

**Mining for Solutions: a Preliminary Report on Research Designed to Engage  
Southern African Miners, Ex-miners, Managers and Policymakers, Clinicians,  
and Communities on Tuberculosis to Improve  
Health Care Delivery**

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## Executive Summary

Tuberculosis (TB) continues to stress many communities and local economies in Southern Africa despite modern advances in technology, the availability of treatment, and awareness provided by international advocacy programs. Research reporting trends in incidence and prevalence of TB in labor sending regions of South Africa (primarily the Eastern Cape) and peri-mining communities is well established. Less understood are the local and regional contexts that prevent clinical programs from reducing these rates. In order to better understand these contexts a team of researchers from Dartmouth College partnered with a team from The University of Witwatersrand to conduct an applied ethnographic study to explore the social and behavioral determinants of TB and related health behaviors. The team applied a community-based participatory research (CBPR) framework, partnering with local, regional, and national groups to uncover the “faces behind the numbers”. This was achieved through interviews conducted with miners, ex-miners, families, communities, clinicians, nurses, managers, and policy makers in Gauteng and the Eastern Cape.

Following six weeks of interviews and participant-observation, the lived experiences of individuals across stakeholder groups could be characterized in four ways. The first, *ecologies of fragmentation*, describes competing systems of parallel work streams and misunderstood goals, the division of physical bodies into value-based units, and a cycle of separation of families seen as necessary for sustainable futures. The second, *culture of invisibility*, evokes the hidden lives of miners and families whose narratives remain untold, the struggles of clinicians to care for suffering patients with inadequate resources, and the disempowered ex-miners who see themselves as having lost their value. The third, *suffocated by production*, highlights the irony of human need to produce and the mines as the only option, the consequence being a cycle of families sending members to the mines to produce, and to die. Lastly, *the masking of TB* points to gaps in TB health education, a need to prioritize TB in mines, communities, and districts, inadequate informed consent processes for recruited miners and current employees, as well as a need for assigning and accepting responsibility for TB management.

To address the findings, we offer several potential opportunities for future implementation and research. Strategically, we encourage the standardization of messaging across administrative levels, the reallocation of resources towards new care models within existing systems and skill development for care teams, opportunities beyond the mines to engage community members, and the expansion of stigma reduction campaigns in communities and clinics. The findings support efforts to expand electronic referral systems to improve patient follow-up. They suggest the integration of tools to engage and inform patients as well as new metrics to improve patient engagement and care coordination. The findings also support a team-based care delivery model built around the trust of patients and their families and communities and shared goals, shared knowledge, and mutual respect within the team. For instance, hiring ex-miners as health-workers to contribute to Ward-Based Outreach Teams (WBOT), or to become lay advisors, could meaningfully improve health seeking behaviors and TB treatment adherence and increase sensitivity to social and cultural determinants. Competency-based training programs to facilitate skill development at various levels within care teams and evidence-based approaches for care team members to work efficiently and effectively together could help address the barriers that fragmentation presents. Integrating health and social care by establishing policies and mechanisms for payment systems that support choices made by service users (ex-miners, children, and their families living in communities) could reduce costs by addressing issues of care coordination to and promote community engagement.

## Introduction

Miners in southern African gold mines have suffered for over a century under the weight of a Tuberculosis (TB) epidemic. Efforts to understand and mitigate the illness burden of TB on miners have largely focused on clinical studies and epidemiological solutions. While scientific knowledge about the nature and scope of the epidemic is significant, interventions have been less successful, signaling the need for a broader, multidisciplinary approach that directly engages miners. A better understanding of the cultural and sociological context of miners and ex-miners can help address the persistent high prevalence of TB infection and continued transmission in the mining sector. Accurate indicators of the needs and wants of those to be served, the miners, ex-miners, and their families and communities suffering from TB, can inform service model design and investments in capacities to deliver different services.

## Background

The 1886 Witwatersrand Gold Rush established the mines and cities around the mines, including Johannesburg. The problems with mine conditions of the early 20<sup>th</sup> century, however, persist in present-day mines in South Africa (Ehrlich 2012). Poor ventilation, crowded living, and deleterious working conditions facilitate the transmission of tuberculosis. Today, miners face the added burden of HIV infection, which increases the risk of tuberculosis by as much as five-fold. This is further complicated by poor treatment adherence that leads to multidrug-resistant strains of bacteria, reduced treatment efficacy, and increased cost. The combination of these disease factors and a multitude of other social and political factors continue to influence the entrenched, centuries-old problems in the mines today (Dharmadhikari et al. 2013). In addition, research has found that, within the mines, clinicians failed to diagnose pulmonary TB in 44% of patients autopsied, incorrectly ascribed pulmonary TB as the cause of death in 29%, and correctly ascribed pulmonary TB as the cause of death in only 27% of patients autopsied (National Institutes of Occupational Health 2015). For ex-miners awaiting compensation for their TB or silicosis, there is a long backlog.

Approximately 120,000 people are employed at South African gold mines (Gold Wage Negotiations 2015), most of whom work at the four major mining houses: Harmony Gold, Sibanye Gold, AngloGold Ashanti, and Gold Fields. Although the majority of employees at gold mines are men, the mining industry has seen a recent increase in the number of female employees, including in historically-male jobs such as drilling (This is Gold 2014). Gold mining operations are generally concentrated in two provinces, Gauteng and Free State, which span the Witwatersrand basin. For all its dangers and its historical importance as a main source of income for many families from rural areas, underground work in a gold mine is a relatively low-paying job. As of 2014, the guaranteed monthly pay for an entry-level underground gold miner was R 10,186 (\$838) including the employer provident fund, medical benefit, and several allowances (Gold Wage Negotiations 2015). The mining unions have long fought with mining companies and the South African government to raise miners' wages and benefits. For graphics detailing these data, please see Appendix I.

Occupational health and safety in the gold mines of South Africa is regulated by a variety of government branches, with overlapping areas of oversight and legislation. The main governmental departments responsible for managing health in the mines are the Department of Mineral Resources, the Department of Health, and the Department of Labour. There are difficulties in this occupational health system including,

as Miller et al. noted, that “[d]omain-contestation among Departments of Health, Labour, and Mineral Resources inhibits formulation of integrated national policies and appropriate resource allocation” (Miller et al. 2011).

In addition to various branches of government, there are several other organizations that are essential in regulating, managing, and organizing labor for South Africa’s mines. These are The Employment Bureau of Africa (TEBA), the Chamber of Mines, and mining unions including the National Union of Mineworkers (NUM), Association of Mineworkers and Construction Union (AMCU), the United Association of South Africa (The Union or UASA), and Solidarity. TEBA historically has served as a labor broker for the mining houses, contracting miners in rural areas and bringing them to the mining houses. Today, TEBA also provides some socioeconomic support to miners, helps mining houses care for the health of ex-miners, and undertakes development work related to TB and silicosis (Moss 2015, TEBA Limited 2015, Thembaletu 2015, USAID 2015). The Chamber of Mines serves as an advocacy and policy organization for mining houses across the industry. All four of the major gold mining houses are members. The Chamber advocates for mining houses and is the primary contact for unions and government. This member organization has also conducted TB reviews and is working to help mining houses coordinate their occupational health policies (Balfour-Kaipa 2012, Chamber of Mines 2014). The four unions--NUM, AMCU, UASA, and Solidarity--represent miners throughout the industry. As of 2015, excluding the Gold Fields South Deep operation, there are 86,852 gold mineworkers who are members of a union out of a workforce of 94,433 employees

### **Improving health in South African mines**

The four major gold mining houses—Harmony Gold, Sibanye Gold, Gold Fields Limited, and AngloGold Ashanti—have worked in recent years on improving their programs to manage HIV/AIDS, TB, and silicosis. They have recognized the impact that silica dust can have on miners’ health and have taken steps to improve working conditions, living conditions, and their disease management strategies. Below, please find a summary of TB, HIV/AIDS, and silicosis information for these four mining houses. For an overview of their health programs, please see Appendix II.

