

Mining for Solutions: Final 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

The mining population in southern Africa has the highest rates of tuberculosis (TB) in the world. Previous efforts to address the disease burden have focused on diagnostic, treatment, and monitoring services. While issues of TB burden are reflected worldwide and are not unique to South Africa, previous international approaches to gain knowledge of local and community preferences of care delivery practices remain limited. Engaging stakeholders is needed to clarify local social, economic, and political factors and will help inform strategies to provide needed access to better health care and outcomes. We recognize the need co-produce knowledge and health with those most impacted by the burden of disease. Therefore, we conducted applied ethnographic research to explore what it means to live with—and disproportionately die from—TB and related illnesses.

The purpose of this research was to illuminate, through the stories of a range of stakeholders, the socio-cultural factors that inform more context driven health care delivery models. As one interviewee shared, *“...this is why your work is so important, because you connect us to what’s actually happening on the ground, when those stories are just too hard to hear.”* We partnered with public and private groups to capture multiple perspectives including: miners, ex-miners, families, clinicians, managers and policymakers in two provinces in South Africa. Our interdisciplinary, multicultural research team applied a Community-Based Participatory Research (CBPR) framework to recruit participants through snowball and convenience sampling. Participant observation supplemented formal and informal interviews and focus groups; audio-recordings and field notes were qualitatively assessed.

Ethnographic interviews with 30 miners and ex-miners, 13 family and community members, 14 clinicians, and 47 managers and policymakers were completed. Our findings characterized meaningful socio-cultural implications around perceptions of TB care that may impact efforts to mitigate and end TB. We elucidate these across four domains: 1) “Ecologies of fragmentation” recognizes disjuncture within and across care settings; 2) “A culture of invisibility” encompasses routine experiences of disempowerment; 3) the theme of “Suffocated by production” scrutinizes the irony of the mining industry as a place of both wealth and despair; and 4) the “Masking of TB” profiles a limited system of accountability and uncertain responsibility.

There is urgent need to engage miners, ex-miners, families, and communities to co-develop, with regional stakeholders, care models aligned with individual preferences and experiences in order to control TB in South Africa. We find that any viable solution requires working within current systems to enhance local capacity to engage TB patients and providers. We conclude that applied ethnography offers the necessary local, contextual insight that can inform the design of new care delivery models that ultimately improve TB screening, diagnosis, and successful management. With these conclusions, we offer strategic and operational responses to our findings that can be readily implemented to improve health outcomes.

Introduction

The burden of tuberculosis globally and in the mining sector

Miners from South Africa's gold mines have suffered the causes and effects of a tuberculosis (TB) for over a century. With estimates of up to 7,000 new cases of TB per 100,000 workers annually (28 times the World Health Organization public health emergency threshold of 250/100,000), South African gold mines have the highest TB incidence rate in the world (Stuckler et al. 2013, World Health Organization 2013). Conservative estimates of an incidence rate of 2,500 per 100,000 are three times the national rate of 860 per 100,000. In fact, the roots of the TB epidemic in South Africa date back to the 1886 Witwatersrand Gold Rush that established the mines and surrounding cities, including Johannesburg. The original mining population included managers from Cornwall and Wales who were infected with TB. Working in close proximity and tough conditions, the disease spread among black laborers. For generations, these laborers helped build the South African economy, yet, today, in addition to occupational health issues, they remain excluded from many of the benefits of social and economic development that mining contributed to. Furthermore, many have migrated to South Africa from other countries to work in the mines. However, when they go home, much of the social and economic benefits stay in South Africa.

The well-documented problems with mine conditions of the early 20th century persist in present-day mines in South Africa (Ehrlich 2012). The inhalation of silica dust specific to underground gold mining leads to silicosis in almost one-quarter of miners and increases their risk of TB infection. Poor ventilation underground, crowded dorms and shanty settlements where miners live, and deleterious working conditions facilitate the transmission of TB as *Tuberculosis bacilli* thrive in dark, closed areas with poor ventilation or low sunlight, and unhealthy lifestyles contribute to risk of infection. Today, miners' risk of TB is compounded by high rates of HIV infection at the mines and in labor-sending communities, which increases the risk of TB by as much as five-fold. Poor treatment adherence has led to multidrug-resistant strains of bacteria, reduced treatment efficacy, and increased cost - all of which have further complicated prevention, treatment, and recovery.

These disease factors combined with the complex set of social, political, economic, and health care delivery factors, contribute to the entrenchment of the centuries-old problems of TB in the mines (Dharmadhikari et al. 2013). Oscillating migratory patterns of people from within South Africa and its neighboring countries, including Lesotho, Swaziland, and Mozambique, to pursue economic opportunities at the mines has contributed to the spread of diseases, including TB, throughout the region and also led to the disorganization of family and social structures. Miners, ex-miners, and families from rural and/or disadvantaged communities throughout the region often lack access to high-quality health services to support in prevention and management of disease. The dynamics of migration, stigma, misdiagnosis, and poverty appear to contribute to challenges in fighting the TB epidemic. Behind competing political and economic interests and professional silos are the voices and experiences of individuals and communities.

TB is highly stigmatized, impacting the willingness of those suffering from TB to seek screening, treatment, and care and the likelihood that those who do seek care adhere to treatment. Stigma compromises familial and community connections, resulting in social isolation and contributing to poor disease experiences and quality of life. The incidence of TB also creates financial hardship in terms of the

costs of accessing care as well as how it compromises or prevents income generation opportunities for patients and families. Furthermore, there is a backlog of ex-miners awaiting compensation from the mining sector for TB or silicosis contracted in the mines. In addition, clinicians continue to miss TB diagnoses at an overwhelming rate. 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). Overall, South Africa has a 69% case detection rate. Thousands of TB cases are missed.

Table 1. Tuberculosis in the Mining Houses

Mining House	TB Incidence	New TB Cases	TB cure rate	New Silicosis Cases	HIV Prevalence	Employees on HAART	VCT Participation
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% (2011)	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

Data is from 2014 unless otherwise noted 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).

Despite efforts to control the epidemic, TB morbidity and mortality persistently threatens the lives of miners, ex-miners, and their families and communities (Table 1). In response, TB in the mining sector has become a priority public health concern in Southern Africa with international recognition. In 2010, Dr. Aaron Motsoaledi, Minister of Health of South Africa said, “If TB and HIV are a snake in Southern Africa, the head of the snake is here in South Africa. People come from all over the southern African Development Community to work in our mines and export TB and HIV, along with their earnings. If we want to kill a snake, we need to hit it on its head.” Recognizing the regional nature of the problem, members of the Southern African Development Community (SADC) signed a Declaration on Tuberculosis in the Mining Sector in 2012. The World Bank and other development partners from around the world have worked to convene stakeholders and mobilize resources, among other activities, to focus on new ways of addressing TB in the mining sector. In 2014, Ministers of Health of Brazil, Russia, India, China, and South Africa committed to a 90-90-90 TB target, 90% of vulnerable groups screened, 90% diagnosed and started on treatment, and 90% treatment success, as part of increased and coordinated efforts to end TB in their countries. The Stop TB Partnership has also identified miners in southern Africa as a key population in their 2016-2020 Global Plan to Stop TB.

