

**UNDERSTANDING FACTORS ASSOCIATED WITH LOW TUBERCULOSIS  
DETECTION IN LOW RESOURCES SETTINGS: A MIXED-METHOD STUDY IN THE  
KINGDOM OF LESOTHO**

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## **Understanding Factors Associated with Low Tuberculosis Detection in Low Resources**

### **Settings: A Mixed-Method Study in the Kingdom of Lesotho**

#### **Abstract**

**Background:** Lesotho has one of the highest tuberculosis incidence rates globally. Yet, according to a new World Health Organization's report, tuberculosis case finding remains low despite government efforts to improve primary health care and significant multilateral and bilateral funding for tuberculosis.

**Methods:** We used a convergent mixed-method approach to study gaps in the tuberculosis care cascade and factors associated with the low tuberculosis case detection in Lesotho's Berea and Khubetsoana regions from March to August 2018. The steps of the tuberculosis care cascade include screening, diagnosis, initiation of treatment, and completion of treatment. We collected data on the number of patients completing the tuberculosis care cascade from one district hospital and one health center. The qualitative component consisted of interviews and focus group discussions with patients and health workers on elucidating the mechanisms associated with low case detection.

**Results:** The tuberculosis cascade evaluation showed that the completion was lowest for the initial step of the cascade, which is symptom screening. Out of an estimated 70,393 visitors to the two health facilities, only 22% of hospital visitors and 48% of visitors at the health center were asked about tuberculosis symptoms even though the policy is to screen every visitor. Only 2% of those screened at each facility said that they had tuberculosis symptoms, comprising 510 people. Among the 510 people with symptoms, 134 (26.2%) of them were diagnosed with tuberculosis. Among those diagnosed with TB, 133 (99%) were initiated on treatment, and the

treatment success rate was 70%. Lack of trained tuberculosis screeners at the health center, overall staff shortages, barriers faced by patients in accessing care, and internal mistrust of tuberculosis screening were identified as drivers of low tuberculosis case detection.

**Conclusion:** Tuberculosis screening finding in Berea and Khubetsoana is low. Lack of adequate infrastructure, skilled human resources, and long distances to the facilities for patients are significant factors behind the low tuberculosis case detection.

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## **Part 1: Understanding Factors Associated with Low Tuberculosis Detection in Low Resources Settings- Mixed method Study in the Kingdom of Lesotho**

### **1. Vignette**

On October 18, 2017, a 50-year-old man named Khotso started to experience cough, fever, night sweating, fatigue, and loss of appetite, followed by significant weight loss. Khotso was living with HIV and was on antiretroviral therapy (ART). He lived in a village in Lesotho's rural mountains. He walked three hours on foot through mountainous terrain to reach the nearest health facility, the Motete Health Center. The Motete Health Center is three hours drive from Seboche Hospital, the nearest hospital. Khotso arrived at the health center at around 10:30 am. It was Monday morning, and many patients were waiting at the facility. After waiting for four hours, he was seen by a nurse. While she suspected tuberculosis, health centers in Lesotho do not have an internal diagnostic capacity for TB. Health facility staff must send samples to the district hospital for examination, and transportation is only provided once a week on Friday. There is no way to store or transport samples. As a result, the health center can only collect samples from patients on Fridays. Therefore, the nurse sent Khotso home with antipyretics and multivitamins and asked him to come back to the clinic four days later (on Friday). Every TB suspect who presents to the clinic on a day other than Friday must return to the health center the following Friday to provide a sample. Khotso was very unhappy, and he was frail. He returned home after four hours on a horse ride, and by the time he arrived home, it was very late, and he was very sick. He started vomiting everything that he ingested, including his ART medication.

Khotso is the father of five children, and he is the sole breadwinner for the family. His wife died of tuberculosis the year before he visited the health center. Khotso's wife had been seriously sick for a year and a half. Initially, she was taking medication from traditional doctors

for around six months. Later her condition gradually worsened, and she went to the Motete Health Center, and they told her the problem was tuberculosis. However, after taking tuberculosis treatment for three months, she could not continue due to excessive vomiting, and she stopped the medication for eight months. Her condition deteriorated, and her family took her to Seboche Hospital, and she was diagnosed with multidrug-resistant tuberculosis (MDRTB). Unfortunately, she died before she could get treatment at the MDRTB hospital.

Khotso made a living through traditional subsistence farming and had a very small plot of land and few goats. However, he had been unable to work for almost two years due to his severe illness and his wife's illness. Khotso could not return to the health center on Friday as requested by the nurse because he was too ill. His situation grew dire, and a relative took him to be seen by a local traditional healer because it was close, cheaper, and accessible to him. The healer provided Khotso with traditional medicine for three weeks, and his health improved for around one month.

After five months, he suddenly vomited massive amounts of blood, and his relative took him back to the Motete Health Center on horseback. His condition was severe, and the facility told them to go to Seboche Hospital. He rented a car—an expense equal to three months of his family's income—and finally, he arrived at the district hospital. He was admitted to the hospital and stayed for two weeks. The laboratory personnel conducted a sputum test using smear microscopy because the GeneXpert machine, which is more sensitive but cannot detect resistance to rifampicin, was not functional. The smear microscopy test was positive, but smear microscopy does not provide any information about drug resistance. Khotso, therefore, started treatment for drug-sensitive tuberculosis. After three months, he went to the Motete Health Center for a checkup test for tuberculosis. Khotso had not improved, and the laboratory result



came back after two weeks; it was still positive for tuberculosis, and his viral load test for HIV was very high (78000 copies/ml). The nurse suspected drug resistance to antiretroviral therapy (ART) and possibly MDRTB after seeing the result. He started to vomit continuously for anything he swallowed. He stopped taking all his medication, including tuberculosis medications and ART, for the next three months.

Two of his children also started to cough and experienced a loss of appetite, and their condition gradually deteriorated. After four months of not taking any medication, he went back to the Motete Health Center with his two children. He was very emaciated; his weight was only 25kg. Sputum and blood were collected and sent to the district laboratory hospital. The results returned in two weeks. All three had developed drug-resistant tuberculosis, and they were all referred to Botsabelo MDRTB Hospital. Botsabelo Hospital is the only MDRTB referral hospital in Lesotho, run by an international NGO called Partners In Health (PIH) and the Ministry of Health. Khotso and his children started second-line treatment for MDRTB, and Khotso's ART regimen switched to second-line medications after the HIV resistance test results showed severe resistance to almost all of the first-line ART treatment. Khotso could not tolerate the combination of second-line ART and MDR-TB treatment. He died one month after the start of the MDR-TB medications. Fortunately, Khotso's two children's condition gradually improved, and both children completed their treatment after 24 months of continuous follow-up. They had lost their mother and father, and they became orphans because of tuberculosis. The scar of the disease will remain with them forever. The history of Khotso is the story of many tuberculosis patients in the rural kingdom of Lesotho.

Who will be blamed for all the suffering of these patients? Is it the fault of the patient or the health system of Lesotho? What are the reasons for the high burden of disease in a community?

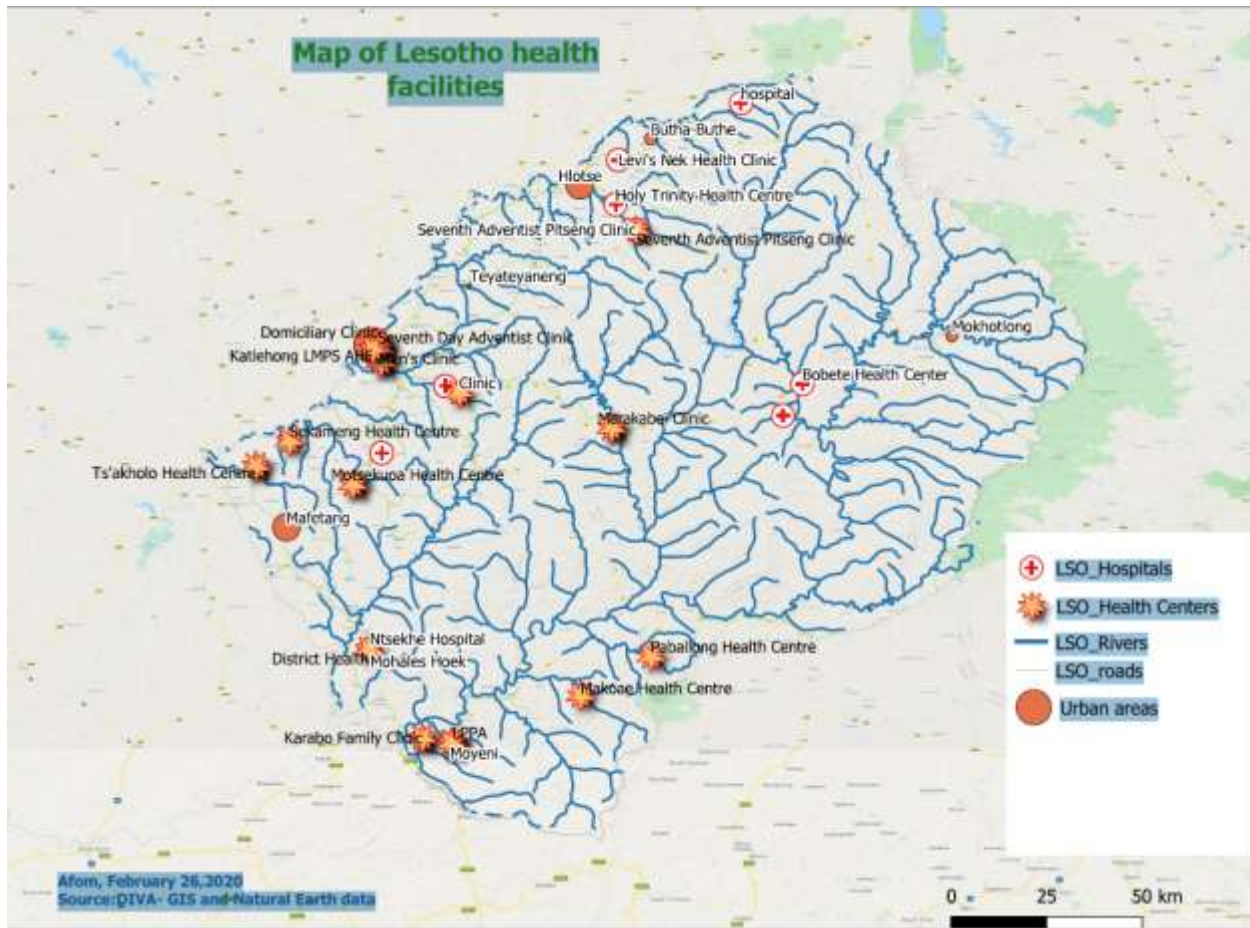


Figure 1: Map of Lesotho health facilities

## 2. History of tuberculosis in the health system of Lesotho

In the pre-colonization era, the people of Lesotho were known as the Basotho and lived in the mountainous region they inhabit now as well as the large plains of what is now Orange Free State, which is home to an enormous gold reef. The Basotho fought various tribes for land prior to 1810 and was finally consolidated by King Moshoeshoe I as Lesotho. Subsequently, the Basotho fought aggressive wars against incursions against the Boer trekkers.<sup>1</sup> Throughout the fighting, the Basotho slowly lost their main arable land and retreated into the country's

mountainous region. The encroaching Boers surrounded the Kingdom. The chief of the Kingdom of Lesotho asked for the British colonial administration to stop the Boer trekker invitation. In 1868, the kingdom Lesotho was occupied by the British administration.<sup>2</sup> The Boer incursions left the Basotho with little land, which was not fertile enough to produce enough crops for their annual food supply.