**Table 1. Tuberculosis in the Mining Houses**

| <b>Mining House</b> | <b>TB Incidence</b> | <b>New TB Cases</b>         | <b>TB cure rate</b>  | <b>New Silicosis Cases</b>  | <b>HIV Prevalence</b> | <b>Employees on HAART</b> | <b>VCT Participation</b>    |
|---------------------|---------------------|-----------------------------|----------------------|-----------------------------|-----------------------|---------------------------|-----------------------------|
| AngloGold Ashanti   | 1.57%               | 447 (2013)                  | 92% (2013)           | 201                         | 30% (2011)            | 3,317                     | 16,000 (61.4% of workforce) |
| Gold Fields Limited | 1.86% (2010)        | 49                          | 85% (2001)           | 15                          | 12%                   | 262                       | 25% of employees            |
| Harmony Gold        | 1.62%               | 568 reported, 353 certified | 93% (across all ARM) | 437 reported, 175 certified | 22%                   | 4,640                     | 33,531                      |

|                 |        |                 |                  |     |     |       |       |
|-----------------|--------|-----------------|------------------|-----|-----|-------|-------|
|                 |        | (25<br>MDR)     | mines)<br>(2013) |     |     |       |       |
| Sibanye<br>Gold | 1.669% | 566 (34<br>MDR) | 61%<br>(2013)    | 264 | 21% | 4,604 | 5,590 |

Data is from 2014 unless otherwise noted, in which case, the year of most current data that could be found is in parentheses. (World Economic Forum 2002, Gold Fields 2010, African Rainbow Minerals 2013, AngloGold Ashanti 2013, Sibanye Gold 2013, AngloGold Ashanti 2014, Gold Fields 2014, Harmony Gold 2014, Sibanye Gold 2014).

## Methods

Early diagnosis, treatment completion, and effective disease prevention are required for mitigating the spread of tuberculosis in this population, yet current practices are falling short of national and international targets to reverse the spread of the disease. In order to enhance current practices, specifically care delivery models and health communications strategies, we have engaged miners and ex-miners as well as their families, communities and caregivers in an ethnographic research project to more fully understand and identify the social, cultural, and behavioral factors that shape their lives. We have also engaged clinicians and care providers and policy makers and managers to understand their experiences in TB service delivery systems and jointly identify gaps and barriers in current practices. The approach lends agency to a wider range of stakeholders and enables the co-creation of value among them

### Research Design & Methods

We conducted an applied ethnography to deepen our understanding of the unique social and behavioral health determinants associated with living and working in close proximity to gold mines in South Africa. We use the term “applied ethnography” to explain how we intended this method to be a practical integration of cultural exploration with service delivery evaluation. It was our intention to explore the social and cultural impact of tuberculosis and associated illness seeking behaviors from a rigorous examination of the lived experiences of individuals across a wide range of stakeholder groups. The use of this method allowed us to “reach the part other methods cannot – that is the views of ordinary people in the real world” (Lambert & McKeivitt 2002:212).

### Standardization of Training

All field researchers participated in ethnographic training led by one of the lead researchers who had extensive teaching and research experience in qualitative methods. The content of the training included techniques for conducting qualitative formal and informal interviews, taking field notes, writing memos, and analyzing qualitative data as well as an introduction to thematic analysis and grounded theory. At the conclusion of daily sessions in the field, the team was led through a thorough debriefing session to clarify method questions, summarize interviews, and share experiences. These formalized “check-in” sessions were valuable to review techniques, answer questions, and build group-based learning. All researchers were trained to submit daily and weekly summaries. This involved focusing attention on environmental factors and features that could not be established in interview sessions. Summaries were in the form of personal reflections and were essential to aid recall of differences in experiences and were necessary to provide context for the subsequent analysis of recorded data.

## **Participant Recruitment**

We used a combination of snowball and convenience sampling of health officials and administrators, miners and ex-miners, and community members led by our partners in South Africa, including colleagues from the Department of Health (DoH) of South Africa. It was our intention to recruit active miners in the earliest processes by reaching out to leaders at the DoH as well as colleagues at the World Bank. Key informants made initial contact and established face validity, the process of identifying the study as having value based on intention and approach. The research team relied on key informants' personal and professional contacts to engage with established community leaders and community members to interview. As part of the snowball sampling process, members of the research team would periodically ask participants to recommend other potential interview participants. The research team would ask permission to contact this individual or ask for the key informant to be first contact. This technique supports recruitment of participants who will be most likely to participate and also recognizes the value of peer-to-peer trust and familiarity.

We also recruited participants by applying methods consistent with principles of community-based participatory research (CBPR), where community leaders and members of the community are engaged from the earliest stages of research to help shape questions, methods, and contribute to findings (Israel, Eng, Shulz, and Parker 2005). Efforts to achieve adequate sample representation were started early in the research process. By working closely with partners, we utilized online technologies to establish shared research goals and mutually beneficial processes of conducting research. These were achieved through consensus. Such an approach emphasized a collective interest in gaining depth of understanding rather than breadth of knowledge.

## **Data Collection**

We collected tape-recordings, field notes, and observational data from formal and informal interviews, focus groups, and participant observation. The use of multiple forms of qualitative data were necessary due to the changing and unpredictable nature of local environments. It was our goal to allow for flexibility in our approach to data collection in order to adapt our processes to local groups and dynamic social situations.

## **Participant Observation**

We conducted participant observation to more fully understand and explore the day-to-day lives of the people who live and work in labor-sending regions and locations around mines, also referred to as peri-mining communities. The technique of participant observation widely used to provide descriptive accounts on various aspects of people's' lives with the goal of understanding "taken-for-granted" assumptions and rules (Charmaz 2006). Becker (1958) describes the participant observer as one who "gathers data by participating in the daily life of the group or organization he studies" by watching "the people he is studying to see what situations they ordinarily meet and how they behavior in them" (Becker 1958:652). We observed ex-miners and their families in their home communities as they went about their daily lives. We also spent time in government offices and clinical settings observing how patients entered and exited clinics, how the process of being seen by a doctor unfolded in real-time, and how the functions of the health department operated.

### **Informal and Formal Interviews with Stakeholders**

We conducted informal and formal interviews and, when possible, audio-recorded interviews. The interviews were team-based and included research assistants from Dartmouth College and the University of Witwatersrand. The teams were deliberately multi-disciplinary, pairing researchers from the United States and South Africa who represented different academic backgrounds, cultural and language traditions. Informal interviews were conducted mainly with community members, families, and clinic staff and were, by definition, not planned, thus enabling us to take advantage of situations that most accurately reflect naturally occurring narratives and more authentic personal experiences (Witzel 2000). Formal interviews were done with managers and administrators sometimes in pairs as well as in small groups of three to four. In many cases formal interviews occurred in parallel with focus groups and other informal settings, where participants were able to establish rapport with the research team prior to their interview.