The Gold Mines

There are approximately 500,000 miners in South Africa and approximately 120,000 are employed in the South African gold mines (Gold Wage Negotiations 2015). While there are hundreds of small and

medium sized and illegal gold mining operations, most gold miners 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 USD) including the employer provident fund, medical benefit, and several allowances (Gold Wage Negotiations 2015). It is estimated that 2 million ex-miners live throughout the region with or at risk for TB. Approximately two-hundred thousand (200,000) of these ex-miners are to be compensated by the Compensation Commission for Occupational Disease (CCOD). It is further estimated that 700,000 ex-miners are to be compensated by the Medical Bureau for Occupational Disease. In many ways working in the mines, characterized by modest wages and the promise of compensation when finished, is enticing to most who view it as a way make a living, improve their situation, and support their families. Despite risks, known and unknown, many people agree to work underground for extended periods of time.

The four major gold mining houses—Harmony Gold, Sibanye Gold, Gold Fields Limited, and AngloGold Ashanti—have worked to improve their strategies to manage HIV/AIDS, TB, and silicosis. They have recognized the impact of silica dust on miners' health and sought to improve working conditions, living conditions, and disease management. Strategies include enhanced screening for TB at mine shafts, integrated HIV and TB services, decentralized primary health care services, improved dust control measures, and data systems and disease surveillance. The following table summarizes TB, HIV/AIDS, and silicosis information for these four mining houses.

The Public Sector

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 Department of Mineral Resources, the Department of Health, and the Department of Labour. Integrating policies and resourcing priorities has been described previously as a challenge across the different entities (Miller et al. 2011). With only 40 occupational health specialists in South Africa, there are critical human resource challenges. In addition, several other organizations 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, contracting miners in rural areas and bringing them to the mining houses. Today, TEBA also provides some socio economic 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, Thembalethu 2015, USAID 2015). The Chamber of Mines 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 over 90% of miners throughout the industry.

Social and structural health care delivery challenges exist at the mines and in the public health sector. While many miners have access to care at the mines, families and communities, also affected, might not have access to these health resources. During leaves in their home communities, many miners experience discontinuity of care. The responsibility for filling gaps in care has fallen on the public health system; during transitions, individuals and families are often left behind.

Delivering care: Implementation barriers

Qualitative research has been used to explore social and structural healthcare delivery in South Africa. The few published studies identified the need for multipronged approaches to improve care and access and adherence. For example, medication adherence could be improved by ensuring patients have a stable food source and ability to work; allowances at work to account for the fatigue caused by their disease; and greater empathy and positive attitudes among health professionals (Goudge and Ngoma 2011). Developing a healthy relationship with their provider is key in patients understanding their illness and returning for usual check-ups, and in keeping patients from “healer shopping” and losing faith in the public health system (Goudge et al. 2009).

Social stigma also impacts the effectiveness of health care delivery strategies. In two urban communities in the Transvaal, community members were found to have negative cognitive and affective reactions towards TB, including feelings of personal threat, social rejection, and social stigma (Westaway & Wolmarans 1994). Anticipated stigma and vulnerability were found to decrease patients’ willingness to be screened for TB in Cape Town (Murray et al. 2012). A study in the Eastern Cape (Cramm et al. 2010) found that local community members tended to have a high knowledge of TB, including how it is spread and that it can be cured with consistent treatment. However, they tended to conflate TB and HIV and with negative social behaviors like drinking and smoking. Many attributed a TB diagnosis or failure to complete treatment to irresponsible behavior on the part of the patient. Overall, the study found that local perceptions about people with TB affected a patient’s ability to adhere to treatment for six months, not other factors such as education, knowledge, gender, or clinic access (Cramm et al. 2010). Another study in Johannesburg found that having TB patients give paper slips with information about the disease and suggest testing to close friends and family could help deal with issues of stigma in the community, although many patients still reported facing negative and accusatory reactions from contacts when they revealed their TB status (Mwansa-Kambafwile et al. 2013).

Efforts to address these and other TB health care delivery challenges in the South Africa have involved community members working to track and help patients through the difficulties of disease including the treatment course, stigma, and the economic burden. A study in a rural district of KwaZulu-Natal province found that well-trained community care workers (CCWs) in villages could help to enhance TB and HIV case finding, TB contact tracing, and linkages to care (Uwimana et al. 2012). These efforts offered important linkages between various health issues. The study suggested that trained CCWs may decrease stigma and discrimination against people with TB or HIV, as their role is a generally accepted intervention in the community (Uwimana et al. 2012:495). A community-wide trial of tuberculosis

preventive therapy demonstrated the effectiveness of peer educators for one-to-one communications and participant advisory groups for two-way communications among stakeholders (Grant et al. 2010).

Despite previous efforts to address the needs of TB patients, knowledge of local and community preferences around care delivery practices remains limited. Furthermore, these studies were not performed in mining communities. Engaging stakeholders to clarify local social, economic, and political factors and will help inform strategies to provide needed access to better health care and outcomes. In the following sections we outline how we engaged stakeholders in the South African mining sector to accomplish these goals.

Our project

To inform the development of care delivery solutions for the fight against TB, we directly sought the opinions and reactions of those most affected. We examined the lived experiences of diverse stakeholder groups to better understand the cultural, social, and economic context of the TB as well as the attitudes and behaviors that impact current TB care delivery. Prior literature identified four areas needing further exploration:

- 1) Knowledge, values, and beliefs about health and illness among miners, ex-miners, their families and communities;
- 2) Lived experiences of health and illness among miners, ex-miners, their families and communities in labor-sending regions;
- 3) Lived experiences of clinicians and other healthcare professionals treating miners, ex-miners, their families and communities;
- 4) Lived experiences of managers and policymakers working to mitigate TB.

Ethnography permitted the rigorous examination of lived experiences of those suffering from TB. Through a systematic approach to data collection and analysis, we hypothesize that we would be able to characterize individual and community preferences about TB care, barriers, and facilitators. We planned to use this community-based data to inform needed patient-reported care delivery strategies and identify gaps in current delivery practices. Taken together, this applied approach offers a multidimensional perspective to address TB in South Africa.

Method

Research Design

We applied a Community-Based Participatory Research (CBPR) approach to guide the facilitation of equitable partnerships across all aspects of research [including analysis] and emphasize the strengths of resources within the community (Faridi et al, 2007; Grande et al, 2012). We engaged clinicians, care providers, policy makers and managers to understand their experiences in TB service delivery systems, to jointly identify challenges in current practices, and to better understand the many assets they can bring to bear. In so doing, we intended for a more inclusive research approach that would allow for a collaborative process of eliciting what matters most to those receiving care and disseminating those preferences to a wider audience.

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 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 permining 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.

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 in multi-stakeholder efforts to address TB. Despite working closely with key informants within the Department of Health, Sibanye Gold, District Offices, and Nongovernmental organizations (NGOs), the politics of jurisdiction limited our access to active miners¹. 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 began 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.

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 Institutional Review Boards of Dartmouth College and The University of the Witwatersrand. 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.

¹ Our team learned from informants that speaking with active miners was not permitted unless we gained permission through union officials. While we received permission from mining houses, once attempts were made to contact miners, interactions were limited. We suspect that 7 weeks is not long enough to build adequate rapport with Miner Unions and Mining Houses to gain full access to active miners. As a team, we were aware of the pitfalls of communicating with active miners without permission and cooperation from the Unions and/or Houses, and refrained from doing so.

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.

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 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 for 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).

Data Analysis

Interview summaries, field notes, and focus group data were qualitatively assessed using a grounded theory approach. Charmaz (2006) and Braun & Clarke (2006) describe this as allowing 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.

Timeline of Work

The timeline of our informal, formal interviews and participant observation emerged 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 the Appendix.

