tinkholelo tsite letifananiswa noma letimataniiswa neTB letikhona ekhaya nobe emmangweni wangakini
- Ngabe kukhona kucinzeteleka tsite lenibhekene nabo ekhaya lobubanga kutsi kube lukhuni kutfole lusito ngeTB.
- Ngabe kukhona kucinzeteleka tsite lenibhekene nabo njengemango lobubanga kutsi kube lukhuni kutfole lusito ngeTB.
- Ngabe kukhona kucinzeteleka tsite ngetenkholo lokubanga kutsi kube lukhuni kutfole lusito ngeTB.
- Ngabe kukhona kucinzeteleka tsite ngenkholo lokubanga kutsi kube lukhuni kutfole lusito ngeTB.
 - Engabe lomkholo ukhashane yini ngekubuka kwakho?
 - Uke wakubanga kutsi tisebenti tetemphilo tingahle tikuphatse kabi?

10. Yini lekukhutsate kutsi ute ufune lusito ngeTB?

Tinsita

- Yini imbangangela lephatselene nawe cobo?
- Yini timbangangela letifaka ekhatsi umndeni wakho?
- Yini timbangangela letifaka ekhatsi ummango wangakini?
- Yini timbangangela letifaka ekhatsi tisebenti tetemphilo?

Appendix 5: Consent Form (English Version)



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

CONSENT FORM

Research Title: An exploration of factors that underlie late presentation of patients into TB care services in the Hhohho region of the Kingdom of Eswatini.

The study has been described to me in a language that I understand to my satisfaction. My questions and concerns about the study have been answered. I understand my part in the research study and I agree to participate voluntarily out of my free will. Confidentiality has been assured and I understand that my identity will not be shared with anyone. I understand that I may withdraw from the research at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

Participant's name.....

Participant's signature.....

Date.....

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville 7535
Tel: 021 959 4111
E-mail: research-ethics@uwc.ac.za

Appendix 6: Consent Form (siSwati Version)



UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

Consent Form (siSwati Version): SIFAKAZELO SESIVUMELWANO

Sihloko salolucwaningo : Kutfola kabanti tizatfu letibangela bantfu kutsi baphute kufuna lusito mayelana nesifo sesifuba sengati esifundzeni sakaHhohho eveni laseSwatini.

Ngichazelwe kabanti ngalolucwaningo ngelulwimi lengiluvisisa kahle. Ngiphendvuleke ngalokwanele imibuto lebenginayo nalapho bengidzinga kuchazelwa kabanti khona ngalolucwaningo. Ngicondzisisa kahle kutsi kusho kutsini kuba yincenye yalolucwaningo futsi ngiyavuma kuba yincenye yalo ngaphandle kwekuphococeleka. Ngicondza kahle kutsi imininingwane lechaza mine angeke ikhishelwe ngaphandle kwalolucwaningo nekutsi itawugcinwa ifihlakele. Ngiyacondza kahle kutsi ngingakhetsa kuphuma ekubeni yincenye yalolucwaningo nome nini ngaphandle kwekuveta tizatfu futsi ngaphandle kwekwesaba kuvimbeleka ngatindlela tsite ekutseni ngitfole lusito ngaphambilini.

___ Ngiyavuma kutsi kutfwetjulwe livi lami kulengcoco yalolucwaningo.

___ Angivumi kutsi kutfwetjulwe livi lami kulengcoco yalolucwaningo.

Libito nesibongo.....

Sayina Lapha.....

Lusuku.....

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville 7535
Tel: 021 959 4111
E-mail: research-ethics@uwc.ac.za

Appendix 7: BMREC UWC Ethics Clearance



UNIVERSITY of the
WESTERN CAPE



07 April 2021

Dr ET Nyandoro
School of Public
Faculty of Community and Health Sciences

Ethics Reference Number: BM21/02/03

Project Title: An exploration of factors contributing to patient delay in seeking Tuberculosis care services in the Hhohho region of Eswatini.

Approval Period: 12 March 2021 – 12 March 2024

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

A handwritten signature in black ink, appearing to read 'Patricia Josias'.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

**Director: Research Development
University of the Western Cape
Private Bag X 17
Bellville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za**

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 8a: EHHRRB Ethics Approval



**ESWATINI
HEALTH AND HUMAN
RESEARCH REVIEW BOARD**
M BRANDZENI HOUSE, 3RD FLOOR, CHURCH STREET
P.O. BOX 5, MBABANE, ESWATINI