### **Setting**

We collected data from three primary locations: West Rand District in Gauteng Province and O.R. Tambo and Chris Hani Districts in Eastern Cape Province. These locations were chosen based on referrals from health officials at the Medical Bureau of Occupational Diseases as well as The University of the Witwatersrand partners. In addition, the One Stop clinics, recent demonstration sites supported by the World Bank to provide integrated health and compensation services to ex-miners, were located in Carletonville in the West Rand District and Mthatha in the O.R. Tambo District.

### **Interview Guide**

An initial interview guide (Appendix III) was developed by Dartmouth researchers, then subsequently pilot tested with University of the Witwatersrand partners and local community members in South Africa. The interview guide served as a preliminary map to orient formal and informal interviews as well as focus groups. Over the course of data collection, iterative assessment, and constant comparison with emerging data, the interview guide was iteratively modified. Methods to understand attitudes, beliefs, and intentions help orient interventions based on how individuals see themselves, evaluate consequences, are influenced by important people in their lives, and feel they control their lives all affect individual intentions and behaviors (Ajzen and Fishbein 1980, 2010).

### **Consent Process**

The research conducted reflected a “respect for persons” principle, which suggests that all consent must be “negotiated” with participants to ensure understanding and acceptability. In this way, informed consent was gained by sharing information sheets with all participants, families, clinical managers, and policymakers. As researchers, we took every effort to meet the needs of participants as determined through discussion of research process and expectations as dictated by the various Institutional Review Boards of the USA and South Africa. The research conducted between April and May of 2015 was approved by The University of the Witwatersrand, Dartmouth College, the Eastern Cape Province Health Department, and the West Rand District Health Department.

### **Data Analysis**

Interview summaries, field notes, and focus group data were qualitatively assessed using a grounded theory approach. A grounded theory approach as demonstrated by Charmaz (2006) and Braun & Clarke (2006) allows researchers to analytically code text based on importance and salience of information.

Charmaz (2006) describes codes as “categories or segments of data with a short name that simultaneously summarizes and accounts for each piece of data” (Charmaz 2006:43). The process of applying initial codes and secondary (theoretical) codes helps to account for individual themes within the data and apply an “analytic frame to build the analysis” (Charmaz 2006:46). The thematic analysis of summarized interview data is widely supported and recognized as an effective methodological approach to assessing large amounts of complex conversational data.

The analysis process was divided into three main steps: 1) individual analysis; 2) small group discussion and thematic analysis; and 3) final consensus through triangulation of small group analysis. The research team first individually completed gist summaries of the formal and informal interviews. This involved reviewing field notes, listening to recorded interviews, and creating summaries based on gist. As part of the individual analysis process, field notes were integrated with gist summaries and later coded by salient themes. At this stage, researchers were divided into two small working groups. Each group worked together through discussion to determine most salient themes based on independent analysis conducted in step 1. The goal of step 2 was to develop major themes, establish which narratives best reflected the major themes, and to propose a meaningful and representative model. In step 3, the groups came together and compared their independent assessments of the data. Through a process of deliberation any disagreements were overcome through group consensus.

## Results & Findings

**Table 3. Demographics of Interviews**

| <b>Participants (type)</b>            | <b>Number</b> | <b>Age Range</b> | <b>Education Range</b>             | <b>Current profession</b>   | <b>Location (where we talked to them)</b>     | <b>Type of interaction (interview, focus group)</b> |
|---------------------------------------|---------------|------------------|------------------------------------|---|---|---|
| Miners                                | 1             | Unknown          | Matric                             | Underground miner   | Home  | Informal interview                                  |
| Ex-Miners                             | 29            | 28 - 66          | None - Standard 6                  | Unemployed, informal work, contract work, part-time work                      | Homes, public park, clinics, One Stop Service | Interviews and focus group                          |
| Family and Community members          | 13            | 23 - 57          | None - Matric                      | Unemployed, professors, informal work, students, housewives, service industry | Homes, clinics, community public spaces       | Interviews and focus groups                         |
| Clinicians and Care Providers         | 14            | 33 - 56          | Standard 11 - MBChB, PhD, Master's | Home-based care, WBOTs, nurses, doctors                                       | Clinics, hospitals, One Stop Service          | Formal and informal interviews                      |
| Health Care Policymakers and Managers | 47            | N/A              | N/A                                | District officials, province officials, MBOD, NGO                             | Clinics, hospitals, district health offices,  | Formal and informal interviews                      |

|  |  |  |  |  |                      |  |
|--|--|--|--|--|----------------------|--|
|  |  |  |  | managers, mining house health managers, Chamber of Mines | organization offices |  |
|--|--|--|--|--|----------------------|--|

### Demographics explained

The main findings we underscore below were drawn from four participant groups: miners and ex-miners, family members, clinicians and care providers, and health care managers and policymakers. Due to the sociocultural and political landscape of the mining sector, a majority of our interview data excluded current miners. The family group includes both the wives and children of former miners. The clinicians and care providers category encompasses doctors, nurses, WBOTs<sup>1</sup>, and community health workers from home-based care organizations. Health care managers and policymakers include health officials from a mining house, district and provincial health officials, representatives from NGOs, and representatives from other organizations involved in the health of those in the mining business. Each section of the results will be divided into four sub-sections to directly address each of the four key themes that we extracted from the data.

Questions about age and educational level were often difficult to communicate with the mineworkers and family members. Many had difficulties in understanding this type of query. Ages could be particularly difficult to get accurate numbers for because many people did not know their age or were only able to offer an approximation of the year they were born. When this question was asked in some interviews, participants would refer to birth certificates or other forms of identification. Due to cultural considerations, it was not appropriate to ask for ages or highest level of education when we interviewed policymakers.

### Timeline of Work

As our methodology dictates, the timeline of our informal and formal interviews and participant observation emerged organically through conversations with various stakeholders during networking and partnership building opportunities. These opportunities formed a critical part of our in-country work and helped inform the diverse perspectives interwoven throughout this report. Most work days included both structured stakeholder meetings aimed at facilitating a bidirectional exchange of information, as well as formal and informal ethnography. This distinction, as well as a breakdown of our contacts and work contexts, is detailed in a comprehensive timeline of our ethnographic work, which can be found in Appendix IV.

### Main Findings

Our qualitative analysis of field notes, interviews, and observations describe four main themes:

- Ecologies of Fragmentation: Broken physical and organizational bodies
- Culture of Invisibility: Stories of disempowerment
- Suffocated by Production: Overcoming the specter of opportunity
- The Masking of TB: Buried experiences of blame and misunderstanding

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<sup>1</sup> Ward-Based Outreach Teams.

A description of our findings will continue by first profiling each of the four themes and how they specifically apply to each of the four sample groups. We begin with *Ecologies of Fragmentation* by examining how miners and ex-miners defined themselves by productivity, families have been broken, clinicians are disconnected from patients and confused by leadership, and policy makers appear locked in debates referred to as “the TB dance”. We continue with exploring what we call *A Culture of Invisibility*, which characterizes miners and ex-miners feeling forgotten, families being unable to break a cycle of poverty, clinicians feeling helpless to meet the needs of their patients, and distance between policy makers and managers and the realities of the citizens and care providers they aim to serve and support. We turn to our third theme, *Suffocated by Production*, where we detail how hunger drives miners to return again and again to the mines, how the mines affect the spirit, situations, and prospects of communities, how clinicians continue to treat their patients, and how policy makers manage a range of interests that may be competing at times. Lastly, we illustrate *The Masking of TB* among miners and ex-miners as a denial of symptoms, among families as misinformation and understanding of TB health risks and prevention, among clinicians as an emphasis on biomedical models and other illnesses and treatments over TB, and among policy makers as weak communication and integration channels for TB which have resulted in integration and implementation challenges for TB treatment and management.