Triangulation and dissemination of findings

The CBPR and grounded theory approaches both emphasize the use of structured member checking in the design. This means that during data collection [interviews and focus groups] the team would verify and check understanding of potential themes. This form of member checking is strongly encouraged to ensure that potential findings accurately reflect stakeholder reactions, attitudes and beliefs. As an additional reliability measure our team planned to present findings across stakeholder groups. This included district health directors, local community leaders, key informants from recruitment sites, and other stakeholders in policy, academic, medical, and administrative capacities.

Results

Table 2. Demographics of participants interviewed

Participants (type)	Number	Age Range	Education Range	Current profession	Location (where we talked to them)	Type of interaction (interview, focus group)
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 managers, mining house health managers, Chamber of Mines	Clinics, hospitals, district health offices, organization offices	Formal and informal interviews

*See below for further discussion

Demographics explained

Due to the sociocultural and political landscape of the mining sector, a majority of our interview data excluded current miners. Environmental barriers included navigating issues of jurisdiction and authority. Our research team determined that with more time to establish meaningful relationships across stakeholder groups like Mining Unions and Mining Houses in South Africa, recruitment of a more demographically diverse group would have been possible.

Participant data presented (Table 2) should be interpreted with caution. The quantitative data reflected approximations and should not be extrapolated or generalized to populations across South Africa. In many cases these data were not verifiable as participants could not show or recall official birthdates or other dates like working contracts and education level. Despite these recruitment and descriptive limitations, the data accurately reflect the social structures that give meaning to lived experiences. According to Geertz, “The claim to attention of an ethnographic account does not rest on its author’s ability to capture primitive facts in faraway places and carry them home like a mask or a carving, but on the degree to which he is able to clarify what goes on in such places, to reduce the puzzlement - what manner of men are these? - to which unfamiliar acts emerging out of unknown background naturally give rise” (Geertz 1973, p16).

Missing active miners

Although we tailored our recruitment approach to key informants, we were limited by their access or willingness to provide access to active miners. Anticipating challenges to recruiting current miners, we actively pursued contacts with the Mining Union, Mining Houses, and the Department of Health through site visits, phone calls, and emails. Other attempts included relying on ministry level contacts as well as district leadership, which provided no further information or collaboration with officials. We also had to work within the landscape of the mine, which involves 8-10 hour days and miners who had very little personal time outside of working, eating, sleeping, and moving from the mine to their home. Our research group hypothesized that miners’ suspicion of our presence and role affected recruitment of active miners. This suspicion, we were told, related to miners’ fears of potentially losing their job, being seen as insubordinate or going against the prescribed ‘party platform’.

Age and education

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.

Geography

While much of the mine workforce comes from neighboring countries including Lesotho, Swaziland, and Mozambique, the majority of miner, ex-miner, and family and community member participants were South African. We interviewed only one ex-miner from Lesotho. Participants' mine experiences reflected those of miners working in and around large mines in South Africa. We recognize the variation in mine-type and size, but acknowledge our interview sample does not reflect this variation. Lived experiences in the many small and medium-sized mines and illegal mines are less well represented in the data. Our data captures the experiences of mine workers who spent a majority of their time underground. In addition, the ex-miners interviewed worked various positions in the mines. Some experiences reflect conditions in the 1980's up to the present. We recognize these differences in our analysis and point them out where relevant. For example, the vast majority of interviewed ex-miners worked underground. This is clarified during an interview where we identify the story of a surface miner compared to a contract underground miner.

The main findings below were drawn from four participant groups: miners and ex-miners, family members, clinicians and care providers, and health care managers and policymakers. The family group includes both the wives and children of former miners. The clinicians and care providers category encompasses doctors, nurses, WBOTs, 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 has been divided into four sub-sections to directly address each of the four key themes that we extracted from the data.

Main findings

Our qualitative analysis of field notes, interviews, and observations characterized the lived experiences of those interviewed as:

- Ecologies of Fragmentation: disjuncture within and across care settings;
- A Culture of Invisibility: routine experiences of disempowerment;
- Suffocated by Production: the irony of mining as both a place of wealth and risk;
- The Masking of TB: limited system of accountability and uncertain responsibility.

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*. We examine how many miners and ex-miners defined themselves by virtue of their ability to be productive,

but that, through a felt need to produce, families have been broken. Fragmentation also manifests because clinicians are disconnected from patients and confused by current bureaucracies, practices, and systems of care. Policy makers appeared locked in debates referred to as “the TB dance”. We continue by exploring *A Culture of Invisibility*. This theme is characterized by miners and ex-miners feeling forgotten and families being unable to break cycles of poverty - conflated with TB illness. Furthermore, this culture of invisibility evokes clinicians feeling helpless to meet the needs of their patients; the realities of the citizens and care providers that policy aims to serve and support remain great, obscuring needs or rendering them invisible. Our third theme, *Suffocated by Production*, explores how the economic needs of families drive miners to return again and again to the mines, even as miners and their kin are aware that such work will likely kill them. This theme also speaks to how the mines affect the spirit: morale and prospects of communities. Finally, *The Masking of TB* operates among miners and ex-miners as a denial of symptoms, and among families as misinformation and understanding of TB health risks and prevention. Among clinicians, this masking occurs when an emphasis on biomedical models for understanding or treating TB obscures the socioeconomic and cultural determinants of health and where TB fits within a landscape of other illnesses and competing concerns. Among policy makers, this masking can be understood as weak communication and integration channels for TB, which have resulted in implementation challenges for TB treatment and management.

To clarify how our findings link to our final recommendations we have included a section at the end of each of the four major findings delimiting recommendations.

Ecologies of Fragmentation

*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*

One of its most prevalent themes to emerge from our extensive data was the concept of fragmentation. Fragmentation was referenced in many different ways, from describing communication gaps between government organizations to defining how value was 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 simultaneously in ways that speak past each other. Although many of these systems are interdependent, misaligned communication strategies and priorities lead to further fragmentation across systems. 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 given their lives to the mines routinely described how their bodies are both literally and figuratively broken as well as divided between two worlds: that of the mine and that of the home community. 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 lungs, for

example. The Department of Health (DoH) regulates compensation for ex-miners' hearts and lungs on the basis of ODMWA while the Department of Labor (DoL) handles compensation for ex-miners' hands and heads on the basis of COIDA. Our findings showed how such fragmented payment schemes cause deep confusion and frustration for ex-miners and create barriers to receiving available compensation and care.

We listened to stories of how work in the mines and life outside the mines contribute to the slow breakdown of bodies; in many instances, ex-miners would say, "*they [their bodies] just are not enough*". Understanding how miners and ex-miners' bodies are treated helps to identify how the system itself is fragmented. 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 unproductive. For one ex-miner the reality of TB hit much harder, for, as he said, "*I'm finished. I'm nada. I'm just, what you call it, a carcass or something*" [translated from Sesotho]. Yet, for young and healthier miners who can return to work, there is hope.

Several miners made statements about the physical dangers they faced in their work underground, 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. Our research team learned that many miners cope with the environment by keeping their heads down and not drawing too much attention. Others mentioned their trips to a local pub or soccer field to get their minds off the dangers of work. Mostly, ex-miners spoke to us about their dependence on each other to cope with such a stressful environment.

Family Members

The importance of family lies at the heart of our data. Fathers, mothers, sisters, and brothers would express how important family and being a member of a family was the foundation of their collective lives.

Fragmentation of families occurs because of migration to work in the mines with the demands and stressors of that work. It affects opportunity, relationships, and social cohesion. 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 matric²*" [translated from Xhosa]. Similarly, the daughter of another ex-miner living closer to the gold mines said, "*People in my community have given up so much on life,*" Families felt disempowered and without opportunity as well as left out of the economic and health systems.