ONE YEAR RESEARCH PROTOCOL APPROVAL CERTIFICATE

BOARD REGISTRATION NUMBER	FWA 00026661/IRB 00011253									
PROTOCOL REFERENCE NUMBER	EHHRRB051/2021									
Type of review	Expedited	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Full Board	<input type="checkbox"/>					
Name of Organization	Master' Student									
Title of study	An exploration of factors contributing to patient delay in seeking Tuberculosis care services in the Hhohho region of Eswatini									
Protocol version	1.0									
Nature of application	New	<input checked="" type="checkbox"/>	Amendment	<input type="checkbox"/>	Renewal	<input type="checkbox"/>	Extension	<input type="checkbox"/>	CT updates	<input type="checkbox"/>
List of study sites	Dvokolwako Health Center									
Name of Principal Investigator	Dr. Eitsha Fmotsenda Nyandoro									
Names of Co- Investigators	N/A									
Names of steering committee members in the case of clinical trials	N/A									
Names of Data and Safety Committee members in the case of clinical trials	N/A									
Level of risk (Tick appropriate box)	Minimal	<input checked="" type="checkbox"/>	More than minimal	<input type="checkbox"/>	High	<input type="checkbox"/>				
Initial study Approval information	Approved	<input checked="" type="checkbox"/>	Study completion date	30/09/2021	Certificate expiry Date	07/10/2022				
Study renewal approval information	Renewal date	<input type="checkbox"/>	Study completion date		End date					
Study amendment approval information	Amendment date	<input type="checkbox"/>								
Study extension approval information	Extension date	<input type="checkbox"/>								
Signature of Chairperson										
Signing date	07/10/2021									
Secretariat Contact Details	Name of contact officers	Babazile Shongwe								
	Email address	ehhrrbeswatini@gmail.com								
	Telephone no.	(00268) 2404 7751/6039								



Appendix 8b: EHRRB Ethics Approval

APPROVAL CONDITIONS

Ref.	Conditions	Indication of conditions (tick appropriate box)				
		Yr 1	Yr 2	Yr 3	Yr 4	Yr 5
1	Implementation of approved version of protocol					
2	Provide a specific insurance cover certificate in respect of this particular study within 14 days of receiving this Ethics Clearance certificate					
3	Update information on adverse events both on the addendum and the informed consent form to include measures for addressing life threatening adverse events that occur at home.					
4	Reporting of adverse events within 5 days of occurrence					
5	Submission of progress reporting for multi-year studies					
6	Submission of end of project report (Hard copy)	✓				
7	Submission of end of project report (Soft copy)	✓				
	Submission of data sets	✓				

List of reviewed documents

Ref.	Documents	Reviewed documents (tick appropriate box)
1	Completed application form	✓
2	Cover letters	✓
3	Evidence of administrative permission to conduct the research by involved institutions/sites (where applicable)	✓
4	Detailed current resume or curriculum vitae of Principal Investigator/s including Principal investigators declaration	✓
5	Summary resume or biography for other investigator(s)	✓
6	Evidence of approval/rejection by other Ethics Committees, including comments and requested alterations to the protocol, where appropriate.	✓
7	Research protocol (see outline in Annex 1)	✓
8	Questionnaires and interview guides (with back-translated versions where applicable)	✓
9	Case report forms (CRFs), abstraction forms and other data collection tools	
10	Participant/subjects Information Statement(s) (where applicable)	
11	Informed consent form(s) including photographic and electronic media consent statements.	✓
12	Advertisements relevant to the study (where applicable)	
13	Source of funding and detailed budget breakdown including material and incentives to participants if applicable	✓
14	Notification form for adverse effects/events.	
15	Proof of payment	✓
16	Proof of insurance cover for research subjects in clinical trials or where applicable	
17	Any other special requirements should be stated, if applicable	N/A

RT

Appendix 9: Dvokolwako Health Centre TB Program Approval

LETTER TO SEEK PERMISSION TO RECRUIT PATIENTS FOR A RESEARCH STUDY

Plot 3/619

Extension 6 Moneni

Manzini eSwatini

August 20, 2021

The Senior Medical Officer

Dvokolwako Health Centre

P.O Box 141

Mliba

eSwatini



Approved to
Proceed as per
ETHELBY
Conditions

Ref: Request for Permission to Recruit Patients to Participate in a Research Study.

Dear Dr. Gule

I write to seek your permission to recruit patients to participate in my research study titled: exploration of factors contributing to patient delay in seeking Tuberculosis (TB) care services.

The patients to be included are those enrolled as late presenters into TB care services in the period January 2021 to December 2021 at Dvokolwako health centre. The patients should be aged above eighteen years and diagnosed of pulmonary TB.

The study is done as part of Masters in Public Health studies with the University Of Western Cape School Of Public Health.

Your assistance will be greatly appreciated.

Yours sincerely

Dr. Elisha Tipotenda Nyandoro.

