Barriers to tuberculosis care delivery among miners and their families in South Africa: an ethnographic study

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SUMMARY

SETTING: South African miners suffer the highest tuberculosis (TB) rates in the world. Current efforts to stem the epidemic are insufficient. Historical legacies and persistent disease burden demand innovative approaches to reshape health care delivery to better serve this population.

OBJECTIVE: To characterize social and behavioral health determinants for successful TB care delivery and treatment from the perspective of miners/ex-miners, health care workers and policy makers/managers.

DESIGN: We conducted applied ethnography with 30 miners/ex-miners, 13 family/community members, 14 health care providers, and 47 local policy makers/managers in South Africa.

RESULTS: Miners/ex-miners felt health care delivery systems failed to meet their needs. Many had experienced unnecessary physical and psychological harm due to limited health education about TB, minimal engagement in their own care, lack of trust in providers, and a system that did not value their experience. Stigma and fear associated with TB result in denial of symptoms and delays in care seeking. Health care providers and policy makers/managers felt discouraged by system constraints in providing optimal care.

CONCLUSION: Our findings describe long-term effects of perpetual TB misinformation and stigma resulting from fear and disempowerment among miners and their families/communities. To reduce the TB burden, there is an urgent need to co-design a care delivery system with miners to better meet their needs.

KEY WORDS: TB; miners; South Africa; stigma; health care delivery

WITH AN ESTIMATED INCIDENCE of 3000 per 100 000, miners in southern Africa have the highest tuberculosis (TB) rate in the world.[1] Mines are the ideal setting for maximizing TB transmission and disease progression. Miners work long hours in enclosed spaces with poor ventilation. Limited sunlight and crowded dormitories allow TB bacilli to thrive and pass between coworkers. Human immunodeficiency virus (HIV) infection and silica dust exposure, which affect approximately 25% of miners, each increase the chance of progression from tuberculous infection to disease 30-fold.[2–6] Furthermore, an estimated 60% of miners are migrants, predominantly from Lesotho, Mozambique, and Swaziland, who leave their families and cross the South African border for employment.[7] The absence of cross-border referral systems contributes to cycles of interrupted or incomplete treatment and TB transmission in the miners' home communities.

Given their geographic concentration and high burden of disease, South African miners have been the subject of much TB research, primarily clinical and epidemiological studies.[8–10] While this work has advanced our knowledge of the TB epidemic and provided evidence for the effectiveness of interventions such as isoniazid preventive therapy,[11] these efforts have failed to reduce the overall TB disease burden in miners. Traditional approaches of both 'passive' and 'active' case finding and treatment[12] have had limited impact on their TB incidence or clinical outcomes. Legacies of apartheid, poor treatment of miners and inadequate communication of company policies have fostered a culture of fear and mistrust,[13] such that comprehensive health screening programs, especially when mandatory, could be construed as employer-driven efforts to cull the workforce or improve company profits.[14] Although the social implications of living with TB, such as fear, shame and stigma, are well described,[15–17] the lived experiences of miners, including their barriers to and preferences for care, have not been studied.

The interplay of historical context with persistent

disease burden urgently calls for innovative, interdisciplinary approaches to health care delivery in mining communities. The complexity of the problem necessitates clarifying the social, economic, and political influences that can strengthen health care delivery strategies in specific contexts. We conducted qualitative research among miners/ex-miners, their families, health care providers, and local policy makers/managers in South Africa to identify the unique social and behavioral health determinants for successful TB care delivery and treatment.

STUDY POPULATION, SETTING AND METHODS

We conducted applied ethnography[18] of TB care delivery in the South African mining sector. Key stakeholders were miners/ex-miners, their family and community members, health care providers, and local policy makers and managers. Miners/ex-miners were South Africans or nationals of labor-sending countries currently or previously employed by one or more mine companies in South Africa. Family/community members included spouses and children of miners and their neighbors living in South Africa. Health care providers comprised doctors, nurses and community health workers from the public health sector, and home-based care organizations. Health care policy makers/managers were from mining companies, district or provincial health departments, or non-governmental organizations involved in the health of miners.