### **Ecologies of Fragmentation: Broken Physical and Organizational Bodies**

**“At the clinics [outside the mines], someone is going to examine you and then tell you there are no pills. How are you going to expect the person to survive?” -Ex-miner**

Considering the extensive nature of our findings, it was our intention to examine the data and determine patterns across our sample. One of the most prevalent themes in the data was the concept of fragmentation. The concept was used in many different ways to describe communication gaps between government organizations and to define how value applied to the bodies of ex-miners. We have adopted the term ‘ecologies of fragmentation’ as a way to frame the nature of health and social systems in South Africa. We base this framing on the extensive work that has described social ecologies as multi-dimensional, systems based, and include both academic and non-academic perspectives (Janes 2004, Craig 2012, Neely 2015). Specifically, we use the term to describe how smaller social, economic, and health systems work independently of larger, more robust social, economic, and health systems. We argue that these independent ecologies of fragmentation have led to broken physical as well as organizational bodies. We explore these in more depth below from the perspectives of each participating group in our study.

#### **Miners and Ex-miners**

The men who had worked in the mines routinely described how their bodies are both literally and figuratively broken—divided between two worlds. One example is how the compensation system, designed to support ex-miners, actually contributes to fragmentation by basing payment on the part of the body that is affected. The Department of Health (DoH) regulates compensation for ex-miners’ hearts and their lungs on the basis of ODMWA, the Occupational Diseases in the Mines and Works Act that provides compensation for occupational lung disease in miners and ex-miners only, while the Department

of Labor (DoL) handles compensation for ex-miners' hands and heads on the basis of COIDA, the Compensation for Occupational Injuries and Diseases Act of 1993 which ensures compensation for disablement or death caused by occupational diseases or injuries that are contracted or sustained by employees during their employment. Our findings showed how fragmented compensation schemes create confusion and frustration for ex-miners with TB.

Stories of how work in the mines and difficult life circumstances contributed to the deterioration of the physical body illustrated how miners and ex-miners perceive themselves and understand illness; ex-miners would say, "they [their bodies] just are not enough". Some ex-miners' said their lungs were so damaged by silicosis or multiple tuberculosis infections that they believed they were "*just the playground of TB.*" In the mines, being sick means being less productive. Yet, for young and healthy miners who can return, there is hope. For one ex-miner the reality of being out of work took away a sense of hope, for, as he said, "*I'm finished. I'm nada. I'm just, what you call it, a carcass or something*" [translated from Sesotho].

Several miners made statements about the dangers they faced in the mines, telling us, "*You're lucky if at the end of your shift you get back to the surface*" and "*It's very rare that people go into that dark side and they make it and come back*" [translated from Sesotho]. The first ex-miner quoted here told us that having his family nearby helped him cope with the pressures of the mining environment and the dangers of the work. In addition, ex-miners spoke to us about the dangers they faced from workmates in this stressful environment. One man said he always tried to be friendly with his teammates underground because "*if you don't cooperate with the people that you are working with, you can easily be trapped. They can kill you. They know that maybe that roof board, it is not stiff. Because you are not cooperating with them, they will align you with that roof board, it will hit you*" [translated from Sesotho].

### **Family Members**

The importance of family in the lives of miners and ex-miners is evident in our data. Family is a foundation as well as a motivator. . One daughter of a miner related her educational difficulties to her father's absence, saying, "*Had my father been around more often I believe I would have been able to complete my matric*" [translated from Xhosa]. The daughter of another ex-miner living closer to the gold mines said something similar when she commented that "*People in my community have given up so much on life,*" alluding to the lack of opportunities and disempowerment of those who feel left out of the economic and health systems.

The nature of the work in the mines and oscillating migration patterns forced families apart, which affected health and happiness of family members. One miner's son said, "*We never had real conversations with our father, we would just be grateful for the fact that he was home*" [translated from Xhosa]. The daughter of another ex-miner remembered the look of fear on her mother's face whenever she would hear about an accident at the mine. Her mother worried that her husband had died or gotten seriously injured. Other wives of miners spoke about the hardships of raising a family alone, with limited support from the husband or extended family, and how this negatively impacted plans for their children's future. They feared infidelity among their husbands and how that would impact their health: "*one of the reasons why we went to the mines to visit our husbands was to see if they were having any affairs, we had our own suspicions and we would decide to go investigate*" [translated from Xhosa].

TB and other illnesses among miners contributed to the fragmentation of the family. One man we spoke with in Mthatha lost both his father and his mother to TB within one year of each other. His father contracted TB and was diagnosed at the mine. He was sent home to recuperate where there was limited follow-up with local hospitals. His mother served as his primary caretaker, but because of her lack of training in TB care and the lack of contact tracing in this area, she contracted TB and died as well. This man had become the head of his household in his early twenties, and had dropped out of school to provide for his six younger siblings and his own baby son. Even with his efforts, few of his siblings completed school, and most migrated away from the area, further splintering his family.

### **Clinicians and Care Providers**

There is consensus across stakeholder groups that the health system that provides various services to the miners, ex-miners, and peri-mining communities is also highly fragmented. A lack of coordination of services, where clinicians give and receive mixed messages, along with a lack of resources, leads to various inefficiencies. Several clinicians and providers noted duplication of services, waste, and a lack of standardization in services. This lack of coordination can often come from the top down; as one WBOT lead said when speaking about her decision to train her community health workers because they had not been trained by the provincial WBOT program, *“People will die while we’re waiting for people up there.”* She knew that the members of her team needed to know how to deliver medications and injections because that was the only way many community members could access the health system. Her fear was that, if she waited for the provincial program to conduct the requisite training, it would be too late for many in her community.

Patient records are among the most prevalent and often discussed areas of confusion among clinicians, nurses, and community health workers. Communication about the current health status of patients as well as poor follow up are seen as major gaps in providing appropriate service delivery. We learned from many health care workers that patients *“slipped through the net”* because of limited availability and access to primary care doctors, a faulty referral system, and gaps in follow-up and contact tracing. Clinicians as well as nurse managers talked about fragmentation as mainly a resource challenge, where clinics lacked essential tools to help their patients and, as a result, routinely experienced limitations on their ability to positively impact their patients. One nurse manager spoke in an interview about volunteering her time to perform the work of three nurses without the use of the internet, phones, or a work vehicle. She described her attempts to manage a growing patient load by training nurse assistants, *“I teach them to do these things but sometimes they don’t understand what it means. Interpreting results is a problem.”*

Fragmentation was also exemplified in the observed disconnect between patients and health providers. Patients and physicians had differing perspectives about how health care should be delivered, including whether patients should be touched, what type of contact patients should have with doctors, and the evidence and implications of treatment courses. This was exacerbated by the fact that few health care practitioners, in particular the doctors, were from the communities they served or lived in the area. This meant they often did not understand the structural forces that impacted their patients’ lives and could adversely affect treatment adherence and outcomes. We did find, however, some clinicians that strove to connect with their patients and understand the difficulties they faced. As one doctor who works with

miners said, *“Sometimes you’re looking after somebody that is so grateful for the fact that now they have someone to look after them [...] With every patient you have to develop some kind of relationships with them.”*

### **Health Care Policymakers and Managers**

Interviews with policy makers explored how new policies were designed to improve current gaps in delivery services, especially regarding ex-miners. We learned from an informal group interview with regional district managers that the presence of a One Stop Service Center at a large regional teaching hospital was unknown. Further, these same district managers were surprised to learn that a national body was contracting services with a private physician. District tuberculosis managers explained how these services should be offered by public sector facilities that already treat patients. In the minds of these managers, a decision made at the national level to outsource services was duplication of services and an unnecessary waste of resources. In the conversation that ensued, a national representative stated that *“It’s only this province that is dysfunctional in terms of occupational health.”* While the district TB managers agreed that steps needed to be taken to improve the local occupational health programs and offered solutions to improve their ability to help migrant miners, it was also clear that miscommunication between the national, provincial, and district levels of health was part of the challenge. The provincial TB managers in the same area also stressed that their *“biggest problem”* was weak communication between provinces, especially as this related to patient referrals, follow-ups, and contact tracing.