The nature of mine work and oscillating migration 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

² The word "matric" represents the equivalent of receiving a GED in the United States or a high school education. This is the last year of prescribed education in South Africa.

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, which made them wary of advising anyone to marry a miner because *“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].*

In addition to migration, TB and other illnesses among miners contributed to the fragmentation of the family as a unit. 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 at the mine and was sent home to recuperate, but received inadequate follow-up at local hospitals. His mother served as his primary caretaker. Because of her lack of training and an absence of contract tracing, she contracted TB and died as well. This man became the head of his household in his early twenties. He had to drop out of school to provide for his six younger siblings in addition to his baby son. Despite his efforts, few of his siblings completed school, and most migrated away from the area, further splintering this family.

Clinicians and Care Providers

There is consensus across all stakeholder groups that the health system that provides various services to the miners, ex-miners, and peri-mining communities is highly fragmented. Inadequate, unpredictable resource allocation leads to inefficiencies. Several clinicians and providers noted duplication of services, waste, and pointed to a lack of coordination and standardization of services. Clinicians recognized the challenges of receiving mixed messages and that because of being uncertain their messaging to others was inconsistent. Lack of coordination often begins at the top; as one Ward Based Outreach Team (WBOT) lead described her decision to train her community health workers because they had not received training from 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 receive the care they needed. Her fear was that if she waited for the provincial program to conduct training it would be too late for those in her community suffering from acute illnesses.

Patient records and health information systems were often discussed as fragmentation in health care delivery experienced by clinicians, nurses, and community health workers. Lack of consistent communication about the current health status of patients and poor follow up are seen as major barriers to achieving individual and population health outcomes. We learned from many health care workers that patients *“slipped through the net”* because of the lack of primary care resources, the faulty referral system, and the limited follow-up and contact tracing. Clinicians and nurse managers talked about fragmentation as a resource challenge, where clinics lacked essential tools to help their patients and, as a result, routinely experienced limitations on their ability to make a difference in the lives of their patients. One nurse manager spoke 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.” This confirmed the need for trained and competent staff. Conversations we had with clinicians underscored that gaps in professionally trained staff and resources to adequately train current staff made daily work difficult.

Sister Mary’s Story

In her late 60’s, surrounded by closets of file folders, Mary sat awaiting our arrival. Wearing what looked like a military uniform, she welcomed our team with a bright smile and infectious laugh. Mary was thrilled to see the members of our team returning with a district health manager who provided authorization for her to share the rest of her story begun two weeks earlier - how implementing the Ward Based Outreach Teams was about getting people care they needed.

Over the course of an hour, Mary presented us her program for implementing WBOTs. She emphasized how little help she received from the federal or district offices to do this work. What she had done was create cardboard maps of her community, including streets, houses, factories, and shops. She had hired Community Health Worker volunteers to canvas this community of over 10,000 and managed to account for names, addresses and health status. She could find any family or member of that family and tell us their name, age, weight, screening and TB management status. She was responsible for over 25 CHWs and had only received resources to support 5. All of her files were done by hand and filed in the closets that lined her tiny office. At any time, she would respond to emergencies or calls, being able to locate sick or injured community members in an instant. When asked how she did it with no resources she said, “...I have to be creative with what we have...”, because, “if they won’t help, we’ll do it ourselves”.

Fragmentation also emerged in the 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 or not, what type of contact patients should have with their doctors, and what treatment meant. This was exacerbated by the fact that few health care providers, especially doctors, were from the communities they served or lived in the area. As a result, they often did not understand the structural forces and local contexts that impacted their patients’ lives and could adversely affect treatment outcomes. We did find, however, some clinicians that worked hard 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 identified service gaps with a focus on ex-miners. In an informal group interview with regional district managers, we discovered a lack of awareness about the presence of a one-stop service center, a critical new and innovative resource, at a large regional teaching hospital. These same district managers expressed shock when they learned that a national body was contracting services with a private physician. They felt bypassed by the Medical Bureau of Occupational Diseases (MBOD) as well as the National Department of Health (DoH). We listened as 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 provision services through the private sector was a duplication of services in

the public sector and a waste of scarce resources. In the conversation that followed, a national DoH representative stated that *“It’s only this province that is dysfunctional in terms of occupational health.”* While in agreement about the need to improve local occupational health programs and offer service delivery solutions, district TB managers encountered challenges in making necessary improvements a reality due to miscommunication, blame, and diffused accountability across national, provincial, and district levels of the care system.

Provincial TB managers stressed that their *“biggest problem”* was weak communication between provinces, especially as this related to patient referrals, follow-ups, and contact tracing. In addition, they worried about the fact that there was *“no referral system between mine hospitals and hospitals here.”* District TB managers worried about how working in South Africa’s gold mines impacted the health of the people in their district and their district as a whole. They did not know who current and former miners were specifically and had no systematic way to take occupational histories to learn about TB infection and risk factors. 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 was perceived as contributing to a higher disease burden. They found management of the unknown disease burden especially challenging because of the size and landscape of the district (many hard-to-reach, small, rural villages), the problems they faced with low adherence as people would go back to work when they felt a little better. They knew death rates remained high, especially among those who were co-infected with TB and HIV.

Conversations with mine health managers, however, illustrated another 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 the DoH. In addition, they felt like they had *“too many bosses”* because of the overlapping and contradicting spheres of influence involving the DoH, DMR, and Chamber of Mines. Their general sentiment was that these entities *“need[ed] to end”* the fights about who regulated and was responsible for health.

Recommendations

- 1) Reduce fragmentation through improving care coordination
 - a) Using a patient-reported measure of care coordination or care integration to inform leaders of gaps in communication across and between care settings.
- 2) Develop new care models by learning what matters most to communities and integrating them into delivery processes.
 - a) Measure patient engagement and report findings to leaders to impact delivery systems;
 - b) This includes integrating carers’ and patient knowledge of disease to support the sharing of information/knowledge to improve delivery of services.
- 2) Highlight the successes of individuals in the system who exemplify desired outcomes and management strategies.

Culture of Invisibility

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

Our work and observations in South Africa are analogous 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 feeling ignored and powerless. What we also acknowledge in this phrasing is the unique loss of personal agency (Marmot et al, 2008 & Marmot 2005) when individuals are made to feel invisible and unimportant.

Miners and Ex-miners

The invisibility that mineworkers face begins with their impoverished lives before finding work in the mines and extends to their experiences as ex-miners. Miners generally come from regions that are historically disempowered and resource-poor for reasons including Apartheid and economic and social isolation. Migrating to the mines is often seen as the only way for people to break the cycle of generational poverty so prevalent in these areas. 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 mine work as their lot in life and believed that it was all they could expect. This could lead 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 their situation, their historical disempowerment and resignation often made it difficult for them to confront and overcome 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 about their health issues in any depth, answer their questions, or show them how they cared. 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 expressed deep distrust, attributing this kind of behavior on the part of clinicians and care providers to *"Doctors, they are*

just there to look to the side of the mine. Because maybe they are being bribed, they have been given something.”

Confusion and death are the results of patients being passed between different health systems. 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 was passed 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 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 refused to 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 DoH 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 invisible and disempowered in the employment and health systems for miners and ex-miners. This was illustrated by a story of a miner who fell sick with TB or HIV and was sent home to recuperate with extended medical leave. 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 USD) a day on transportation, about twice a week”* to see the doctors [translated from Xhosa].