Moreover, there was not enough land for grazing their animals. The Basotho were vulnerable to famine and different diseases. The people became reliant on the incomes of cross-border work in diamond and gold mining in South Africa.<sup>2</sup> Ironically, much of the mining work was the Orange Free State, formerly Basutoland. By 1910, led by Afrikaans speaking Boers, South Africa won their independence from the United Kingdom. The leadership oppressed indigenous Africans, whether in South Africa or migrants from Lesotho and elsewhere.

Before 1906, there were no sources indicating the prevalence of tuberculosis in Basutoland. Yet, tuberculosis was famously a disease of mine workers. In 1912, a tuberculin test survey was conducted in Lesotho, and tuberculosis infection was more prevalent among adult males who traveled to South Africa for mining work (36%) than among adult males who did not travel outside Lesotho work (15.5%).<sup>3</sup> Extractive industries central to the Boer regime and the antecedent to even more restricted formal apartheid laws of 1948 resulted in overcrowding of Black Africans—whether South African or Basotho – in working living conditions in the mining industry. In addition, loss of farm land at home resulted in famine conditions with exacerbated the spread of tuberculosis when the miners returned home to Lesotho.<sup>3</sup>

Neither the government of Lesotho nor the British colonial office paid attention to the tuberculosis problem until 1957 when WHO technical experts conducted a tuberculosis survey. That year, the survey found a tuberculosis disease prevalence of 0.5% of the population.<sup>4</sup>

Following the survey, the British colonial administration started to pay attention and launched tuberculosis testing and treatment. Following WHO recommendations, the administration began to use x-ray and sputum to test suspected TB cases. In 1967 and 1968, new tuberculosis services were established, including the initiation of data recording and mycobacterial culture and the founding of treatment centers.<sup>4</sup> However, continuous disagreement between WHO and the British colonial administration over access to services and treatment centers increased until the WHO Africa region and United Kingdom head office resolved the dispute. Following independence, the small improvements in tuberculosis services were not maintained because of operational challenges. Staff recruitment started to decline, which affected the tuberculosis program significantly.<sup>4</sup> Lesotho's initial tuberculosis control program rapidly declined partly due to a lack of socio- cultural understanding of the local context of the technical experts from WHO and partly due to inadequate planning and coordination between Maseru central lab and district facilities.<sup>4</sup> With an ineffective tuberculosis program in place, Lesotho's health system was strongly affected by a double burden of HIV and tuberculosis.<sup>4</sup> With little territory, limited resources, and a heavy dependence on the remittances of migrant labor to the South African mines, HIV and tuberculosis have rampaged across Lesotho, now home to the highest tuberculosis incidence and among the highest rates of TB/HIV coinfection, according to the WHO 2020 Global Tuberculosis report.<sup>5</sup> The prevalence of HIV among miners is four times that of the general population.<sup>6</sup> In some mining centers in South Africa, around two-thirds of the people who were working in the mining had HIV.<sup>6</sup>

The colonizers' exploitation of resources and destruction of the nominal health system they created during independence built a massive gap in the health system of developing countries such as Lesotho.<sup>1</sup> The lack of resources and legacy of weak leadership inherited from

the colonizers was also a stumbling block for strengthening health systems in developing countries. Colonial powers also continued to interfere with the internal affairs of the nations after independence and ultimately paralyzed the socio-economic-political and cultural context of colonized countries such as Lesotho.<sup>7</sup>

### **3. The current state of tuberculosis care in Lesotho**

Currently, the health system of Lesotho is affected by a double burden of HIV and tuberculosis. Like many other African countries, the health system of Lesotho has been significantly influenced by a shortage of health workforce, lack of adequate supplies, and depletion of resources to respond to the population's health demands.<sup>8</sup> There are limited resources and a lack of alignment of the existing resources with the disease burden for the entire Basotho population. The incidence of tuberculosis in Lesotho is the highest globally, with a 654 per 100,000 population. The 2019 prevalence of multi-drug resistant tuberculosis (MDRTB) was 5.2 % among patients who have never been treated for TB before and 6.6% among patients previously treated for tuberculosis,<sup>5</sup> which is among the highest in sub-Saharan Africa. In Lesotho, the incidence of HIV among tuberculosis patients is 62%, which is among the highest in the world.<sup>5</sup> Lesotho has the second-highest HIV prevalence globally, with 25.6% of adults infected with HIV and an HIV incidence of 1.1%, according to the Lesotho Population-based HIV Impact Assessment (LePHIA) report 2017.<sup>9</sup> In Lesotho, there are around 1140 HIV-negative people and 840 people living with HIV dying annually of tuberculosis.<sup>5</sup>

According to the 2020 WHO report, only 51% of Lesotho's total estimated tuberculosis cases are diagnosed.<sup>5</sup> Therefore, 49% of tuberculosis patients are neither diagnosed nor treated in Lesotho. According to the 2014 Lesotho Demographic and Health Survey, 50.5% of men and

40.9% of women aged 15-49 exhibited tuberculosis symptoms and did not seek further evaluation or treatment.<sup>10</sup> This shows that part of the gap in tuberculosis detection may be because people with tuberculosis symptoms do not come to health facilities to seek medical care. Possible barriers to accessing tuberculosis services include lack of accessibility, affordability, and health services availability.<sup>11</sup> Also, the quality of available health services, availability of transport, and a patients' economic situation can significantly affect health-seeking behavior. These factors have resulted in low tuberculosis detection in Lesotho and may negatively impact the tuberculosis treatment program's outcome.

Lesotho's geographic location is very mountainous, and many places are hard to reach. It is challenging to provide health services to these populations who live in these hard-to-reach areas of Lesotho.<sup>12</sup> These areas are accessed by plane, especially during winter, because roads are impassable. There is a special department under the Ministry of Health of Lesotho called Lesotho Flying Doctors, who support these hard-to-reach health facilities through a plane. Lesotho Flying Doctors oversee some health centers in the highlands of Lesotho. Partners In Health also supports seven health facilities in these hard-to-reach areas in four districts of Lesotho.

The availability of diagnostic equipment, human resources, and a good supply chain is crucial for timely diagnosis and treatment. In Lesotho's hard-to-reach areas, weak patients may not be able to return to health facilities repeatedly to get services and receive their results. However, there are no tuberculosis diagnostic services in many health centers of Lesotho, including those in hard-to-reach areas, making tuberculosis challenging.<sup>12</sup> Sputum samples are transported to the district hospitals for diagnosis. The turnaround time for results is long due to

the lack of continuous access to transport. The patients get results late, and ultimately the outcome of treatment is affected.<sup>12</sup>

Migrant workers from Lesotho encounter a particular challenge in accessing tuberculosis care.<sup>13</sup> Many workers migrate to South Africa to search for mining and agriculture jobs. In South Africa, access to medical services is very limited for migrant workers, and medical services' affordability is a big problem. Workers are reluctant to tell their employers about their illness, fearing that they might be dismissed from work.<sup>13</sup> Moreover, in the mining sector, it is hard to access adequate diagnostic and treatment services.<sup>13</sup> Most of the cases among people working in the mining industry are diagnosed late, and treatment outcomes are terrible.<sup>13</sup> Some patients die, and some also develop drug-resistant tuberculosis, which is very hard to treat. Moreover, the delay in accessing treatment results in ongoing tuberculosis transmission in the mining sector communities and beyond.<sup>13</sup>

#### **4. The economic influences on tuberculosis service delivery in Lesotho**

The economic factors that shape tuberculosis's persistence in Lesotho and beyond are vital for better strategic designing and intervention of tuberculosis elimination in Lesotho and beyond. The Kingdom of Lesotho is a kingdom in Southern Africa, enclaved in South Africa.<sup>14</sup> Lesotho has around 2.1 million inhabitants, with a GDP of \$ 1299 with a Gini coefficient of 44.6, meaning that Lesotho has an unequal wealth distribution.<sup>14</sup> However, relatively, the Gini coefficient of Lesotho is better than the other Southern African countries. Lesotho is classified as a lower-middle-income country.<sup>14</sup> Economically, the Basotho depend on traditional subsistence farming, mining industries, and small business. According to the recent 2020 World Bank report,

the national rate of unemployment is 23.6%.<sup>14</sup> Around 75% of Basotho live in a rural area.<sup>14</sup> There is high inequality between rural and urban, rich and poor communities in Lesotho.<sup>14</sup>

The burden of tuberculosis affects the economy both through its impact on affected families and on governments' national budgets.<sup>15</sup> The burden of tuberculosis is devastating to families and the country's economy because it attacks the economically productive adult population. The economic impact of tuberculosis on a country is huge because it affects those of reproductive age. The burden of the diseases can cause a massive loss on the economy of any country, particularly developing countries.<sup>15</sup> When working adults get tuberculosis, because of their physical weakness, they do not go to work for a long time, affecting the family and its finances. Many patients also lose their jobs after they get sick with tuberculosis, and they become a burden on their families and can also transmit the infection to their families.<sup>16</sup> The cost of tuberculosis diagnosis, treatment, and transport to visit health facilities can also be very high.<sup>15</sup>

Globally, poverty has been associated strongly with tuberculosis infection and poor patient treatment outcomes, affecting health-seeking behavior.<sup>17</sup> Tuberculosis disease worsens poverty by affecting patients and their family's ability to work, causing an overall loss of income in families.<sup>18</sup> Lack of money makes patients seek health services late.<sup>17</sup> The disease impacts most of the marginalized and vulnerable groups in society. The double burden of HIV and tuberculosis can expose patients and their families to financial upheaval.<sup>19</sup> Tuberculosis is a curable disease, and the available therapeutics are sufficient to combat the diseases—the epidemiologic trends in tuberculosis are directly linked to societies' changing political and economic interests. Political and economic interests shape the persistence of tuberculosis in Lesotho and Southern Africa.<sup>19</sup>

In the 1920s, many rural farmers migrated to urban areas to work in the mining and agriculture sectors. As a consequence of drought and there was a shortage of food in the area.