In addition, TB managers from the same district were worried about the fact that there was *“No referral system between mine hospitals and hospitals here.”* As this district supplies the majority of migrant miners to South Africa’s gold mines, the managers worried about how this impacted the health of people in their district. They did not know who current and former miners were specifically and had no systematic way to take occupational histories. Because the mining houses sometimes send patients home for sick leave and because miners who come home over the holidays may be sick, the fragmented communication system between the mines and labor-sending regions could contribute to a higher disease burden. They found this especially challenging because of the vastness of the district, the problems they faced with low adherence as people would leave for work again when they felt a little better, and the high death rate, especially among those who were co-infected with TB and HIV. Conversations with mine health managers, however, illustrated the other side of this fragmented system. They spoke about their struggles to manage TB because they rarely received information on follow-up for contacts of their miners with TB from NGOs or national bodies. In addition, they felt like they had *“too many bosses”* because of the overlapping and contradicting spheres of influence in health.

### **Culture of Invisibility: Stories of Disempowerment**

**“In the year 2002, my mother fell heavily ill; she had TB. While they were treating my father they had never bothered to check on the rest of the family, nor did they check on the family while they treated my mother” [translated from Xhosa]. -Son of a miner**

We have chosen to borrow the term “invisible” from the novel “Invisible Man” by Ralph Ellison, a first-hand account of an American black man living an admirable life in the shadows. We also recognize the

rich historical accounts of invisibility among the underserved and marginalized. Our work and observations in South Africa are analogous in many ways to Joao Biehl's presentation of invisibility characterizing the hidden AIDS epidemic in Brazil. According to his ethnography, epidemiology and surveillance data failed to accurately capture how AIDS was devastating the lives of Brazilians (Biehl 2007). By adopting this term we seek to provide context to the many stories we heard from black South Africans recounting their own experiences of being ignored and undervalued. What we also acknowledge in this phrasing is the unique loss of power that follows when individuals are forgotten or disregarded by society. When voices go unheard, they lack the significance to make change. To demonstrate the power of the collected stories to illustrate how invisibility leads to disempowerment, we examine their meaning in relationship to Ellison's novel of perseverance and Biehl's accounts of individual overcoming.

### **Miners and Ex-miners**

The invisibility of miners and ex-miners begins in their lives before entering the mining sector and extends to their experiences after leaving work in the mines. They generally come from regions that are historically disempowered and resource-poor, where migrating to the mines is often the only way to try to escape from the cycle of poverty. One ex-miner described his community, a township in a gold mining area, as *"Terrible. This place. It's no place to live, to tell the truth. I don't even want to talk about it. No, this is not a place to live."* Another man from the same area agreed, stating, *"There is too much gold here. I don't have to go there for gold, it's in the dust. I'm still in the mines."* A second-generation miner from a rural community in the Eastern Cape said he was glad his son worked at a mine, since *"he drives three cars because of the mines"* [translated from Xhosa]. Many of the men we spoke with had internalized their poverty and viewed working in the mines as their lot in life and all they could do for a brighter future.

This often led them to blame themselves for their lack of understanding or ability to further their lives. One man from a peri-mining community told us that *"People are very ignorant—the thing is that many people have never went to school. There are few people who went to school."* Although many of them expressed frustration about the situation, their historical disempowerment and resignation often made it difficult for them to break out of that cycle of invisibility. As one ex-miner and community leader told us, *"I'm not trying to be racial, but the people in the useless type of jobs, it's our black people [...] If you're a black person, then you are coming from one bad situation to another bad situation."*

Many of the ex-miners felt lost in the medical system. They often laughed or expressed disbelief when asked in interviews if clinicians ever took the time to speak with them in depth about health issues or answer their questions. This was illustrated through stories like that of the ex-miner from Lesotho, who said that the doctors and nurses at the local clinic *"just take our sputums and go. Nothing [is explained]"* [translated from Sesotho]. One ex-miner attributed this to the fact that *"Doctors, they are just there to look to the side of the mine. Because maybe they are being bribed, they have been given something."* Patients are passed between the different health systems at the mines, in their home communities, and in the public sector and this can lead to confusion and death. We spoke with the son of a miner from a rural community outside of Mthatha, who had died from what was potentially MDR-TB. When he contracted TB at the mine in Gauteng Province, he was told to take sick leave and go home to the Eastern Cape Province to recuperate. His case went to the local hospitals, but there did not seem to be sufficient follow-up to help him manage the disease, especially as his condition worsened. Every day, his sons would have

to carry him 20 km on a mattress to the hospital because he was too weak to walk; even the movement of the mattress caused him pain. The local doctors didn't do check-ups at home or admit him to the hospital. Eventually, he died on the road on the way to the hospital. Better communication between the mining house's health services and the public health sector could have helped this man because the local hospital could have been better prepared to receive him and give him the level of care that he needed so that he did not die an invisible ex-miner on a rural road.

### **Family Members**

Family members felt that their needs were not being met by the systems that employ and care for miners. This was especially illustrated when a miner fell sick with TB or HIV and was sent home for an extended medical leave to recuperate. One widow of a miner told us in a focus group in Queenstown that, when her husband contracted TB, *“there was no support from the mines, we struggled [...] we would spend about R 600 (\$49) a day on transportation, about twice a week”* to see the doctors [translated from Xhosa]. Family members also told stories of the challenges they faced when they tried to care for a husband with TB. As another woman in the same focus group commented, *“Taking care of a sick person was very hard, especially because there was no money by the time my husband's condition worsened [...] everything is reliant on you, there is no support from the extended family, you have to make a plan as a wife and sometimes ask for money from your own family”* [translated from Xhosa].