We trained six field researchers in the ethnographic methods of conducting formal and informal interviews, field notes, participant observation, and data analysis with thematic analysis and grounded theory.[19–23] We collected data from West Rand District in Gauteng Province, and O R Tambo and Chris Hani Districts in Eastern Cape Province. These locations were suggested by health officials from the South African Medical Bureau of Occupational Diseases, Johannesburg, and the University of the Witwatersrand, Johannesburg, South Africa, for existing interest and efforts to integrate occupational health and compensation services for miners/ex-miners.

Recruitment

We used both snowball and convenience sampling. Recognizing the value of peer-to-peer trust among marginalized populations, we relied on key informants' personal and professional contacts to recruit in communities. As our access to current miners was limited, we focused on recruiting ex-miners.

Verbal informed consent was obtained after sharing information sheets and discussion with participants to ensure individual understanding and acceptability.

Participant observation and interviews

We observed ex-miners, their families and neighbors engaging in their usual activities in their homes and communities. We spent time in government offices and clinical facilities, making notes of patient flow, clinical encounters, and health department operations. We collected observational data in multiple settings to support the validation of content.

We developed a topic guide for interviews and focus groups that we pilot-tested among community members in South Africa, and iteratively modified (Table 1). Working in pairs balanced for sex, ethnicity, and disciplinary background, we conducted focus groups and informal and formal interviews, audio-recording them when permitted. We also collected narratives through informal interviews with study participants.[24]

Data collection and analysis

Our research team reviewed research protocols and data collected daily for reliability. Members submitted daily and weekly summaries to aid recall of observed differences in experiences and to provide thick description for the subsequent analysis of context.

Multilingual team members translated interviews and focus group data collected in Tswana, Sesotho, Zulu, or Xhosa into English, and entered these into a database. Transcripts were qualitatively assessed using a grounded theory approach, as described in the literature.[25,26] We patterned our analysis on the procedures outlined by Corbin and Strauss;[27] this approach is widely recognized as an effective methodology for analyzing large amounts of complex observational and interview data.[23,25,28,29]

The iterative analysis process involved three cyclical steps: 1) individual analysis, 2) small group discussion and thematic analysis, and 3) consensus through triangulation of small group analysis. First, field notes were individually summarized, then grouped by emergent themes. In step 2, two groups of analysts determined the most salient themes by repeated review, selected narratives that best reflected those themes, and independently proposed a representative model. Finally, both groups came together to finalize findings. Disagreements were resolved through discussion and group consensus.

The Institutional Review Boards of Dartmouth College (Hanover, NH, USA), University of the Witwatersrand (Johannesburg), Eastern Cape Province Health Department (Bhisho), and West Rand District Health Department approved the study (Krugersdorp, South Africa). As a waiver for written informed consent was obtained from the institutional review boards that approved this study, verbal informed consent was obtained after sharing information sheets and discussion with participants to ensure individual understanding and acceptability.

Table 1 Standard in-depth interview and focus group discussion questions by participant group

Participants	Interview questions*
Miners/ex-miners (n = 31)	How and why did you start working in the mines? What was it like being recruited to work in the mines? What types of information were you given about safety concerns and the work you would be doing in the mines? Can you tell me what you know about TB? Where did you get this information? Before you became a miner, did anyone ever talk to you about the risk of getting TB from working in a mine? Who was that? What did they tell you? Can you describe your or others' experiences with the mining company clinic? When do you go there? For what types of problems? How are you treated? Who are the most important people in your daily life? Tell me how you would describe a typical visit to the health center What are the most important ways to talk about health with you and your friends?
Family and community members (n = 13)	Tell me about yourself and your family Describe a typical day for you What happens if someone gets sick? Can you tell me what you know about TB? Where did you get this information? Where does someone go if they are ill? Who are the people you would ask if you had a health question? How do you feel about the health services that are offered in your community? In general, what words would you use to describe your health? How might you describe the health of your friends and relatives?
Clinicians/health care workers (n = 14)	Describe a typical day at the clinic. Who do you see? How do you help them? What do you do if a miner is diagnosed with TB? If a miner visits the clinic and complains of respiratory problems or coughing, what do you do? What do you think are the main reasons that a miner might not complete his anti-tuberculosis treatment? Tell me your thoughts and feelings related to getting health care
Health care policy makers and managers (n = 47)	What is the relationship between working in the mines and TB? What responsibilities do the mining companies have if an employee is diagnosed with TB? In your opinion, what are the biggest barriers to implementing more widespread TB testing? If a miner has TB, where are they diagnosed and treated? How do you feel about the services that are offered? What do you think are the best ways for miners and their families to receive health information about TB?