Moreover, there was a rapid expansion of industries in South Africa.<sup>20</sup> Severe economic adversities and people's movement from the southern African countries such as Lesotho, Eswatini, and Mozambique to areas with mining industries led to the spread of tuberculosis throughout the entire region. The urban poor lived in overcrowded slums with shortages of food and environmental hygiene, exposing the communities to tuberculosis, diarrhea, and malnutrition. It was expensive to keep people affected by tuberculosis in the sanatorium, and mining authorities repatriated the African workers to their homes. The repatriation of tuberculosis patients from mining facilities to their homes in the 1920s contributed significantly to the spread of tuberculosis in Southern Africa.<sup>20</sup> Many families died due to tuberculosis. However, the British colonizers had justified their actions by saying that "Africans dislike being placed in the hospital and preferred returning to their own homes and treated by their native doctors when they became ill."<sup>20</sup> Around 60% of the repatriated tuberculosis patients died within two years after returning to their homes.<sup>20</sup> Furthermore, in the 1930s, there was a severe drought and economic depression in Southern Africa and globally. Since many people lost their livestock during the great depression of 1930, animal products like meat and milk products were deficient, which led to malnutrition for many people, especially children.

In the 1970s, around 60% of the mineworkers in South Africa were from neighboring countries such as Lesotho, Mozambique, and Eswatini.<sup>13</sup> According to a study conducted by Basu et al. in 2009, around 230,000 men migrated to South Africa from the neighboring countries to work in the mining sector each year. Over 50,000 Basotho men were migrating to South Africa each year to work in the mining sector, and around 60% of them returned home once a month.<sup>21</sup> The high movement of people in the mining industry hinders care, diagnosis, and adherence to tuberculosis medication. The prevalence of tuberculosis in the mining sector in

South Africa is one of the highest reported globally.<sup>21</sup> The prevalence of tuberculosis in the South Africa mining sector is estimated at 7,000 per 100,000 miners in South Africa and around 1,000 per 100,000 miners in other southern African countries.<sup>21</sup> The risk of tuberculosis infection among miners is ten times as high, and the risk of death 3.6 times as high as in the general population.<sup>21</sup> The people who work in the mining industry experience substandard treatment and follow-up and a high drop off from care, leading to the development of resistant tuberculosis.<sup>6</sup> In Lesotho, around a third of the incidence of MDR-TB and extensive drug-resistant tuberculosis (XDR-TB) were among miners and ex-miners.<sup>6</sup>

Miners work for long hours in underground trenches with overcrowding and less exposure to sunlight, and transmission among coworkers is very high. HIV infection and silica dust exposure increase TB disease risk, affecting approximately 25 % of the miners.<sup>13</sup> These Basotho that work in South Africa leave their families, crossing the border to South Africa. They hide their health problems because they fear losing their jobs if their employers know about their medical conditions. And also, they do not want to go back home because they may lose their position permanently.

The social and economic changes in Southern Africa and Lesotho due to the expansion of industrialization, agricultural and mining sectors have shaped the spread and persistence of tuberculosis in the region. People migrated to towns to search for jobs because they lost their fertile land. The change in the Basotho people's socioeconomic situation resulted in a significant increase in tuberculosis spread among the population. The social and economic conditions shaped the persistence of tuberculosis in the region. Tuberculosis is a curable disease, and the available measures are adequate to tackle tuberculosis progression successfully. Why does the

challenge of tuberculosis persist as a dangerous and deadly disease despite the availability of technologies to treat tuberculosis effectively?

## **5. Social determinants of tuberculosis in Lesotho**

The social determinants of health are environmental conditions that create ill health in the population. These conditions are environments where people are born, live, and grow. These environments are socially constructed and influenced by the vast gaps in wealth distribution.<sup>22</sup> There is a greater vulnerability to illnesses and diseases as a result of adverse economic conditions.<sup>22</sup> The inequity created within societies is systematic and developed by social norms, policies, and practices.<sup>22</sup> This inequality creates the inequitable distribution of power, wealth, and resources.<sup>22</sup>

In his theory of social suffering, Kleinman explains that socioeconomic and sociopolitical forces shape disease distribution and outcomes. Structural violence and deep poverty create conditions in which tuberculosis can flourish.<sup>23</sup> The pain and suffering that stem from untreated infections are not limited to the patients but extend to families and social networks as a whole.<sup>23</sup> Mukherjee notes that health disparities between the rich and the poor will not be eradicated without attending fundamental social forces such as poverty, housing, unemployment, and lack of access to health services.<sup>24</sup> Premature death and ill health result from the fundamental social structural forces in society.<sup>24</sup> The distribution and outcome of infectious diseases between the rich and poor communities and between wealthy and impoverished countries are broad. This disparity is due to the social, economic, and political inequalities among communities.<sup>25</sup>

Dubos stated that “Tuberculosis is a social disease; its understanding demands that the impact of social and economic factors on the individual to be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body.”<sup>26</sup> Tuberculosis kills millions of people and disproportionately affects individuals in impoverished and vulnerable communities. The lack of sharing of resources and failure to appreciate the complex social and economic aspects of health and disease contributes to tuberculosis disease's persistence in developing countries. This amounts to willful neglect of a disease that disproportionately the poor and disadvantaged segments of the population.<sup>27</sup> Early identification of tuberculosis saves lives, money, and time. The lack of resources results in more loss of life from tuberculosis cases. As Bethune stated, “There is a rich man’s tuberculosis and a poor man’s tuberculosis. The rich man recovers, and the poor man dies because he/she cannot afford to live”.<sup>28</sup> The lack of access to food, housing, and health services results in impoverished people not getting treatment or preventing tuberculosis.

Under the British colonial rule, medical officers in the British administration blamed African people for their higher susceptibility to the disease without understanding how the living conditions of the Black African people differed from those of the white colonizers; specific examples included impoverishment, overcrowding, and malnutrition. With the harsh living conditions imposed by the white employers (e.g., low wages and poor working environments), African people were forced to live in overcrowded settings and with severe malnutrition.<sup>29</sup>

Poverty creates an optimum environment for tuberculosis to flourish and become more deadly and challenging to control.<sup>30</sup> Widespread impoverishment in communities increases the probability of getting an infection and tuberculosis's progression into an advanced stage. Also, poverty limits access to quality healthcare services and the ability to adhere to treatment. Lack of

money for transport, drugs, food and diagnostic fees creates conditions where patients cannot receive timely medical care, and delays are associated with illness progression to the most advanced stage.<sup>30</sup> Treatment completion is severely hampered in the face of medication stock-outs and lack of money for transport or for purchasing drugs.<sup>30</sup> Creating awareness of the root cause of tuberculosis diseases and providing social support for those who need it are important preventive measures to fight the tuberculosis epidemic.<sup>31</sup> Interventions should put the patient and community first and be delivered in an inclusive and participatory approach. Social and economic changes in societies can significantly reverse the incidence of tuberculosis in the world.

The socioeconomic conditions of different groups in a society significantly affect the distribution and incidence of tuberculosis.<sup>32</sup> The colonizers in Southern Africa, including the British, imposed low-wage policies and limited land access for the Black African farmers to maximize extractive industry. Also, there was a persistent drought in Southern Africa. The mortality rate of tuberculosis among the Black Africans working in the mining industry was three times higher than the domestic workers because domestic workers were getting better access to food and living in less crowded houses.<sup>33</sup>

The rising tide of tuberculosis among Africans in 1948 also corresponded with the stricter imposition of apartheid laws limiting movement, employment, and access to diagnosis and treatment access.<sup>33</sup> There was a shortage of beds for isolation and a lack of funds for treatment. As a result of delayed treatment, treatment outcomes were poor, and many patients whose lives might have saved were dying from tuberculosis. Failure to isolate patients with tuberculosis increased transmission within communities. Most of the patients were the primary breadwinners

for their families, and the families were exposed to economic hardship and risk of getting tuberculosis. Many people were dying from the same families.<sup>33</sup>

While considering the health and societal inequality, social interventions should target the vulnerable groups who have a higher risk for diseases and a higher probability of being excluded from the health services.<sup>30</sup> The vast majority of tuberculosis cases are from vulnerable parts of communities. Global tuberculosis control cannot succeed unless we reach these marginalized populations with quality health services and without financial hardship. Moreover, the lack of transport, food, housing, and employment affects patients' lives, well-being, and families. As a result, this leads to the spread of the infection. To address the social determinants, health policy alone cannot eliminate tuberculosis; tuberculosis would have stopped half-century ago if it could. In this case, social, medical, and political policies are inseparable.<sup>23</sup> The international community needs to align our medical, social, and political policies and strategies to eliminate tuberculosis from the world.