Anna’s Story

Anna’s father is depressed and withdrawn from the tuberculosis he contracted from the local gold mine. Anna and her mother have been his caregiver for years, earning no money in anticipation of compensation from the government. Anna is bright, energetic and in her early 20’s. With a high school education she longs to create a better life for her family. She has tried to enroll in multiple courses for a job outside of the mines, but has been had no luck - they tell her it’s too expensive. After failing to gain a certificate following a one year course in public relations, Anna went to a local mining house for a job. Although she passed her screening she was refused a position without explanation. On her way out, she was approached by an official. He said, if she paid him 5000 R, he could get her a job. Wanting to be honest and succeed on merit, she refused.

Anna is from a peri-mining community outside Johannesburg, which many still call a township. As a child she learned about her community’s history, but this meant nothing in comparison to the dirt streets she walked every day. Encircled by mountains of discarded gold waste, the inescapable presence of the mines elicit feelings of loss and anxiety about the future. Unwilling to give up like so many of her peers who struggle for escape, she remains desperate for a solution. When she thinks about her parents and how much they have done for her, she battles the frustration of having so little to give them in return.

Family members also told stories of how they felt invisible in their communities 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 move out of 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

Learning and collaboration across providers and practices could help elevate quality of care at individual and population levels. We found that many health care workers were demonstrating outstanding dedication and service to their patients. However, they were the outliers in a fragmented delivery system with diffused accountability. They were neither recognized for their efforts nor their potential to be of even greater service as positive examples for others 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 needed support and connectedness in order to deliver quality care in their communities. One believed that *“If we do our work well, the burden of disease will be minimized.”* Another nurse assistant said, *“I just want information, I just want to be trained.”*

At the same time, the ways in which health care providers spoke about patients often contributed to the invisibility that patients felt. 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 wait in day-long queues in hopes of seeing a highly trained clinician. This can contribute to a sense of isolation among patients, who felt that their health concerns do not matter to clinicians.

In many cases, the people we spoke with were more interested in seeing someone who could offer help. Many of the ex-miners we spoke with were most interested in seeing a doctor for serious problems. When asked if they preferred a nurse or community health care worker to a doctor, the general sentiment was no. According to many, it was believed that nurses provide care at the clinics. Doctors were only selectively available, and everyone we talked to seemed to know that. For these reasons, many men refused to go to a clinic, stating they lacked trust in community health workers. Some of our observations

in clinics and from speaking to patients suggest that 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.

Health Care Policymakers and Managers

In a conversation with a high-level policymaker, the overwhelming sentiment was one of concern for the divide between what happens in policy-making and what happens for the people as a result of it. It was believed that official policy documents that detail 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. Their resulting skepticism contributed to half-hearted implementation efforts. In interviews with district level health authorities, academics, and non-governmental organizations, data quality was expressed as a fundamental problem with far-reaching implications. It was suggested by clinician managers and administrators that current data and information systems hide the realities of average South Africans.

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 manager 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. Therefore, our research drew attention to a recognized gap in service delivery - that of connecting with miners and their families once they leave the services of the mines.

Recommendations

- 1) Professional incentives
 - a) Allow clinicians and care providers (nurses, CHWs, WBOTs) to spend more time with patients because that’s what both think will improve care.
 - i) Supporting more face-to-face time between care providers and patient, family, and community members will allow for opportunities to connect policies with daily practice and needs.
 - ii) Well trained, supported, and connected care providers (nurses, CHWs, WBOTs) offer important capacity for health systems in addressing TB.
 - b) Support programs that foster home care and community-based services - there are many examples where this model is successful and how it helps.
- 2) Responsive care teams
 - a) By integrating home health care and WBOT programs with patient-reported data on what is most important to patients, care teams can be more responsive

Suffocated by Production

They don't care about it, they just want to get gold and get profit. -Ex-miner

To be suffocated means to die from lack of air or an inability to breathe. We chose this word because it relates directly to stories told by ex-miners and their experiences underground – the heat, the dust, the moisture, and the brutal working conditions. We use the word production to help paint a picture of the “everyday violence” (Scheper-Hughes 1992) experienced by miners and ex-miners and their families and communities related to their need to produce as a way out. 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. Producing for the family and supporting children was more important than the risk of dying - the lure of opportunity. The dangers of working and living around mines reflect the power of the economic system to penetrate every aspect of a miner's life.

The seemingly inescapable future of communities pinned down by the institution of mining hangs over individual and collective futures. Further, the lure of opportunity, where mining risks are viewed as something not fully seen but known, encapsulates the concept of social violence. Medical Anthropologist Arthur 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 social forces 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). The stories and experiences we collected show that opportunity has its rewards and its risks, but the need to be economically productive (including generating wealth for others at the expense of the self) leads communities and families closer to death.

Miners and Ex-miners

In many cases, miners are viewed by their family members and employers as producers – supporting family and making a profit being understood as the priority. 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 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.*” Miners are treated like commodities when they produce and costs when they cannot. 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 accounts of men working in poor health, their lungs severely damaged by TB or silicosis, to earn more money to send home. As one ex-miner told us, “*Healthy comes second. Work comes first. Health is a secondary item.*” This understanding is often supported by the policies of the mining

companies where these men worked. 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 lived with the fear that he may not return home the next day. He knew he had to provide for his children.

The forces that drive men to work in these difficult conditions vary. Most 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]. Instead of function or quality of life, miners fear how sickness will impact their ability to provide for their families. This resilience and strength of character was seen as admirable by many we interviewed.

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 were seen as the provider, often the sole avenue for families to break their cycle of poverty by earning enough money to support a child’s education. Nevertheless, many family members recognized the negative impacts that the mines had on their lives; 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 look for work in the mines rather than pursue 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 disadvantages the patient and, based on our interviews, creates mistrust of the health system. We observed doctors in a district meeting say how pressure on the primary health care system coupled with provider frustration and limited recognition of effort leads to burnout. In a system already burdened, depressed physicians will negatively impact both patients and providers. These district doctors 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 whom 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, pushed themselves far beyond their limits to provide the best health care possible and to address the social and economic 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.*” This doctor is fulfilling the needs of wants 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 producing health care data demanded by the system than on the actual outcomes experienced by patients. 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 necessarily 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 whether 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, particularly to help measure progress towards different national and international targets like 90-90-90. While targets are useful for achieving urgent health goals, a narrow focus on treatment in the targets and data collected can have a negative impact on actual outcomes and patient experiences.

In addition, many of the district health officials we spoke with lamented that the pressure to achieve better HIV results meant that there was often less funding for TB and a more limited focus on individual diseases rather than the comprehensive health needs of patients and the realities that TB and HIV are closely tied to one another. Our ethnography highlighted ways in which the demand by health systems for data did not incorporate the lived experiences of the miners or effect better outcomes - contributing instead to the general goal of data production and leaving out the voices of the miners

The production of narrowly defined results and data-oriented mentality within the public health system was also strongly present among health professionals at the gold mines. As one mine nurse said about her employer, “*Remember, we are a mine, we must produce gold and gold and gold.*” The way that the mining houses approach TB prevention and treatment is analogous. 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 omnipresence of these

programs--DVDs, posters, periodic health talks, and talks at the miners' induction--means that they can become background noise with minimal effect on knowledge, attitudes, and behaviors. The quantity of programs implemented, without sufficient tailoring to the target audience and evaluating for health outcomes, is limiting the effectiveness of the mining houses' efforts to address TB. Furthermore, 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. They quite poignantly expressed, "*you can't combat TB in a month.*"

Recommendations:

- 1) Co-develop with miners, ex-miners, family and community members, clinicians and care providers, and managers and policymakers social interventions for preventing and managing illness;
 - a) Work with communities to develop alternative opportunities for miners and ex-miners to support their families rather than more competition for mining jobs.
 - b) Recruit and support opportunities for ex-miners as community health workers.
 - c) Partner with ex-miners and families to foster community-based support teams to help promote good health behaviors.