In addition, family members talked about their disempowerment within their poor communities, even as they tried to get ahead and find ways to overcome poverty. One woman who is the daughter of an ex-miner and who has searched extensively for work at mines said, *“I look at myself and I say I wanna do better, but how?”* Attending university has been difficult because of the cost, and she is currently unemployed. When she spoke about health in her community, she added, *“It would be great if people feel like they can take their health into their own hands.”*

### **Clinicians and Care Providers**

The health care system is comprised of countless clinicians and care providers that go above and beyond the call of duty to care for TB patients in the mining sector like the doctor mentioned in the previous section. We found that many health care workers who were undertaking outstanding service to their patients were not fully recognized for their efforts and could be used to a greater extent as positive examples for others to learn from within the health system. One WBOT lead, who created her own system to train her thirty-three community health workers and to keep track of the almost 10,000 houses they manage by color-coding her handmade maps, said, *“Here, it's everyone for herself. You survive by being creative. If you're not innovative, you'll go nowhere.”* Another WBOT lead at a clinic within the same sub-district had never heard of this woman, and struggled to help community members because she had not been paid in a year and had no protective masks. These health care workers genuinely believe that *“If we do our work well, the burden of disease will be minimized.”* How can they be empowered to provide quality care in their communities? As another nurse assistant said, *“I just want information, I just want to be trained.”*

The way that clinicians and care providers spoke about and to patients, however, could also help contribute to the invisibility that patients felt. Health care workers can contribute to this invisibility, even

unwittingly, through the language they use to speak about patients amongst themselves or address patients during consults. One health care provider told us that “*Clients should not expect to be seen by a doctor [...] We should not create the expectation that clients will be seen by a doctor every day.*” We heard from many community members that it was very hard to see a doctor and that certain nurses with advanced training were also hard to see. Many community members who expect to see a highly trained clinician wait in day-long queues. This can contribute to a sense of isolation among patients, who feel that their health concerns do not matter to clinicians or that a highly trained health care professional is the only source for high quality care, when in fact certain aspects of TB treatment and care can often be delivered just as well, or even better, by members of a care team with lower levels of specific training but skills in relating to patients and communities.

### **Health Care Policymakers and Managers**

In a conversation with a high-level policymaker, the overwhelming sentiment was concern for the disconnect between what happens at the policy level and what gets translated to the people. It was widely held among those we spoke with that official policy documents that detail health programs and interventions are highly regarded in international arenas as comprehensive and accurate. Yet, middle managers were unclear about the origins of data that informed these reports. In many interviews at the district level, with academics, and non-governmental organizations, data quality, relevance, and use was a concern. It was suggested that the realities of average South Africans are hidden from clinicians, managers, and administrators. One manager commented, “*I sometimes shield myself from the realities [of miners].*” She said this was necessary so she would be able to continue her work in the mining sector. This same woman also commented, “*If you get an occupational lung disease, you are very lucky if you get paid. Your chances are better if you are at the mine.*” This, she believed, was because of the limited resources and limited outreach beyond the mines, which meant that ex-miners were not seen or paid attention to. Another mine health manager added that, because they did not do enough follow-up and engagement in the community, “*We’re not closing the loop of what happens on the other side*” in terms of TB.

### **Suffocated by Production: Overcoming the Specter of Opportunity**

**“They don’t care about it, they just want to get gold and get profit.” -Ex-miner**

To be suffocated according to the dictionary definition means to die from lack of air or inability to breathe. We chose this word because it relates directly to many of the stories told by ex-miners and their experiences underground—the heat, the dust, the moisture, and the brutal working conditions. We created a play on words using production to help paint a picture of the struggles of miners, their families, and other community members. In many ways, the “everyday violence” (Scheper-Hughes 1992) they experienced was related to their need to work in the mines as a means of making a living and a way out of poverty. There was a clear connection between mines and production as well as the understanding or myth that working in the mines was analogous to salvation. Many people explained how the risks of dying were not enough to keep them from applying for work underground. In many cases, the potential opportunity that was associated with working in the mines to support family were more important than the risk of dying. The specter of opportunity, where mines are viewed as something that is not fully seen

but known, encapsulate the concept of social violence. Kleinman has provided some clarity to help understand the way indeterministic social violence frames “everyday life” of people oppressed by a larger system of power. Inspired by Kleinman’s ideas, we applied the term *specter of opportunity* to illustrate how our ethnography “implicates the social dynamics of everyday practices as the appropriate site to understand how larger orders of social force come together with micro-contexts of local power to shape human problems in ways that are resistant to the standard approaches of policies and intervention programs” (Kleinman 2000:228). We explore our findings of collected stories and experiences to show that opportunity has its rewards and its risks, but despite precedence, the need to produce inevitably leads communities and families closer to death.

### **Miners and Ex-miners**

Ex-miners’ stories illustrated how they were both literally and figuratively suffocated while working in cramped tunnels underground as they struggled to breathe through dust masks soaked by sweat and covered in fine dust particles.

In many cases, miners are viewed simply as producers. A widow of a miner stated, *“In our daily struggles we often think that had I gotten my husband’s compensation at least one of our children would have been successful”* [translated from Xhosa]. One ex-miner conceptualized his problem with mining as, *“It’s just like you are in the underworld. It’s just a slavery--that is slavery in the mines. Because, you find in the mines, it’s like a builder who doesn’t have a house. He has built so many houses but he doesn’t have a house.”* This production mentality can turn miners into commodities when they produce and costs when they are no longer able to produce. As an ex-miner put it, *“I can attest to say they end up firing me because they say I can no longer bring production for them. So about my health, nada”* [translated from Sesotho].

We heard dozens of accounts of men working beyond healthy limits to produce and earn more money to send home, their lungs severely damaged by TB or silicosis. As one ex-miner told us, *“Healthy comes second. Work comes first. Health is a secondary item.”* One ex-miner said in a focus group in Queenstown that in the mines, *“nobody cared about our health, the sole purpose of us being there was to produce gold. Our gain was not important and having symptoms of TB was not seen as important”* [translated from Xhosa]. Another ex-miner talked about the contract he had signed at the mine as a death contract, saying, *“There’s that paper you are going to sign, and that paper that you going to sign, you are signing for your death. Because each and every day you are doing it at your own risk.”* He accepted the risk and the fear that he may not return home the next day because he knew he had to provide for his children.

The forces that drive men to work in these difficult conditions are varied, but boil down to “hunger”. As one ex-miner living near the mines said, *“This thing of hunger is the thing that is pushing people to work in the mines.”* His statements were echoed by two ex-miners from a rural town near Queenstown in the Eastern Cape, who stated in a focus group, *“Nobody told us about the mines; poverty did”* [translated from Xhosa] and that *“we dared death in order to feed the family”* [translated from Xhosa]. These men worried about what would happen to their children if they were not able to continue their role as the provider. As one ex-miner commented when asked how he coped with the risks, *“We just wanted that money. When you go home, the children goes hungry.”* Another man expressed similar sentiments when

he told us, *“What hurts most is being hungry, not having any food to eat and being in an impoverished state”* [translated from Xhosa]. Ex-miners fear how sickness will impact their ability to produce.

### **Family Members**

The family members we spoke with were driven to create a better future for their children; the success of a child could earn her graduation photo a pride of place in the combined kitchen and living room of a two-room home in the rural Eastern Cape. As one widow of a miner lamented, *“I wish I had enough money to educate my children so they could get better jobs than their father”* [translated from Xhosa]. Mines have come to be seen as the provider, often the sole avenue to ensure that families could break out of the cycle of poverty by earning enough money to provide for the education of their children. At the same time, many family members recognized the negative impacts that the mines had on their lives, in spite of the economic benefit; one miner’s widow told us, when speaking about her children’s futures, *“I would not encourage them [to go to the mines] because I have already seen and experienced the hardships with their fathers”* [translated from Xhosa]. Her limited finances, however, make it much more likely that her children will engage in mining instead of completing another career as she hopes.