## **6. Implications of delayed diagnosis and treatment of tuberculosis**

Early diagnosis and treatment results in improve tuberculosis treatment success and minimizes community spread.<sup>34</sup> People in whom tuberculosis diagnosis and treatment are delayed are more likely to have complications such as chronic lung disease and hemoptysis (like Khotso). These chronic and acute, chronic complications of tuberculosis have killed millions of people throughout the world for two centuries. Thus, a primary reason for the slow progress against tuberculosis is incomplete and late diagnosis and delays in putting patients on effective treatment.<sup>35</sup> Most transmission occurs after symptoms start and before the initiation of treatment.<sup>35</sup> The risk of disease transmission increases as the time interval between the

tuberculosis first symptoms and treatment initiation increases. Thus, speedy diagnosis and treatment initiation is crucial for effective tuberculosis management.

Delays in tuberculosis diagnosis can occur both before and after the patient enters the health system.<sup>36</sup> Some of the reasons for care-seeking delays may be financial, geographical, or transportation barriers to accessing health care services.<sup>11</sup> After the patient enters the health systems, delayed diagnoses can occur due to lags in getting lab results and beginning treatment.<sup>36</sup> People with tuberculosis who visit health facilities may not get diagnosed during their first visit to make multiple visits to health facilities. At times, they are forced to seek help from multiple health facilities.

The diagnostic process may end up costing people with tuberculosis to lose a significant portion of their income. One study in Ethiopia showed that patients' medical and non-medical expenditures on tuberculosis care represented 31% and 42% of their monthly income, respectively.<sup>37</sup> These significant financial expenses severely affect the ability of patients to seek treatment services.<sup>37</sup> Additionally, more than a quarter of patients had to consult two or more health facilities for accessing diagnostic services within or outside their district.<sup>37</sup> As a consequence of the repeated visit to different health facilities, the financial burden on patients is enormous.<sup>34</sup> The delays in diagnosis lead to a higher mortality burden and an increased financial burden on health systems and communities.<sup>15</sup>

Studies from different countries in sub-Saharan Africa have identified factors contributing to delayed diagnosis and treatment. A study conducted by Yimer et al. in Ethiopia found that patients residing in rural areas have a three-fold increase in experiencing treatment delays when compared to patients living in urban settings.<sup>38</sup> The limited diagnostic resources and lack of trained personnel at the primary health facilities contributed to delayed tuberculosis

diagnosis compared to those who first visited hospitals.<sup>38</sup> Extrapulmonary tuberculosis is difficult to diagnose, and patients often had to return for several consultations with the same health personnel across multiple clinic visits to obtain a diagnosis.<sup>39</sup> A study from Ghana found that constraints to improving access to tuberculosis services included a shortage of adequately trained health workers, lack of health insurance coverage, lack of infrastructure, centralized health services, and lack of coordination between public and private health institutions.<sup>34</sup> Some studies also mention that cultural barriers like seeking traditional healers' treatment, in addition to limited accessibility, affordability, and quality of health care services, contribute to treatment delay.<sup>40</sup>

Substantial delays have been measured in both seeking care and after a person with tuberculosis enters the health system. A study conducted in Ghana showed that people with tuberculosis delayed seeking medical care an average of 59 days after symptom onset, while delay due to the health care system was, on average, 45 days.<sup>34</sup> A study conducted in Iran showed that the average delay from the start of tuberculosis symptoms to the initiation of treatment was 73 days.<sup>41</sup> The delays in tuberculosis diagnosis, treatment, and follow-up were affected by socioeconomics, population distribution, diagnostic facilities, availability of health services, long distance to health facilities, and rural residence.<sup>41</sup> These findings are similar to the tuberculosis situation in Lesotho. Lack of tuberculosis diagnostics in the health facilities, geographical barriers, shortage of workforce, and patients' economic situation cause unnecessary delay of diagnosis and late enrollment on treatment.<sup>41</sup> Research conducted in Lesotho found that treatment initiation among people with rifampicin-resistant tuberculosis was only 60.6%.<sup>42</sup> The remaining 39.4% were either linked to care in the neighboring country South Africa or not diagnosed.<sup>42</sup>



## **7. The gaps that need to be fixed**

Tuberculosis is a preventable, treatable, and curable infectious disease.<sup>43</sup> The fast decline of tuberculosis deaths in many developed countries during the past several decades provides convincing proof that eliminating the world's tuberculosis threat is possible.<sup>43</sup> There has been a rapid expansion of tuberculosis screening, diagnosis, and treatment services over the last decades worldwide. However, current decline rates are less than half the annual reduction target of 4-5%, necessary to meet the WHO End TB Strategy goals.<sup>44</sup> There is a need to focus on the universal access of tuberculosis services and improve the quality of tuberculosis services along the care cascade to eliminate tuberculosis from the world.<sup>45</sup>

Evaluating the tuberculosis care cascade can help understand the gaps in tuberculosis service delivery.<sup>46</sup> Identifying points where patients may drop out of care is essential for planning the best strategic interventions to fix the tuberculosis program's gaps in Lesotho. A study conducted on the tuberculosis care cascade gaps in India's public sector estimated that 28% of all people with tuberculosis never accessed tuberculosis screening and that 16% of those who accessed tuberculosis screening and had the disease did not get diagnosed. A further 13% of those diagnosed with tuberculosis did not start treatment, and 14% of those who started on treatment did not complete their treatment (See figure 2).<sup>47</sup>

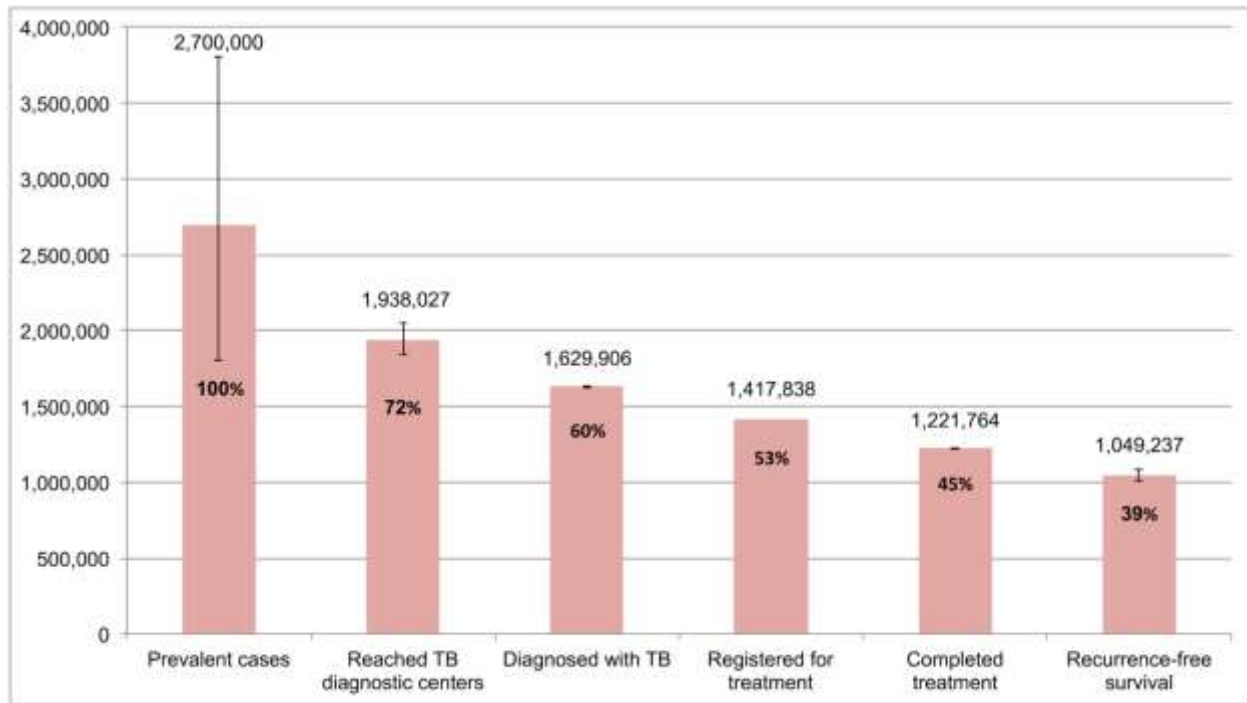


Figure 2: The cascade of care for tuberculosis in India's public sector, 2013. Reproduced from Subarraman et al. (reference 47) with permission from the authors.

A study conducted in South Africa, tuberculosis care cascade, showed that 5% of these people with tuberculosis never accessed testing, 13% out of those screened did not get a diagnosis, 12% out of those diagnosed did not start treatment, and 17% out of those started on treatment did not complete their treatment.<sup>48</sup> Moreover, the study conducted in the 30 high-tuberculosis-burden countries showed that 35% out of the people with TB did not receive a diagnosis, 5% out of those diagnosed with tuberculosis were not started on treatment, and 11% out of those started on treatment did not complete their treatment.<sup>49</sup>

We need to reach the missing tuberculosis patients, diagnose them, put them on treatment without delay, and assure their retention in treatment until they are cured. Tuberculosis is not transmissible after two weeks of the start of appropriate treatment.<sup>50</sup> Therefore, early diagnosis and early start of treatment for tuberculosis can save lives and prevent the spread of tuberculosis infection. Expanding active case-finding and putting every detected patient on treatment requires

sufficient staffing and resources. Tuberculosis control programs need to be equipped with the best diagnostic technology, and providing decentralized services is a key element to delivering modern tuberculosis care.<sup>51</sup>

The vast majority of poor people with tuberculosis neither have access to health services nor can afford health services.<sup>43</sup> The availability and distribution of testing facilities are not accessible to most impoverished patients. Based on the WHO report 2020, in Lesotho, 49% of people with tuberculosis disease are neither diagnosed nor treated.<sup>5</sup> The strategies to identify the most marginalized and vulnerable communities, such as people living with HIV, household contacts of tuberculosis, migrants and prisoners, mineworkers and their families, and ex-mineworkers, have critical importance for controlling tuberculosis worldwide.<sup>43</sup> Having reliable data and timely detection and management, and following up on tuberculosis cases helps prevent premature death and avoid transmission.<sup>52</sup> The ultimate goal of improved tuberculosis case detection is to reduce new infection and transmission and prevent avoidable mortality due to tuberculosis. Evidence-based approaches complemented by reliable and robust health information systems have critical significance for filling tuberculosis detection gaps.<sup>45</sup>

Tuberculosis case detection strategies should be based on the local health system context for effective program implementation. This approach can quickly identify any challenges in the care cascade. It will help identify and design quick and appropriate interventions.<sup>36</sup> Improving patient access to health services and encouraging people to use available health services can improve the overall tuberculosis program. Proper alignment between health service availability and patient health-seeking behaviors can improve tuberculosis detection and notifications.<sup>53</sup> Moreover, understanding barriers to access tuberculosis health care services should be the first step in designing a new implementation strategy for fixing the tuberculosis care cascade. The

tuberculosis cascade gaps can inform us of areas where patients might be lost.<sup>46</sup> Some of the critical steps that are needed to fix to fill the gaps of tuberculosis care cascade include:

***Reducing fear, stigma, and discrimination:*** Fear, stigma, and discrimination may be seen when families are concerned about impoverishing medical expenses, disease transmission, or sickness.<sup>54</sup> These factors substantial barriers to accessing health care and a cause of diagnostic delay and poor tuberculosis treatment outcomes.<sup>54</sup> Due to lack of support from family and friends, many tuberculosis patients faced social isolation. As a result, they hide their symptoms for a very long time and seek help once their condition reaches an advanced stage, at a point where it is harder to treat.