Masking of TB

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

Across stakeholder groups, TB was perceived as ubiquitous yet hidden from public consciousness. Despite its prevalence and the public health risks associated with it, people, in general, were unlikely to know much about its clinical features, how it is spread, or how to treat it. We chose to describe a large segment of our data as *the masking of TB* to refer to widespread confusion and lack of knowledge about particular characteristics of TB. Many South African organizations support health information and promotion activities in the mines and clinics. Yet confusion and a lack of knowledge among people at risk of TB infection is especially surprising.

Our data also raise questions that experiences of living with and surviving TB have been undervalued. The fact that meaningful stories remain untold limits public awareness and the quality of health care interventions. We also heard many instances of shifting the responsibility for managing TB infection among clinicians and care providers. Blame for TB infection and treatment adherence often falls on the shoulders of patients. Our understanding of this problem is shaped by Luna Dolezal's (2015) reflections on the shame in the clinical encounter. She notes that 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 the *Masking of TB* and provide examples across our groups 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.*” This lack of knowledge and understanding about TB leads to stigma and makes people wary of disclosing disease to family members or seeking care at a local clinic. Many of the ex-miners we spoke with in Khutsong township had negative feelings about their interactions with the health care system and clinician and care providers. One ex-miner told us that few people want to go to the local hospital. He said, “*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.*” Negative experiences with health facilities make people 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. Some were diagnosed after they had repeated incidences of flu 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.

Because few efforts have been made to help these men and their families and communities understand TB in a way that will fit their cultural perspective, they continue to get sick and pass the disease onto their family members. They are often stigmatized for their illness because of their family’s fears that the infected will pass the disease to the rest of the family. One ex-miner related how he was discriminated 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.*”

A lack of understanding is compounded by how TB is talked about in the mining houses. Topics in occupational health and disease are not discussed in a clear and comprehensive way, even with miners who are sick. 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 with few opportunities to clarify the nature of a TB infection. Instead, TB was often understood as directly and only 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 other factors that increase risk of TB infection. A man from Mthatha said he “*associated my sickness with my work at the mines because of the dust and smoke underground*” [translated from Xhosa].

One ex-miner said that the problem with many TB education campaigns in the mine he worked in was that, *“Those posters of TB, they just put it on the wall, they don’t explain it to a person.”* It fails to account for how health is tied to job security, a lack of educational opportunities, and negative attitudes towards and experiences with existing health care delivery systems. As a result of weak health information and communication strategies, miners are often reinfected with TB; it will *“retake”* them or is *“recycled”* in their bodies, as they said. This has negative long-term health effects, as an ex-miner who had *“retaken”* TB medications three times said, *“I can not even blow that [spirometer] because I feel myself I’m still sick, even though there are not those symptoms”* [translated from Sesotho].

Few of the ex-miners we spoke with received accurate, relevant 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 that he had contracted while a miner, shared his father’s story: *“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]. How could this man protect himself, his workmates, or his family when he was only told that he had *“chest problem”* instead of getting his TB explained? How could he adhere to treatment or work to get better if he did not even understand what was wrong? This lack of support for people to help them understand 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, all of whom had experienced TB in their family, also had limited knowledge and inaccurate beliefs about TB. One miner’s son described his experience with TB, 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]. 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.”* Misunderstandings about the disease itself are compounded by misunderstandings about TB’s relationship with HIV. Many people believe TB and HIV 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 or said, *“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 heard that health education for families was even more limited than health education for miners. Stigma and misunderstandings were exacerbated by the fact that, even though wives served as caregivers, neither the mining houses nor the local health facilities gave family members TB information. Further, they did not provide follow-ups to monitor that informal caregiving that occurred within families was safe and effective. 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]. Family and community caregiving is a valuable service to the public health system and the mines where the diseases were

contracted; however, quality and outcomes won't be achieved without adequate health information, integration, and local support systems.

Clinicians and Care Providers

Clinicians and other health care workers contribute to the masking of TB and the disease's negative impacts when they blame patients for difficulties in treatment adherence. One mine nurse became upset when she spoke about treatment defaults, saying, "*it's on your behavior*" whether you get sick. She disparaged 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. While it is clear that she cares about the outcomes of her patients (not always reflected in the stories we heard of doctors giving pills and never following up), her attitude of blame perpetuates negative attitudes towards TB health services, driving people away from the health system. 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.*" Blaming patients fails to account for social, cultural, economic, historical, community, and political factors that influence people's health, behaviors, needs for care, and ability to get the support they need to adhere to treatment.

Health Care Policymakers and Managers

On many occasions, we experienced the deliberate evasion of uncomfortable stories by administrators and high-level managers. Individual circumstances varied, but generally the stories we shared interested administrators, who admitted they preferred having others collect this kind of data. During a group interview, a policymaker in a position of authority explained that it is much easier to avoid seeing and hearing stories from the field because of the effect it will have on her work. With regards to our approach for collecting stories from those most affected by TB, 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 policy administrator that interested parties talk around the issues and develop solutions, however accountability is diffuse and implementation challenges remain unsolved. Some policymakers suggested that our purpose should be to ask "*why had the conversation around institutional failure to solve TB gone underground?*" This 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 blamed low adherence on the system, instead of the patients, "*You can have a system that's supportive enough to actually get people to come on treatment.*"

Recommendations:

- 1) Overcome the "Masking of TB" (stigma and accountability) through measuring what matters most to patients to improve accountability
 - a) Collect and disseminate patient-reported outcome data for better allocation of resources among care teams to interventions with greatest success.

- b) Sharing data between care teams to encourage competition and support best practices.
- 2) Use measures/tools that empower clinicians and care providers to deliver care that is responsive to individual and population preferences
 - a) Co-develop measures and tools with miner and ex-miners to help clinicians better meet their needs
- 3) Partner with ex-miners through community health worker programs (WBOTs)
 - a) Recruiting ex-miners into health care delivery design and implementation processes to promote jobs, support trust, and build stronger relationships between communities and the system

Conclusion

These findings provide convincing evidence that previously held suppositions about the sense of disempowerment and hopelessness or the role of stigma, for example, were true and pernicious. These confirm and add to current social science literature detailing how TB continues to disproportionately affect the underserved in peri-mining and labor-sending communities. In the following paragraphs we demonstrate how this ethnography helps shape what can be done for TB in South Africa and we offer recommendations based on these.