### **Clinicians and Care Providers**

We heard repeatedly about how doctors and nurses *“push the queue”* or *“push the pill,”* referring to their rush to see as many patients as possible in a short amount of time. This focus on total patient volume rather than quality of the clinical interaction or value disadvantages the patient and, based on our interviews, has created mistrust of the health system. Clinicians in a district meeting said that the huge pressure on the primary health care system coupled with health care providers’ frustration resulting from the limited attention paid to their successes could cause burn-out. These district clinicians wondered if the mission and vision of primary health care was still in the hearts of all those who provide it, or if it had been *“dislocated by the difficulty of the situation.”* Many of the health care providers we interviewed, from home-based care providers working on no pay and with no protective equipment, to nurses who saw miners they could not truly help because of their training relative to the difficulty of the task, pushed themselves far beyond their limits to provide the best health care possible and to address the multi-layered issues that impacted their patients. This is why one doctor who works with miners told us that *“it’s mixed feelings in terms of how I feel when looking after the patients. Because some of them at least there’s life, you can talk to them, have a good conversation, others you can see that, you know what, you’re just hoping and praying that at least they’ll enjoy some compensation money before they actually pass away.”* These types of doctors are fulfilling the wish of one ex-miner, who said, *“The best thing that they can do, doctors should fight for us, to say we must be compensated, because we’ve got kids that need to be looked after”* [translated from Sesotho].

As we learned in a meeting with provincial TB officials, the referral process itself also encourages health care providers to focus more on data than on a patient’s treatment success. When a health care facility refers a patient, whether within districts, across districts, or across provinces, the patient’s TB outcomes—sputum negative, died, defaulted, etc.,--belong to the referring facility. For these facilities, good outcomes mean that the patient was not lost to follow-up when he was transferred or moved but do not address questions of whether the patient is taking treatment or of his understanding the treatment’s purpose and use.

## **Health Care Policymakers and Managers**

Through our conversations and observations, it became clear that there is no shortage of data about TB, HIV, and other illnesses in South Africa. What was unclear, however, was where this data was coming from, what was motivating its collection, and how organizations could be sure that the data truly reflected the realities on the ground. We heard from many district and provincial TB managers that they were pressured to gather more data and fulfill different national and international targets.

Within the gold mines, this production mentality was also strongly present. As one mine nurse said when talking about her employer, “*Remember, we are a mine, we must produce gold and gold and gold.*” We heard from members of mine management, along with from ex-miners themselves, how the mining houses focused on giving the miners nearly constant information about diseases, safety, and healthy living. The sheer number and omnipresence of these programs--including DVDs, posters, periodic health talks, and talks at the miners’ induction--means that they can become background noise. The mine health managers we spoke with expressed concern about the lack of sustainability that came from running their TB education and awareness programs in this way because the challenge is that “*you can’t combat TB in a month.*”

## **The Masking of TB: Buried Experiences of Blame and Misunderstanding**

**“I didn’t realize that I had the TB. When I am coughing too much at the mines, I go to the clinic at the mine. They just give you medicine, tell you what to drink, no check up, nothing” [translated from Tswana]. -Ex-miner**

Among those South Africans we met TB was thought to be everywhere and at the same time virtually hidden from public consciousness. Unless you live in an area heavily affected by the illness, it is likely you won’t know much about its clinical features, how it’s spread, or how to treat it. We chose to describe a large segment of our data using the phrase *the masking of TB* to refer to the widespread confusion among sampled participants over particular characteristics of TB. The data also shows that experiences of living with and surviving TB remain isolated. Instances of repeated infection or experiences overcoming infection to later acquiring silicosis aren’t often shared. Observed instances of shifting responsibility for managing TB infections and blame falling on the shoulders of patients can be understood through Luna Dolezal’s (2015) reflections on the shame in the clinical encounter. As she noted, shame, often expressed among TB patients as fear of stigma, “can lead to many potentially harmful behaviours such as dishonesty within the clinical encounter, avoidance of seeking medical attention, not following through with medical treatment, and even negative health outcomes as a result of the shame itself” (Dolezal 2015:8). This shame can also come from cultural perceptions of negative behaviors that make one more predisposed towards a particular illness (Sontag 1989). Below we present findings that reflect a systematic *Masking of TB* and provide examples across our sample of participants.

## **Miners and Ex-miners**

The miners and ex-miners we interviewed often spoke of TB as a strange illness that was somehow connected to the dust underground and potentially to trash in the community or dust from the mine dumps. One ex-miner referred to TB as an “*issue that is taking place underground [...] Because it’s not*

*only by the dust, it's all by different chemicals around that facility or underground. So you find that maybe it depends again on your immune system.*" In the communities where ex-miners are from, this lack of knowledge and understanding about TB could lead to stigma that made them wary of disclosing the disease to their families or seeking care at a local clinic. Many of the ex-miners we spoke with in Khutsong township told of interactions with clinicians who did not listen to them or did not care for them. These clinicians did diagnostic tests and sometimes dispensed pills, but rarely gave other relevant health information. One ex-miner told us that few people want to go to the local hospital because *"when you get to that hospital it stinks, it smells bad, it smells bad. Last time, my brother was dead, he was in an accident, he was in that hospital, I had to go collect that corpse. I was even vomiting."* Another man from the same community agreed, saying *"The hospital is a storeroom where you go to die."* These experiences with health facilities make them even less willing to go to doctors because they may fear that the hospitals are only places where they go to die. Therefore, many of the men we spoke with would wait, from fear, misunderstanding, and lack of support, until they were very sick before they would go see a clinician. They spoke of how they only were diagnosed after they had repeated flus or weakness, while others had to be dragged to a clinic by their wives or because their illnesses had progressed so far that they collapsed. Those with TB are often stigmatized for their illness because of their family's fears that the infected will pass the contagion to the rest of the family. One ex-miner related how he was discriminated against by his family because *"When I was working at the mine, when I got ill, at home they were suspecting that maybe I don't have TB, maybe other illness, maybe HIV, so people called me names."*

At the mines, the presence of TB was often understood as directly related to the dust. As one ex-miner in a focus group in Queenstown said, *"we were told that one of the ways to prevent being ill is to spray water on the area to which you will drill in order to have the dust settle fast"* [translated from Xhosa]. While this may help decrease silicosis, it disadvantages miners in terms of their ability to protect themselves from TB. Diseases are not always talked about in a clear, comprehensive, and empowering way, even to miners who are sick, so they may not be aware of other ways they could contract TB and what they could do to mitigate risks. Another man from Mthatha said he *"associated my sickness with my work at the mines because of the dust and smoke underground"* [translated from Xhosa]. Many of the ex-miners told us that they never received education or awareness about TB during their time in the mines, or that it only occurred during the induction trainings but with few opportunities to clarify the nature of a TB infection. One ex-miner said that the problem with many TB education campaigns was that, *"Those posters of TB, they just put it on the wall, they don't explain it to a person."*

In addition, few of the ex-miners we spoke with were given information about their illness when they sought treatment at the mining house's clinics. A man from a rural town near Mthatha, whose father had died from TB he contracted while a miner, related his father's story, where *"Father started falling ill while in the mines, he was admitted into the hospital and later discharged and sent back to work. He fell ill again and consulted a doctor in the mine hospital, they only told him that he had 'chest problems' and not necessarily that he had TB"* [translated from Xhosa]. A lack of knowledge and support for miners to manage their health and mitigate risks for contracting TB can lead people to believe comments like the following from a man interviewed in Queenstown, who said, *"[...] TB is incurable even when you take your treatment, we know that; because this thing is in your lungs and lungs are life, if there is a problem with your lungs your life is over"* [translated from Xhosa].