***Active case finding:*** Some people in Lesotho live in rural high mountainous areas, and access to tuberculosis care and diagnosis is limited.<sup>12</sup> Decentralization of diagnostic services and building proper referral systems is critical for access to tuberculosis services in rural communities.<sup>12</sup> In high-tuberculosis burden countries such as Lesotho, timely diagnosis of TB remains a significant challenge. To overcome the high burden of tuberculosis, as Harries et al. suggest that “resources for tuberculosis control should be prioritized to improve screening performance through an active case finding.”<sup>55</sup> The Lesotho National Tuberculosis program’s priority should be to find the missing cases of tuberculosis. Without finding the missing cases, the spread of tuberculosis will never end. It is challenging to control the tuberculosis epidemic even if we successfully cure every diagnosed tuberculosis patient. Following Yuen et al., “trying to eliminate tuberculosis without stopping transmission would be like trying to empty a basin full of water without first turning off the tap that fills it”.<sup>56</sup> Tuberculosis programs should prioritize reaching all the

missing tuberculosis cases and provide them an appropriate, effective, and efficient services along with all the steps of tuberculosis care cascade.

***Increased access to sensitive and rapid diagnostic tests:*** In Lesotho, tuberculosis services generally diagnose tuberculosis using GeneXpert MTB/RIF and x-ray. Patients with suspected tuberculosis submit sputum specimens to the health centers, sending them to the district hospital.<sup>12</sup> Patients are forced to report to the health facility several times to complete the tuberculosis evaluation. Repeated trips to the health facility result in lost wages and increased costs for transport and x-ray services.<sup>57</sup> In Lesotho, someone diagnosed with tuberculosis must provide two sputum samples for examination, and patients are usually asked to give the second bottle the next day. Increasing the availability of diagnostic capacity and the decentralization of testing to the peripheral health centers is essential for improving tuberculosis detection. The algorithm of tuberculosis screening should be considered when undertaking these active case finding interventions. Highly sensitive screening tests and precise confirmatory tests are crucial for early diagnosis and detection of tuberculosis.<sup>58</sup> Diagnosis is one of the main points where tuberculosis patients drop off due to several factors. Allocating enough resources to build the tuberculosis diagnostic system and robust supply chain management is critical for controlling the tuberculosis epidemics.

***Health information and monitoring system:*** Effective utilization of data at all levels is very critical for providing evidence-based decision-making to improve quality tuberculosis services.<sup>59</sup> Improving data synthesis, recording, storage, and data usage for strategic decision-making is vital for tuberculosis program implementation. It is essential to optimize data to address

programmatic gaps in tuberculosis service delivery.<sup>60</sup> The documentation of tuberculosis trends at national and sub-national levels and subsequent allocation of resources to cover the disease burden where the need is most critically important for controlling tuberculosis epidemics.<sup>52</sup> Reliable and disaggregated data is vital for quality patient services. Routine evaluation of the tuberculosis care cascade at all levels is crucial to address tuberculosis programmatic gaps in a timely fashion.<sup>60</sup>

***Providing universal access to social support:*** The adverse effect of tuberculosis's financial consequences on patients and their families damages patients' well-being and families.<sup>43</sup> Ensuring adequate shelter and a safe living environment, reliable food supply, and financial support provision through a cash transfer program for patients with limited resources can close the tuberculosis care cascade gaps.<sup>43</sup>

## **8. Conclusion**

Despite effective therapeutics for treating and preventing tuberculosis since the 1940s, tuberculosis has remained the deadliest infectious disease until COVID-19 surpassed it in 2020. Tuberculosis has disproportionately affected vulnerable and marginalized societies worldwide. Globally, there are vast gaps in the tuberculosis disease burden seen between the wealthy and impoverished countries and communities. The nature of the disease makes tuberculosis a social disease as much as a biomedical one. People who contract tuberculosis are primarily from economically and politically vulnerable communities. Halting the tuberculosis epidemic and stopping transmission is critically important to prevent the spread of new tuberculosis cases. Identifying tuberculosis cases and immediately putting them on treatment can effectively control

tuberculosis diseases. Building a resilient and robust health system is necessary to allow for adequate access to quality health services. Moreover, the provision of effective and efficient tuberculosis health services requires that patients are not exposed to financial hardship; this is critically significant for controlling and eliminating tuberculosis in Lesotho and beyond.

There are three key elements to stopping tuberculosis diseases. First, there must be adequate supplies, human resources, and health infrastructure. Second, the availability of resources at each health facility should be aligned with the burden of diseases and patient load in the catchment population. Third, tuberculosis primarily attacks the most economically and vulnerable segment of societies; thus, support for patients is a key instrument in fighting tuberculosis diseases.

To eradicate tuberculosis in Lesotho and beyond, we must demand equity and health as a human right for everyone in the world. The suffering of most susceptible and marginalized people, such as Khotso and his family, should come to an end. Developing countries, such as Lesotho, should work hard to align the availability of health resources with patient care-seeking through a patient-centered approach. Creating a patient-centered tuberculosis care cascade requires an analysis of all care service points: tuberculosis screening, diagnosis, treatment initiation, and treatment completion. Assessing the tuberculosis care cascade will help address programmatic gaps in care-seeking, diagnosis, and treatment.

## **Part 2: Understanding Factors Associated with Low Tuberculosis Detection in Low Resources Settings: A Mixed-Method Study in the Kingdom of Lesotho**

### **Introduction**

Globally, around 30 percent of people with tuberculosis (TB) are neither diagnosed nor treated for tuberculosis.<sup>5</sup> The incidence of tuberculosis in Lesotho is the highest globally, with a 654 per 100,000 population.<sup>5</sup> The prevalence of multi-drug resistant tuberculosis (MDR-TB) is 5.2 % among tuberculosis patients who have never been diagnosed with tuberculosis before and 6.6% among patients previously treated for tuberculosis, which is among the highest in sub-Saharan Africa.<sup>5</sup> In Lesotho, the tuberculosis detection rate is only 51%, meaning that nearly half of tuberculosis patients are neither diagnosed nor treated in Lesotho.<sup>5</sup> Undiagnosed tuberculosis can lead to the persistence of the disease and transmission of tuberculosis within families and communities.<sup>56</sup>

The timely detection of tuberculosis and putting people with tuberculosis on effective treatment immediately have paramount importance in controlling tuberculosis transmission.<sup>61</sup> However, in low-resource countries such as in Lesotho, tuberculosis diagnosis is mainly accomplished through passive case-finding. Patients come to the health facilities when they get sick with tuberculosis.<sup>35</sup> People who cannot access health care remain without a diagnosis.<sup>62</sup> A health system that relies on passive case-finding cannot stop tuberculosis transmission within communities.<sup>63</sup>

It is essential to examine the factors contributing to low tuberculosis diagnoses and stem the tide of tuberculosis in Lesotho. It is vital to understand the reasons for low tuberculosis detection and identify specific barriers to tuberculosis detection that can then be addressed. We conducted a mixed-method study to evaluate the tuberculosis diagnosis and treatment cascade



and understand the reasons for gaps in tuberculosis detection in Berea district, the Kingdom of Lesotho. This study is expected to help the Lesotho tuberculosis program design strategies to improve tuberculosis detection.