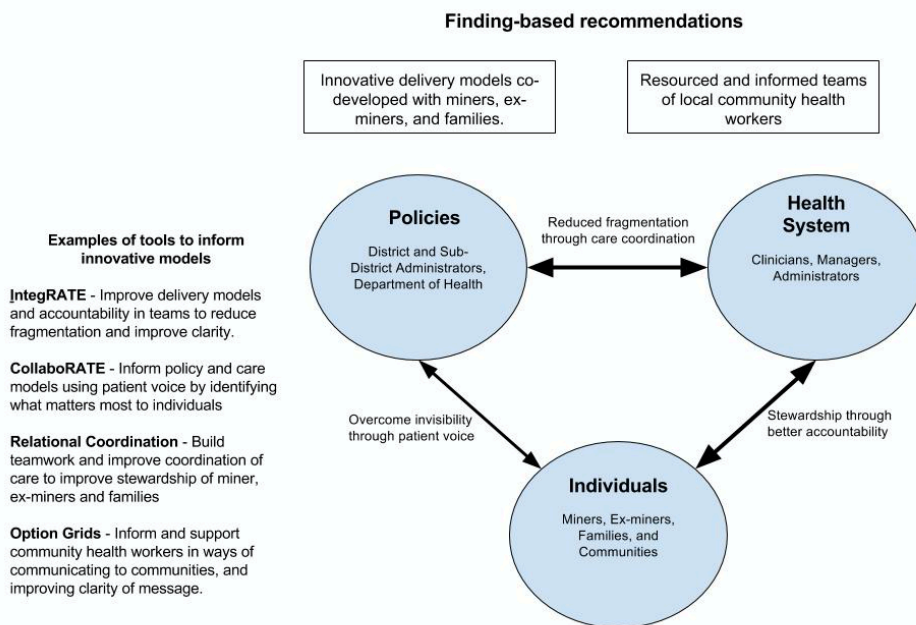


Figure 1. Innovating health delivery in South Africa TB care

The ethnography brings to the foreground many of socio-cultural dynamics and perceptions of TB care that substantively impact mining communities and TB control. Previous assumptions regarding access to care, fragmentation, and under-resourced communities were confirmed. However, nuances of our findings elucidate just how impactful TB in the mines has been and remains in the lives of individuals, families,

and their communities. The four main thematic findings, restated in brief here, reflect participant language, feedback, and reactions. We found that the health system is a collection of fragmented ecologies and interdependent groups working in parallel. Further we witnessed a system where individual perceptions of isolation, fear, and abandonment hang over people like a shroud, keeping their stories hidden from those with the power to effect change. In many ways the ubiquity of the mines, their massive presence across all aspects of life in South Africa, creates difficult-to-escape pressures on communities, both in death and life - giving many few options for health and livelihood. Ultimately, the effects of TB and the risks for mine workers and their families are often not shared or well understood. Efforts to mitigate TB, therefore, often receive attention at the policy level, but rarely extend to gain needed community-based support.

At the heart of the South African mining landscape emerged the strength and resiliency of mining communities and families. We need only reflect on Sister Mary and Anna's unwillingness to give up, and many of the miners, who continue to fight to be productive. 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. It was also clear from our interviews that compensation for occupational TB and silicosis is important to ex-miners and their families as a means of addressing immediate needs. We found that focus on compensation for illness does not provide miners or their families with a long-term solution to help them break the cycle of poverty. Therefore, compensation needs to be considered alongside medical and social interventions. The problem of TB in peri-mining and labor-sending communities goes far beyond compensation and demands multidimensional interventions.

While some have argued that populations in the peri-mining communities outside Johannesburg have been “over sampled,” our findings suggest that very few researchers have engaged ex-miners and their families through a process of eliciting preferences to determine what matters most to them. This new approach, centered on a process of stakeholder engagement, helped participants question their own assumptions and facilitated new insights. As discussed previously in *Demographics Explained*, a majority of our interview data excluded miners due to local sociocultural and political issues. 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 their stories, lived experiences, and comments were robust examples of current descriptions verified by mining staff, clinicians, and other researchers. An additional limitation was navigating the different languages of South Africa during data collection. In some instances, where translator “over-involvement” became an issue, the accuracy of the questions asked came under suspicion. Follow-up review by native speakers helped to clarify and address inaccuracies in data and the use of key informants provided intended depth and richness of data.

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.

Strategic and operational responses to the findings

Upon conclusion of data collection, we formally presented preliminary results and analysis to district and sub-district managers at the West Rand District Health Office in Krugersdorp, and to Health Administrators from Chris Hani District and Province Health Administrators from the Eastern Cape. We also presented to diverse group of stakeholders, including physicians, researchers, and government representatives at the University of the Witwatersrand School of Public Health. The goal of these meetings was to share insights, generate discussion, and receive feedback that could be integrated into reports and shape future implementation plans. Discussion and feedback supported and clarified the results and analysis.

Many of these strategic and operational responses have been applied in other contexts to improve healthcare delivery and outcomes. Each response is meant to be developed and implemented with broad stakeholder engagement, including the miners and ex-miners and their families and communities that will live with the consequences. Strategic opportunities capture elements that could be integrated into regional, national, and local policies and frameworks for addressing TB in the mining sector. Operational opportunities capture actions that can be taken on regional, national, and local levels to drive better health outcomes and patient experience at lower cost.

Strategic Responses to Findings

- 1) Co-Develop new delivery models through stakeholder engagement, learning what matters most to communities, and integrating preferences into care delivery processes.**

Innovative care delivery strategies may positively disrupt the current care practices and drive expected improvements to mitigate TB in South Africa (Fay et al., 2015 & Joseph-Williams et al, 2013). To achieve acceptance, value, and sustainability, innovations must be designed around what matters most to patients, families and communities. Engaging communities throughout the design and implementation of new models of care is the only way to ensure this (Pinto et al., 2012). As we demonstrated in our findings, Community Health Workers fail to meet district screening quotas due to fears of CHWs sharing confidential health information in the community. In another example, we learned from ex-miners and their families that compensation for occupational diseases was more important to them than seeing a doctor. We know that eliciting individual and community preferences can inform innovative models of care delivery but also support the effective implementation of those models across the continuum of care. This needs to be done with informed and resourced teams, constructed with those who can relate directly with those affected in communities.

- 2) Invest in current health care delivery systems to deliver integrated care in communities.**

As the clinicians noted, tremendous waste emerges through redundancies in providing silo care in communities. Clinicians and care providers articulated a need for more training, better integration across systems of care, and greater accessibility to care for patients. They were consistently overburdened with tasks such as data collection, under-resourced relative to patient needs and expectations, and disconnected from other clinics and hospitals. In addition to clinician burden, patients reported travelling great

distances at devastating personal cost to access care. Although systems exist to overcome these distances, they are not working. Responding to this repeatedly expressed patient concern might involve using currently idle medical vans or trucks to screen communities hundreds of kilometers from central hospitals. Current programs to refit former ambulances for this service have been offered as possible solutions.

Findings further demonstrate, miscommunication and misunderstandings often result in poor treatment adherence, mixed messages, lack of care utilization based on mistrust, and poor knowledge of TB and self-management of illness. Supporting community-based solutions at the district level is needed. The success of “Sister Mary” is an important reminder that South Africa is full of motivated individuals who are ready and willing to do what it takes to improve life inside communities. Her story also illustrates that doctors are not necessary for providing health information and psychosocial support to patients. Community-based teams, managed by a capable lead nurse can be highly effective in relating to patients and communities. Given our findings, these teams need to be equipped with basic medical knowledge, trained in communication and information management, and resourced to provide care in communities. This means providing medical masks, transportation, and cell-phones.

Based on our current understanding about challenges of communication and medicine, it is advisable to consider ways of integrating messaging strategies to improve patient outcomes. We know that like in South Africa, patients in other countries experience fragmented care, inconsistent messaging, lack of information and confusion (Elwyn, Thompson, John, and Grande, 2015). Using tools developed with communities will help communicate and manage information that is context specific and meaningful (<http://rsrc.brandeis.edu>). We also know that short, one page tools, like decision aids and smartphones have been proven effective in many settings for empowering patients, particularly those that are behavior dependent for prevention and treatment adherence like TB. Competency-based training programs delivered in-person or online can support professional development in these areas.