### **Family Members**

The family members we spoke with had a limited understanding of TB, even though they all had experienced its effects in their families. One miner's son who had dealt with TB related the symptoms to mental illness, saying, *"I don't know how I got the TB or what kind of TB it is, I would occasionally have mental disturbances"* [translated from Xhosa]. This can lead to stigma and to a lack of willingness to talk about TB in the home because, as another man said, *"When you grow up, when you talk about TB it's like it's something, like it's a disease where you are going to die, you are going to die, you see, that's why I didn't want to hear someone saying 'you've got that TB.' Oh I was mad, it's like I am dying [...] It's a death sentence."* This is compounded by the relationship between TB and HIV, which many people believe are permanently associated. One widow of a miner said that community members believed her husband had HIV when he was diagnosed, no matter what she did, *"You often tell people that your husband has TB and the people would disagree [saying it's HIV]...it hurts a lot"* [translated from Xhosa].

We also observed that health information and education for families was limited, resulting in stigma and misunderstandings exacerbated by the fact that, even though wives were serving as informal caregivers, they were not connected to health resources; instead, as a miner's widow said, *"the nurses and doctors would never explain anything to us, we would be excluded from the consultation"* [translated from Xhosa].

### **Clinicians and Care Providers**

Clinicians and other health care workers can contribute to the masking of TB. One mine nurse became visibly upset when she spoke about defaulters, saying, *"it's on your behavior"* whether you get sick and disparaging patients who did not take treatment because the mine was *"putting a lot of energy in you"* with its health education campaigns and free medication. She felt like asking defaulters, *"With all this messaging, where were you?"* and *"Why are you killing yourself?"* and then referred to those patients who failed TB treatment as *"bipolar"* because they did not understand the mine's messages. Negative attitudes towards patients among providers can drive people away from the health system and contribute to stigma. Another health care provider in a district meeting said that there was a sense that *"clients don't understand that they need to do their part for us to do our part."* These perspectives do not take into account the sociocultural, economic, historical, community, and/or political factors that influence people's beliefs about opportunities for achieving better health.

### **Health Care Policymakers and Managers**

We were told, *"this is why your work is so important, because you connect us to the what's actually happening on the ground, when those stories are just too hard to hear."* In an informal interview, we were told by a high-level administrator that implementation challenges remain unaddressed in much of the work and expertise focused on the TB epidemic in South Africa. Some policymakers suggested that a research question should be *"why had the conversation around institutional failure to solve TB gone underground?"* as it could help to reveal the origins of the misunderstandings and misinformation that masked TB and contributed to poor outcomes. Another manager in a mining organization recognized opportunities for system improvement: *"You can have a system that's supportive enough to actually get people to come on treatment."*

## Conclusion

The stories we collected and the observations we made over seven weeks are framed by the four major themes identified in our data:

- Ecologies of Fragmentation: Broken physical and organizational bodies
- Culture of Invisibility: Stories of disempowerment
- Suffocated by Production: Overcoming the specter of opportunity
- The Masking of TB: Buried experiences of blame and misunderstanding

At the heart of the South African mining landscape emerged the strength and resiliency of mining communities and families. In the context of fragmented family structures, relatives of miners and ex-miners who have not been equipped with the knowledge and resources to serve as caregivers while preserving their own health continue to care for their loved ones. Despite hardships that many miners and ex-miners have faced, they continue to prioritize providing support, care, and resources to their families – often at the cost of their own physical and mental health.

While our findings offer insight into health delivery systems in South Africa, interpretations may vary. The ethnographic approach we used was new to many of our partners in South Africa and to many of people we interviewed. The use of a new approach centered on a process of stakeholder engagement helped participants question their own assumptions and facilitated new insights among stakeholders. A majority of our interview data excluded miners due to local sociocultural and political issues around recruitment of active miners without the permission of mining unions. While the majority of the men we interviewed were ex-miners, a large proportion of this group had stopped working in the mines as recently as 2014. Consequently, we believe strongly that the stories, lived experiences, and comments from this group are robust examples that stand up to current descriptions verified by mining staff, clinicians, and other researchers working in this area. The use of key informants gave our data the intended depth rather than breadth that we had planned. An additional limitation was navigating the different languages of South Africa during data collection. In some instances, where translators were used as partners in interviews, the accuracy of the questions asked came under suspicion. Follow-up review by native speakers helped to clarify and address inaccuracies.

The fragmentation of the structure of the family unit and the system of tuberculosis care delivery juxtaposed with themes of invisibility and isolation underscore the importance of redesigning care delivery models around the needs and wants of those to be served. For instance, many former TB patients we conversed with spoke of their own or others' visits with traditional healers, or *sangomas*, who utilize herbal treatments and advocate for certain lifestyle changes - approaches that have been called "*dangerous competitors*" to the biomedical model by health care managers. Our data suggests potential for mining and public sector clinics to ally with local *sangomas* and other community leaders and structures to offer culturally sensitive, effective care and deliver knowledge through trusted channels. While biomedical approaches cannot be eschewed in the battle against TB, more holistic approaches that encompass the emotional and psychological effects of TB as well as the social determinants of health could improve outcomes. It was clear from our interviews with all stakeholders across the categories interviewed that compensation for occupational TB and silicosis is important to ex-miners and their families as a means of addressing their immediate needs. At the same time, an exclusive focus on

compensation for illness does not provide miners or their families with a long-term solution to help them break out of the cycle of poverty.

Efforts to interweave perspectives from all stakeholders and conduct cross-cutting analyses of our data have illuminated several key themes necessary for contextualizing future research and developing a more effective health care delivery system. TB in the South African gold mining sector is multi-dimensional involves a wide range of stakeholders: miners, both current and former, their families and home communities, health care workers, mining companies, mine worker unions, local and national governments, and NGOs. Drawn from our analyses, the following takeaways can facilitate the contextualization of our proposed recommendations:

- In the search for a better and healthier future, the voices and experiences of families and communities offer meaningful information and insight for the development of new models and communications strategies.
- Efforts to beat tuberculosis are currently constrained by an overemphasis of biomedical models for care delivery and the prevalence of stigma.
- Ethnography serves as an effective tool in South Africa for building partnerships and finding gaps in care delivery.

## Opportunities for Future Research and Implementation

Analysis of data resulted in the identification of opportunities for future research and implementation. Individually or collectively, they can serve as hypotheses to be tested through disciplined experiments and learning. Each is supported by the data and integrates a range of stakeholder perspectives. Upon conclusion of the data collection phase, we formally presented preliminary results and analysis to district and sub-district managers at the West Rand District Health Office in Krugersdorp, as well as to a diverse group of stakeholders, including physicians, researchers, and government representatives at the University of the Witwatersrand School of Public Health. The goals of these presentations was to share insights, generate discussion, and receive feedback that could be integrated into preliminary reports and shape future implementation plans. For reference, our presentation slides can be found in Appendix V.

### **Strategic Opportunities**

- Standardize core health messages that empower district and sub-districts to deliver care that is context specific and patient-driven;
- Reallocate resources towards strengthening current delivery systems through skill development and team-based care;
- Develop new delivery models through the use of tools to learn what matters most to those to be served, metrics for patient engagement and care coordination, and supporting care teams

### **Operational Recommendations**

- Create opportunities for ex-miners to gain employment as community health workers through the Ward-Based Outreach Teams (WBOT) program;
- Provide opportunities for clinicians and managers to spend more of their time in communities;
- Partner with ex-miners to create patient-to-patient TB support groups in local communities;
- Train clinicians to avoid and mitigate stigma through the use of mobile technology

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