## **Methods**

### **Study setting**

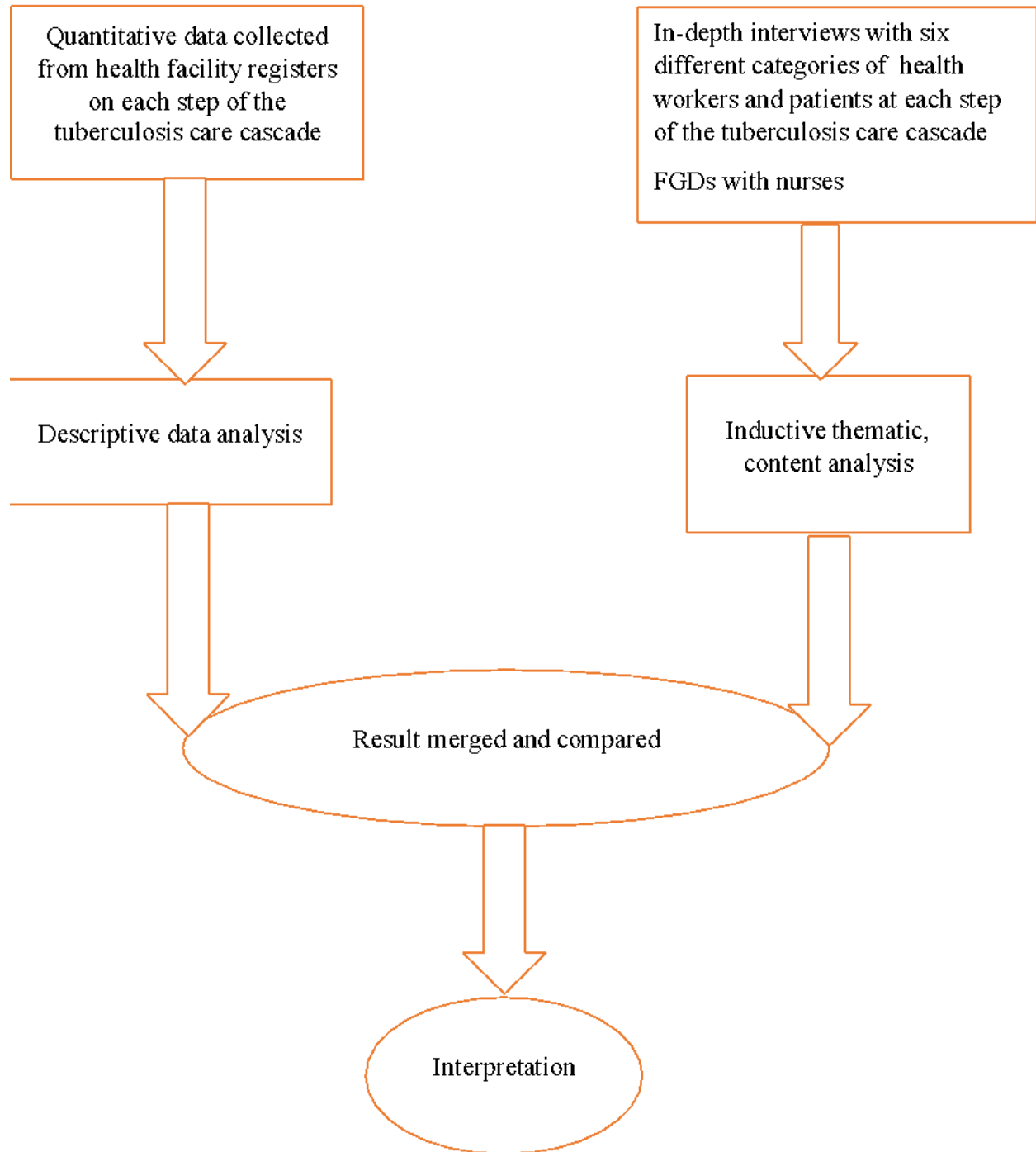
The study was conducted in Berea Hospital and Khubetsoana Health Center. Berea Hospital has located around 40 km from Maseru, the capital city of Lesotho. Khubetsoana Health Center is located near the outskirts of Maseru-the capital city of the Kingdom of Lesotho. In Lesotho, all visitors to a health center are supposed to be asked about tuberculosis symptoms. If they report symptoms, sputum should be collected for testing. People diagnosed with TB are initiated on treatment; treatment is free.

Berea Hospital has GeneXpert MTB/RIF, microscopy, and x-ray services for the diagnosis of tuberculosis. However, Khubetsoana Health Center does not have any diagnostic facilities. Sputum samples are transported in a scheduled manner twice a week to Maseru Queen Elizabeth II Hospital using a contracted service called Riders on Health. Laboratory results are sent back from the hospital laboratory to the health center. The health center then contacts patients and requests that they return to the health facility to discuss their results. The turnaround time for laboratory results is, on average, one week. Both Berea Hospital and Khubetsoana Health Center have tuberculosis treatment services.

## **Study Design**

In this study, we used a convergent mixed-method design in which qualitative and quantitative data were collected at the same time to complement and explain each other (Figure 3).<sup>64</sup> Qualitative and quantitative data were analyzed separately, and findings were then integrated for a deeper understanding of the barriers to completing the tuberculosis care cascade.

Figure 3: Convergent mixed-method design of the tuberculosis care cascade in Lesotho



### **Quantitative data collection**

We sought to assess the tuberculosis care cascade for all people who attended the two health facilities during March-August 2019. We estimated the total visits to each health center during this period based on monthly reports to the district health management office, summing up the total visits made to the outpatient department, ART clinic, antenatal clinic, under-five clinic, and family planning clinic. In addition, we collected aggregate data from health facility registers on people screened for TB symptoms, people who had sputum collected, sputum samples received and ran by the laboratory, people diagnosed with tuberculosis, and people starting and completing tuberculosis treatment.

### **Quantitative data analysis**

Given the study's descriptive nature, quantitative data were analyzed using descriptive statistics to understand the tuberculosis care cascade gaps.<sup>36</sup> The percentage of people completing each step in the care cascade was calculated by dividing the number of people who completed it by the number who should have completed it.

### **Qualitative data collection**

Purposeful sampling was used to identify participants for qualitative data collection.<sup>65</sup> A multi-vocal approach was ensured by including participants who had a wide variety of experiences with the tuberculosis care cascade in Lesotho. We conducted a single round of semi-structured in-depth interviews with 15 health workers; variation was ensured by purposefully sampling for various professional backgrounds (i.e., district health manager=1, tuberculosis program coordinators=2, village health workers=4, tuberculosis screeners=4, lab personnel=2,

and implementing partners=2). We also conducted a single round of semi-structured in-depth interviews with 24 patients; purposeful sampling ensured representation from patients at different points along the TB care cascade. Patients were recruited in relatively equal numbers at each point of care: (i.e., screening=6, diagnosis = 6, treatment = 6, completion of treatment=6). Two focus group discussions (FGDs) were conducted with nurses; each FGD included 7 participants for 14 participants.

All interviews and FGDs were conducted by local research assistants trained in qualitative data collection methods. According to the participant's stated preference, interviews took place in a private room at the study health facilities and were conducted in Sesotho or English. Interviews and FGDs lasted on average between 60 and 90 minutes and were audio-recorded with permission. Interviews followed a semi-structured interview guide that was developed for each population. For example, health worker interviews and FGDs with nurses addressed training, supervision, and practices related to diagnostic, testing, and screening activities and supplies. The patient interview guide covered topics related to care-seeking experiences, including access to services and treatment and barriers and facilitators to receiving appropriate diagnosis and care. Afom Andom (AA) and Hannah Gilbert (HG) regularly reviewed transcripts to monitor data quality and ensure fidelity to the research aims. Feedback was shared with the research assistants by AA, who conducted weekly calls to discuss interview quality and provide continuous training.

## **Qualitative data analysis**

We used an inductive, thematic content analysis approach to identify key concepts related to gaps in screening the tuberculosis cascade.<sup>66</sup> A subset of transcripts was open coded by Afom Adom (AA) to identify content-related barriers and facilitators to appropriate screening. Hannah Gilbert (HG) reviewed the open coding results; discrepancies were resolved through discussion, and the final concepts were developed into a draft codebook. The codebook was piloted and revised by AA and HG; the final codebook was used to code the dataset using Dedoose version 8 qualitative data management software. Coded data were analyzed inductively by AA to identify an initial set of descriptive themes labeled, defined, and supported with excerpts from the data. The initial draft of the thematic categories was created by AA, reviewed by HG, and revised by AA through an iterative process. The final products are a set of four thematic categories that explain low tuberculosis screening in health facilities.

## **Ethics approval and consent**

This study was approved by the National Health Research Ethics Committee (NH-REC) of the Kingdom of Lesotho (ID91-2020) and by Harvard Medical School, Human Study Committee (protocol: IRB20-0109). All people who participated in the interview and FGDs provided written informed consent.

## Results

### Care cascade indicators

Table 1 displays the numbers and percentages of people who completed each step a person must pass through to be diagnosed and treated for tuberculosis, i.e., being screened for symptoms, getting a tuberculosis test, starting treatment, and completing treatment. Only 22% percent of hospital visitors and 48% of visitors at the health center were asked about tuberculosis symptoms, of which 2% said they had symptoms. However, the completion of the other cascade was higher. Over 70% of people at both facilities had sputum collected if they were symptomatic and had lab results recorded. In addition, almost all patients diagnosed with tuberculosis initiated treatment. The proportion that completed treatment was 68% at Berea Hospital and 74% at Khubetsoana Health Center.

*Table 1: Tuberculosis care cascade for people attending Berea Hospital and Khubetsoana Health Center during March-August 2019*

Care cascade step	Berea Hospital		Khubetsoana Health Center	
	Number	(%)	Number	(%)
Health facility visits	45699		24694	
Symptom screens administered (% out of health facility visits)	9841	22%	11840	48%
People with symptoms (% out of symptom screens administered)	218	2%	292	2%
People with sputum collected (% out of people with symptoms)	205	94%	209	72%
People with sputum sent to the lab (% out of people with sputum collected)	190	93%	209	100%
People with lab results (% out of people with sputum sent to the lab)	144	76%	200	96%
People with bacteriologically confirmed TB (% out of people with lab results)	71	49%	24	12%
Total TB diagnoses of all forms	90		44	
People who started TB treatment (% of people with TB diagnosed)	90	100%	43	98%
People with successful treatment (% of people who started treatment)	61	68%	32	74%

The largest gaps that we found in the quantitative assessment in the care cascade were at the initial steps related to screening. Therefore, we focused on the qualitative analysis of this portion of the cascade.

## **Qualitative findings**

Our study's qualitative portion revealed four thematic categories that help explain the low percentage of visitors screened for tuberculosis and the low percentage reporting symptoms in the Berea district. The thematic categories are: (1) Overall staff shortage in health facilities; (2) Lack of adequate training for screeners; (3) Structural barriers create delays that shape patients' care priorities and (4) Internal mistrust among health care workers about the accuracy of screening leads to redundant procedures. Figure 4 shows how these emergent themes intersect.

### **1. Overall staff shortages in health facilities**

#### **A. Workforce is not tailored to health facility needs**

Health care worker participants in the qualitative study acknowledged that there were significant staffing gaps at health facilities across the district. They attributed these shortages in part to hiring policies at the central level, noting that staff distribution across different health facilities in the district was not based on the actual on-the-ground needs of a given clinic. Every clinic was allotted the same number of health care workers regardless of the volume of patients reflected in available data about their catchment population. There is a high expectation for the volume of work that health facilities are expected to perform. While new programs are continuously being added, there is no corresponding increase in the clinic's staff.