3) Measure and support provider and patient engagement in order to improve prevention and treatment adherence

Individual knowledge about illness and disease helps clinicians to discuss the pros and cons of specific treatments and decisions. Yet a review of evidence tells us that knowledge alone is not enough to improve behaviors - clinicians must also be aware of barriers to informing their patients about decision making (Joseph-Williams, Elwyn, and Edwards, 2014). We also know that one of the leading barriers to improved patient outcomes is fragmentation, miscommunication, and patient confusion. If clinicians are supported to meet the needs of patients, prevention and treatment adherence efforts can be contextualized and meaningful. Using this approach and evaluating practice may reduce burdens on the health system. For instance, a TB patient who understands the risks of nonadherence may be more likely to risk travel only when needed and be in a better position to self-manage their own illness. We know that for many ex-miners, their knowledge about TB was self-described as “limited” - for example, many ex-miners didn’t know the risks of spreading TB nor the risks of reinfection. These and other examples were characterized by the “Masking of TB”.

We believe that a simple, three-question, patient-reported measure of shared decision making process, CollaboRATE (www.collaboRATEscore.org) can accurately report how well patients are engaged at the point of care. Knowing that a majority of those we interviewed do not trust care providers or believe they actually listen to patients, this measure can be used in clinics to feedback patient sentiments to health administrators. We also have experience using CollaboRATE data to feedback scores to clinicians to alert them to the missing communication strategies. We also know that based on lessons learned from Ecologies of Fragmentation, that a patient-reported measure of shared decision-making would be useful for training nursing and Community Health Workers in ways of more effectively communicating with patients. As we reported earlier, many participants often laughed or expressed disbelief when asked if clinicians ever took the time to speak with them about their health issues in any depth, answer their questions, or show them how they cared. A tool that would help both patients and clinicians have more meaningful consultations must be integrated carefully into a context like South Africa. Further, we believe this kind of cultural shift would be a radical shift in training. However, we know that current processes are in place to allow for testing of this measure in small participating health centers in Gauteng and Eastern Cape.

Understanding how living conditions, longevity of work underground, sexual activity, and substance abuse increase the risk of TB infection would help people begin to dismantle factors that contribute to TB's persistence. If they knew the risks of working conditions at the mines, miners may still decide to go for economic opportunity. However, they'd be better able to manage and mitigate the risks individually and collectively, thereby reducing the prevalence of disease. Tools such as newly developed TB- and local context-specific Option Grids (www.optiongrid.org) could support risk analysis and decision making.

We observed several health information programs in the public health system at the mines. Limitations of these included lack of engagement of the target audience in developing health messages, weak evaluations to measure effectiveness and improve, and failures to reach those not actively seeking care or in a captive population like workers at the mines.

4) Identify and support low-cost social interventions for preventing and managing illness

Many ex-miners and family members reported concerns about educational and employment opportunities. They lived in overcrowded homes and isolated communities. Increasing access to quality education for children of miners and ex-miners could help create different employment and livelihood opportunities for the next generation. Supporting wives and widows to earn an income in their community could help relieve the economic burden faced by families. Other issues affecting TB health care delivery uncovered in our data including the disintegration of family and community structures in labor-sending communities due to migration, stigmatizing attitudes, and gender and human rights barriers also require non-medical approaches. For medical interventions to be most effective, the health care system needs to collaborate with other sectors to address social and economic factors that influence TB. Identifying simple, low-cost social interventions that could substitute for expensive medical care could lead to better outcomes and patient experience at lower cost.

Operational responses to findings

1) Empower and train clinicians and providers to deliver care that responds to patient needs and wants to reduce care fragmentation and lack of agency

Simple, standardized health communication tools tailored for target populations can be used to effectively inform patients about their health issues and create meaningful conversations between patients and providers in choosing together how best to address it. Studies have shown that when patients are informed, engaged and supported in decision making, and supported achieving their health goals, they are more likely to follow through on healthy behaviors and pursue less invasive, costly health care strategies. Providers experience higher satisfaction in their work for developing meaningful relationships with patients and achieving better results.

2) Engage with miners, health care providers and communities to confer agency and combat stigma.

Stigma was identified as a significant barrier to healthy and health-seeking behaviors among those with or at risk for TB. Stigma was driven by the lack of accurate, culturally-relevant information on TB, misunderstandings about TB association with HIV (still, a highly stigmatized disease), and patient blaming. In order to meaningfully address stigma, information, education, and communication materials need to be adapted to target audiences. People in the communities affected by TB hold information about target audiences' attitudes and beliefs relevant to the development of effective stigma reduction campaigns. Employing these people to develop and refine campaign materials for target audiences could help ensure their effectiveness.

3) Empower ex-miners as community health workers through Ward Based Outreach Teams (WBOTs).

Ex-miners with TB are often dismissed from work at the mines or unable to return to work at the mines. In addition to TB, they suffer from a lack of employment opportunities. WBOTs are under-resourced, yet they are well positioned to deliver high quality care in the community. Ex-miners, as part of WBOTs, would offer a unique ability to develop trusting, lasting relationships with miners and other ex-miners and their families and communities for their shared experiences and understanding of the problems to be solve. This could complement existing WBOT strengths and help manage and mitigate the risks of TB, support adherence to treatment course, and provide need care and psychosocial support. At the same time, it would create meaningful employment opportunities for ex-miners and serve as an example of an alternative pathway for earning an income.

4) Engage with ex-miners and miners using patient-to-patient TB support groups to confer agency to others to ensure visibility in communities.

Outside of WBOTs, ex-miners could also delivery TB support services to ex-miners and their families in the communities. Ex-miner associations in South Africa, Lesotho, Swaziland, and Mozambique are already performing some of this work. They go door-to-door to check-in on fellow ex-miners and their families. They also advocate for the needs of ex-miners and their families and represent the voices that are

often suppressed in local, national, and regional dialogues. Again, ex-miners are a trusted source of information and support for TB patients and their families. Connected with existing systems of care, they could provide referrals to higher levels of care and supply meaningful new data to existing health information systems.

5) Co-develop incentives for clinicians, managers, and policymakers to learn about context and the realities of illness in order to integrate this understanding into TB policies and practice

Too often, high-level stakeholders and care providers lacked an understanding of the context of the mines, peri-mining communities, and labor-sending communities. They were also overburdened with day-to-day tasks with little slack time to observe, study, and experience the contexts from which those they aim to serve come. This often creates disconnect between policies and practices and the actual needs and wants those policies are meant to address. As a result, implementation of technically sound policies and practices falls short of meeting their intended impact. While spending time at the mines and in the communities where miners and ex-miners live would help equip clinicians, managers, and policymakers to develop more context-relevant policies and practices, the everyday demands of their job make this impossible. Measures of patient and community engagement in the design and development of policies and practices could help motivate clinicians, managers, and policymakers to integrate context and lived experience into high-level decision-making.

Need for delivery science to support implementation

In this study, ethnography was used to describe the situation at and around the large gold mines in South Africa and in a labor-sending region in South Africa. While this offered new data and insight, understanding the many dimensions to the problem of TB in the mining sector and the effectiveness of implementation efforts requires continued and broadened ethnographic inquiry. To do things differently leadership can leverage evidence produced from this ethnography to support the design and implementation of strategies and programs that require an understanding of local context to implement successfully (Mulley, Richards, and Abbasi, 2015).

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