*“If there is ANC [antenatal clinic] care day, you may find that those mothers who have come for their service when they are pregnant, you may find that it is not easy for you to supervise /mentor that nurse on your program [TB program] because he/she is dealing with another patient. You understand that in this case, the nurse is working at ANC and also dealing with TB patients; the supervisor is not able to talk to her about the TB program while she is still busy helping patients at MCH [maternal-child health]. It is not easy to talk to the nurse because the work will be overwhelming”. [Health worker, ID# 1]*

*"This [allocation of human resources] was done by the Ministry of Health. I do not know what they were basing themselves on when they came up with it. Different clinics have different catchment areas. For example, Khubetsoana, Ha Koali, and Mahlatsa have different catchment areas, but the staffing is the same; it is like they decided that all clinics will have the same number of nurses without considering the catchment areas, performance indicators, OPD attendance, and how many people are on TB treatment. It is like the staffing is not based on our data. It is like they just decided that at the hospital, we need five doctors and 100 nurses just like that.” [Health worker, ID #2]*

One consequence of understaffing is that all staff are expected to provide all forms of care, regardless of their training or affiliation with a given program. Furthermore, as the staff is expected to swap roles to meet care demands continuously, individuals often work without taking any breaks. Staff whom complete night shifts cannot return home in the morning because nobody can take over their shift. When staff falls ill, they hesitate to take sick leave because they

know that this will result in a lack of coverage at the facility. As a result, the work-life balance of the staff is significantly compromised. Participants noted that this leads to burnout and negatively affects their ability to do their job.

*“Because of the population we are serving, we are still understaffed. For example, the TB [tuberculosis] department is at the back of this facility, those who are already on treatment do not book them daily, and we only book them on Tuesday and Wednesday. This is because we are short of nurses, and we cannot afford to have a nurse who works only with TB patients. This is one of the restrictions we have of not having enough human resources.” [Nurse, FGD, Khubetsoana Health Center]*

## **B. Staff divide time among multiple programs**

To compensate for overall staff shortages, health facility staff operate under a work-sharing model. Under this model, each staff member switches between programs on any given day to ensure that all activities in the facility are staffed. This results in a lack of specialization, which negatively impacts TB screening services.

*“I feel like each program has to have a health care worker that focuses on working on it. So, they do not have to work on multiple programs simultaneously but still bear in mind that they will have to go on leave, whether sick leave or any other leave. They are working at night and have to be off the following day such things, and in the clinics, those things are not happening. You are on call; you deliver two pregnant women; in the morning, there is a long queue waiting for you outside, and you have to carry on doing your work.” [Health worker, ID #2]*

### **C. Lack of ownership over screening activities**

Screening is commonly performed at entry points to the health facility before a patient sees their caregiver. Health care worker participants were concerned that no single designated individual was responsible for carrying out tuberculosis screening within a health facility. Screening activities are shared among multiple clinic employees. At any given time, the screening could be performed by an implementing partner, a village health worker, a lay counselor, or other staff members. Screening is often the responsibility of an employee whose primary position is to support another non-tuberculosis program. Screening activities are generally allocated on a day-to-day basis.

*“We have a challenge with the TB screening that is why we are not getting most of the patients with TB. Because we do not have trained TB screeners, people who are doing the screening are just the facilities' employees. Moreover, they take turns in screening TB; if this week is the lay counselor, the other week will be the VHWC [village health worker coordinator]. It is just nobody's department, so the screening is not done correctly; nobody owns the screening department because no one is trained about screening. That is where the challenge is, and that is why at times when you find samples collected [missed], nobody is feeling responsible because they will say [he/she was] not there that week; it was so and so. So screening is not owned by the TB screening department. If there were trained TB screeners, it would have been beneficial.”[Health worker, ID #14]*

The shared nature of this screening process means that no single person takes responsibility for tuberculosis screening in the health facility. While staff understands that they are required to

screen when asked to do so, they do not see it as their job. Participants expressed concerned that this lack of ‘ownership’ effectively eliminates the traceability of screening activities and results in an overall decline in the quality of tuberculosis screening.

*“I do it because I find it necessary to do so and because of the staff shortages. It is not in my job description, but because the VHW [village health worker] was already doing that, I had to continue screening patients.” [Health worker, ID # 6]*

*"There is no specific person assigned for TB screening. Anyone on duty is the one screening for TB, hence why it is sometimes not properly done. Few people are...screened at MCH only from implementing partners." [Nurse, FGD, Berea Hospital]*

## **2. Lack of adequate training for screeners**

Employees from other programs who were asked to perform tuberculosis screening in addition to their work explained that they were not formally trained on how to screen for tuberculosis. They are provided with screening tools but did not receive specific training on how to use them correctly. The tuberculosis screening tools are closed-ended questions about key symptoms such as fever, cough, weight loss, and night sweating. These ad-hoc screeners learned about screening on the job, either through informal feedback from colleagues or observing nurses when they screened patients. Continuous refresher training was not offered.

*“I think the gap is visible when the TB screeners are not clear of what to do or how to screen TB in the facilities, especially the lay counselors. If somebody has not been trained or lacks a refresher, the results of the screening by the screener will usually be*

*bad because he/she may miss some patients who have TB and say that they are not presumptive TB patients. So that will impact badly on the TB detection.”*

*[Health worker, ID # 1]*

*“The people who screen for TB in Berea hospital have never received specific training on how to screen TB. They have just been given the screening tools to screen patients for TB.” [Nurse, FGD, Berea Hospital]*

*“We got it once or maybe two times, but usually what happens is that we have meetings as VHWs [village health workers], and during those meetings, we discuss different topics [including TB], and this helps us remember what we had forgotten. And when we have a problem with certain topics, we ask the nurse to help us with them.”*

*[Health worker, ID#8]*

Health care workers and the management team members were concerned that poorly trained screeners could not uniformly apply the screening tool. Furthermore, without training on how to deliver the screening tool, some participants worried that screeners were not properly explaining questions to patients. This resulted in inaccurate answers to the screening question, leading to missed presumptive cases, inaccurate documentation of tuberculosis cases, and compromised care. Patients with active tuberculosis could return home without a proper diagnosis.

*“We miss most of the patients. Most of the TB patients are missed during the screening, and they go home with TB, which was not detected during the screening because of the way they ask questions. Patients respond, and [screeners] miss them, and they go home*

*without being known that they are presumptive TB. Furthermore, they go home, and the disease spreads to the families and communities. Later on, they come back very ill, and sometimes they are too ill even to complete the treatment and die in the process because they missed the first time they went to the facility during the screening." [Health worker ID #14]*

*"The weakness may be the staff members [TB screeners] not asking the patients the screening questions in a standardized way; they ask them differently on different days." [Health worker, ID #1]*

*"Because of lack of training, we are missing TB cases. This will result in the rapid transmission of tuberculosis infection, and this can be exacerbated by a lack of knowledge on how to prevent TB infections. Lack of training also affects the documentation of the outcome of tuberculosis treatment particularly on the outcome of died TB patients." [Nurse, FGD, Berea Hospital ]*

*"As I said, we will not be able to give good quality, and that leads to poor services where people are being turned back, delayed results, and the patients no longer trust the system. The patients complain about coming to facilities and giving the sputum then not knowing their results and this affects their trust in the system and that why they do not come to access services, they come when they are very sick and this the reason why we have such a high death rate when it comes to TB." [Health worker, ID#2]*

While participants acknowledge that training is essential for effective and efficient tuberculosis screening, there are simply no funds available to train staff on screening procedures.

*"I think the ministry always mentions the issues of not having funds. Otherwise, every facility could choose people who could be trained for TB screening. But it is the challenge of unavailable funds for the training." [Health worker, ID #14]*

*"We are actually trained by the national TB and Leprosy program, and we do the step-down training if we have been trained. But you may find that there are some hindering issues like hiccups with the funds when we have to decentralize the training." [Health worker, ID#1]*

*"As I said, it is financed. Human resources are the things we lack. So, if we could get support when it comes to these, we can be very effective." [Health worker, ID#2]*

### **3. Structural barriers create delays that shape patients' care priorities**

#### **A. Long travel and clinic wait times negatively impact how patients feel when visiting a health facility**

Patients and health workers in our sample described the challenges that they faced when attending health facilities. They had to travel long distances to the facility and often wake up early and leave their homes before mealtime. Many had to walk long distances as part of their journey and often struggled to pay for transport. Upon arrival at the facility, many patients were already weak and fatigued, and they knew that they would face an additional hours-long wait before a provider could see them.

*“We always queue for a long time at the gate. It brings a lot of fatigue and dizziness.”*  
*[Patient, Berea hospital, ID#7]*

*“The first point, I should start by the very same health centers that go to, the TB Clinics, we have a great problem, a person is already very sick, like I have told you that sometimes I even struggled to have food, I have already left home having not taken enough food. When you get to the facility, you get here at 8:00 am only to get consultations at 12 [noon].”* [Patient, Khubetsoana health center, ID#9]

*“Most of the patients walk long distances to go to the facilities and when they are very ill, particularly during the bad weather, cannot walk. Moreover, they cannot take a taxi because they do not have money, which means they will not go to the facility.”* [Health worker, ID#14]

*“It takes many hours [to go to the facility] because the cars [did not] come straight here [facility], they wait for a passenger.”* [Patient, Berea hospital, ID#10]

*“Most of the time, [it] is the distance that [hinders] the patient’s accessibility of the facility. Most of the facilities are not accessible because most people have to travel for some distance to reach the facility.”* [Health worker, ID#15]

## **B. Health care workers recognize that long wait times compromise screening**

Health care workers understood that patients were focused on seeing their providers as quickly as possible to receive care and begin their challenging trip home. From their view,



patients prioritized being seen by the clinician. They viewed screening activities as a potential delay that added additional wait time to their already hours-long wait for care. Health care workers expressed concern that, in their view, patients provided answers to a screening question that would not trigger additional interventions and prolong their time at the clinic.

*“Another one is when they come here [hospital] for services just as you saw that long queue outside the gate, I think that happens in almost all clinics there is always a long queue. The people know that they are going to be screened for TB, and if they answer “yes” to one of the questions, that means you are going to take longer to get services because they make you give the sputum and wait for the results and all that.” [Health worker, ID # 2]*

*The patients complain that the counselors or TB screeners make them wait too long, therefore waste their time. For example, I often overheard the patients talking on the corridors complaining that the TB screeners waste their time; therefore, the patients would rather respond 'no, no, no' on each and every screening question asked." [Nurse, FGD, Khubetsoana Health Center]*

*“ Once a patient has any TB symptoms, he/she is ordered to send the sputum to the TB clinic, so this makes patients unwilling to give out all the answers when being screened.” [Nurse, FGD, Berea Hospital]*

#### **4. Internal mistrust about the accuracy of screening leads to redundancy**

After a patient passes through the tuberculosis screening process, they will be able to see their provider. While screening should have already been carried out by a health worker that day,

nurses reported that they do not trust the screener's assessment. Therefore, lacking confidence, they take on the additional task of re-screening patients for tuberculosis during their clinical visit.

*"To add to what my colleague has said, even after the counselor or TB screener has screened the patient, the nurse also screens the patient again. This is done because a patient can provide a 'no' answer to the counselor when being screened, only to admit to having such a symptom when they get to the nurses. So, we always make sure that we ask signs and symptoms of TB at every point that the patient gets to." [Nurse, FGD, Khubetsoana Health Center]*

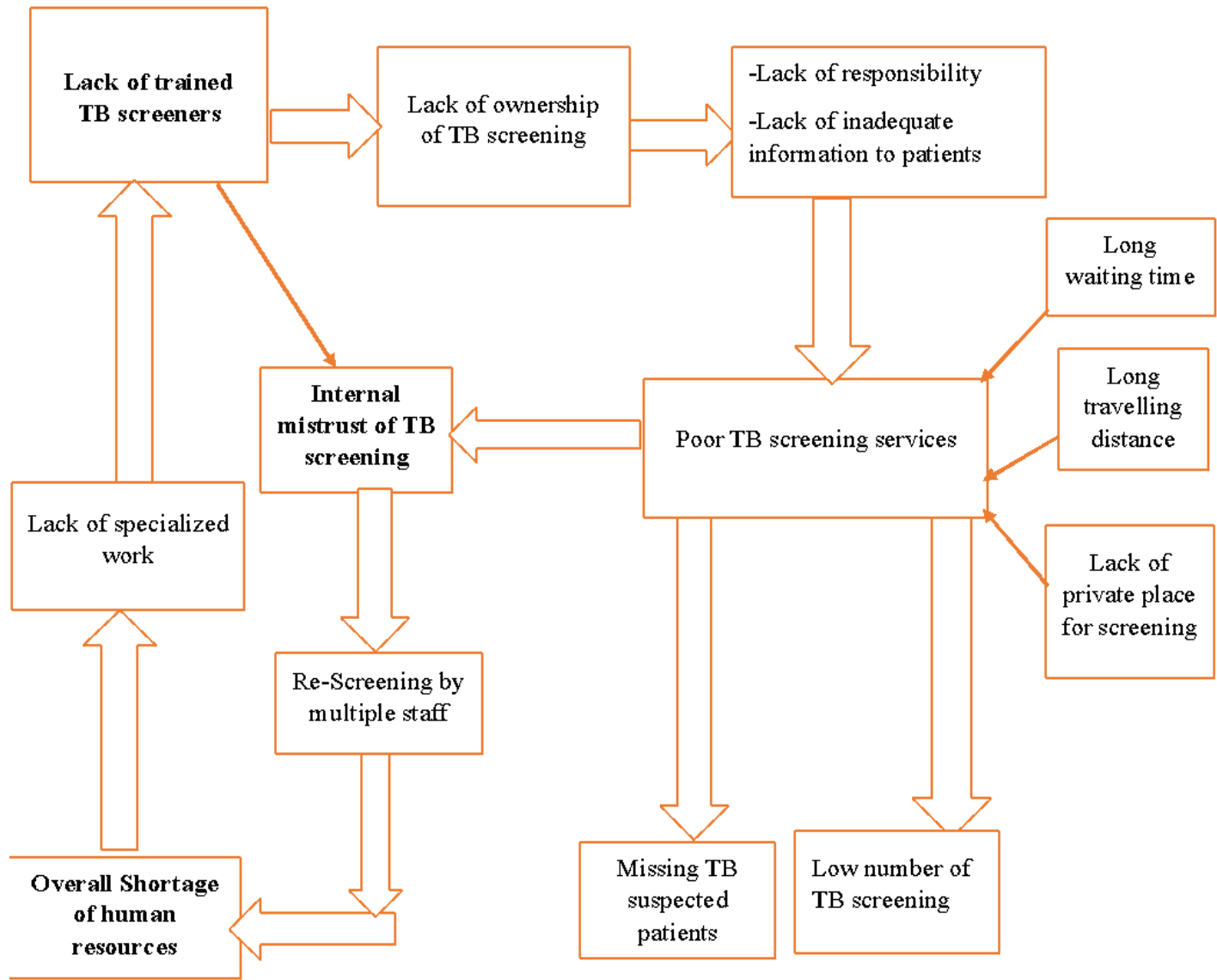
*"[We] re-screen the patient because the patient may be carrying a note that shows that he/she has been screened for TB, but if the clinician feels like re-screening the patient, they do so." [Health worker, ID #1]*

Nurses screen in the consultation room based on physical manifestations – that means that they could be catching the disease only in later stages. When nurses re-screen patients during clinical consultations, this adds time to the patient visit, overloading nurses who are already stretched incredibly thin by their clinical duties. This creates service inefficiencies, with highly trained clinicians performing work that can be carried out by minimally trained screeners – a misuse of scarce human resources.

*"Loss of weight is one of the skills I use to assess a presumptive TB patient. Sometimes, once the patient gets into the consulting room, you recognize that the patient is emaciated as a nurse. Sometimes just by looking at the patient's clothes, you will see that they no longer fit on the owner of the clothes. Another assessment is just the physical*

*appearance; like when a patient has military [miliary] TB, he/she will not mention night sweats. It is only when I recognize these that I will know the patient is a presumptive TB patient." [Nurse, FGD, Berea Hospital]*

Figure 4: Conceptual framework representing barriers to tuberculosis screening



## Discussion

In this study in the Kingdom of Lesotho, the initial screening steps of the tuberculosis care cascade had the lowest completion. We found that less than a third of visitors at the hospital and around half of the visitors at the health center were asked about tuberculosis symptoms, even though the policy is to screen every visitor who comes to the health facilities for any reason.

Four main obstacles to effective tuberculosis screening were identified: an overall staff shortage in the health facilities, lack of adequate training for screeners and health workers in the health facilities, structural barriers create delays that shape patients' care priorities, and health workers' mistrust of the initial screening process, which leads to redundant repeated screening.

Our findings showed that the overall shortage of staff and lack of trained and dedicated TB screeners contributed to the low completion of tuberculosis screening. Studies conducted in Ethiopia<sup>67,68,69</sup> and Nepal<sup>70</sup> on tuberculosis detection barriers also showed that the shortage of human resources and lack of training among health care workers were the main barriers to low tuberculosis case detection. There were insufficient health workers in these studies, and only a few health workers were trained on tuberculosis. The lack of staff created an increased workload among staff and contributed to poor service quality, long health services delay, and low patient satisfaction. In contrast, knowledge gaps and high staff turnover significantly compromised tuberculosis detection. In addition, the study in Nepal found that geographical locations were a significant barrier in accessing tuberculosis services, particularly in peripheral health facilities. Therefore, tuberculosis programs need to ensure that they have adequate, well-trained, and incentivized tuberculosis screeners in all health facilities. Allocating dedicated tuberculosis screeners based on the need and patient workload at all health facilities will help provide tuberculosis screening services and minimize tasks with other programs.

Evaluating the tuberculosis care cascade is essential to identify the most critical gaps in the tuberculosis program.<sup>46</sup> Our study found that the most considerable losses from the care cascade were at the initial screening steps. For example, a study conducted by Kim et al. showed that across all 30 high-tuberculosis burden countries, 35% of people with tuberculosis did not receive a diagnosis; in contrast, 25% of people who were diagnosed failed to initiate and complete treatment.<sup>49</sup> However, the relative contributions of pre-and post-diagnosis cascade losses differ across countries. For example, a study in India showed that 28% of people with tuberculosis never accessed diagnostic centers, representing the most significant number of people lost across all the care cascade steps.<sup>47</sup> However, an evaluation of the South African tuberculosis care cascade showed that only 5% failed to access testing; the care cascade's most significant gap was successful treatment completion.<sup>48</sup> These studies are critical because the analysis can help programs decide on the best strategies for closing the cascade gaps.

We found that the weak health system in Lesotho contributed to frustration among patients and the low quality of tuberculosis screening contributed to the low completion of the care cascade. Our findings identified gaps in five of the six domains of the WHO framework for the building blocks of health systems.<sup>71,72</sup> We found a lack of human resources, access to quality tuberculosis services, adequate funds for training and hiring of staff, and governance and leadership in prioritizing and allocating the workforce. Moreover, the distribution of staff in the health facilities was not based on the need and patient workload, so data usage for program optimization was low. Weak health systems and barriers in leadership and governance, services delivery, health informatics, health financing, human resources for health, and pharmacy and supplies significantly impact tuberculosis programs.<sup>73</sup> Therefore, sufficient staffing with fair distribution, adequate supply of essential commodities, and proper monitoring and evaluation of

performance using effective data utilization is critical for controlling and eliminating tuberculosis.

The study has some limitations. First, the quantitative and qualitative study was conducted only in two health facilities. Therefore, the result of the findings may not be generalizable to the rest of the country. However, by conducting interviews and focus groups with both patients and various healthcare workers, the data capture a range of experiences at both the community, facility, and district level. Another limitation is that we could not consult primary data on numbers of visits due to the difficulty of obtaining the relevant historic registers from the hospital and clinic; however, we obtained numbers based on secondary data (reports) from the district health office. Finally, this study employed a convergent design, and the quantitative data identifying the significant gap in tuberculosis screening was not apparent until after the qualitative data collection was complete. As a result, we did not probe in great detail about patients' screening experiences; we, therefore, limited insight from patients' perspectives about the tuberculosis screening process.

## **Conclusion**

The strengthening of the health system is crucial for an effective and efficient tuberculosis program. The availability of well-trained, supervised, incentivized, and dedicated tuberculosis screeners are crucial for an effective tuberculosis screening program. Furthermore, it is essential to improve tuberculosis screening services at all health facilities and community levels. Screening is the entry point to the tuberculosis care cascade. We need to reach out to all the missing tuberculosis cases and immediately stop treatment to prevent the unnecessary spread of tuberculosis in the community and among family members.

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