* We completed in-depth interviews with each of the 31 miners/ex-miners and 13 family/community members, and with 7 of the health care workers and 3 of the managers/policy makers. We also conducted 3 focus groups with health care workers and 2 with managers/policy makers, with 5–8 participants present at each. TB = tuberculosis.

RESULTS

We completed 54 ethnographic interviews and 5 focus groups with 30 miners/ex-miners, 13 family/community members, 14 health care providers, and 47 policy makers/managers (Table 1). Participant demographics and interview specifics are shown in Table 2. We labeled the strongest TB-associated theme that emerged as the 'masking of TB'. This 'masking' combines widespread lack of knowledge about TB, the stigma and fear that result in part from lack of knowledge, and the structural and symbolic

Table 2 Demographics of participants interviewed and interview specifics

Participants	n	Age range years	Current profession	Location of interview	Type of interaction
Miners/ex-miners	30	28–66	Underground miner, unemployed, informal work, contract work, part-time work	Homes, public parks, clinics, one-stop clinics	Informal interviews, interviews and focus groups
Family and community members	13	23–57	Unemployed, professor, informal work, student, homemaker, service industry	Homes, clinics, community public spaces	Interviews and focus groups
Clinicians/health care workers	14	33–56	Physicians, nurses, home-based care, community health worker	Clinics, hospitals, one-stop clinics	Formal and informal interviews
Health care policy makers and managers	47	NA	District officials, province officials, the Medical Bureau for Occupational Disease, NGO managers, mining house health managers, Chamber of Mines	Clinics, hospitals, district health offices, organization offices	Formal and informal interviews

NA = not available; NGO = non-governmental organization.

violence that occurs when TB is hidden from public consciousness.

Widespread lack of knowledge about TB

Miners/ex-miners and their family/community members knew little about TB's clinical features, how it is spread, or how it is treated. Many miners/ex-miners believed that TB is caused by dust underground or from the large mounds of mining waste near the mine surface. Such misunderstandings contributed to the unintentional spread of disease to co-workers and family members. It may also have led to risks of re-infection, which miners described as how TB can 'retake' them or is 'recycled' in their bodies.

Miners/ex-miners were confused about the employment consequences once diagnosed with TB. While policy dictates that miners are not fired because of TB, several ex-miners told us about being 'asked to leave their job' as a result of their TB. Miners diagnosed with TB reported being told there were no other opportunities for them in 'friendlier or safer locations'. Similarly, family members had limited knowledge about TB. One miner's son described his experience, saying, 'I don't know how I got the TB or what kind of TB it is', and another who was convinced that:

> …it's a disease where you are going to die….That's why I didn't want to hear someone saying 'you've got that TB'….It's a death sentence.

Many miners/ex-miners told us that their company did not provide appropriate TB education during their employment; any TB education occurred only during induction trainings, without opportunities for clarification. One miner said the problem with TB education campaigns in the mines is that:

> …those posters of TB, they just put it on the wall, they don't explain it to a person.

During a mine visit, our team observed dozens of unclear or complicated health posters and TV screens that repeated the same safety video every 10 min. Miner education also did not appear to address how health is tied to job security, educational opportunities, or prevailing negative attitudes towards or experiences with existing health care systems.

Once diagnosed and on treatment, miners felt they rarely received accurate, relevant information about their illness at the mine clinics. A man whose father died from TB while working in a mine reported that when his father:

> …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.

A lack of information about how successful TB treatment can be led miners to believe:

> TB is incurable even when you take your treatment, we know that; because this thing is in your lungs and lungs are life.

We learned how limited health education was for families. Although wives often served as care givers, many reported that neither the mining companies nor local health facilities provided them with TB information. As a miner's widow said:

> …the nurses and doctors would never explain anything to us, we would be excluded from the consultation.

TB stigma, fear and distrust of the health care system

Miners often denied having symptoms to their families because of the shame associated with TB and its association with HIV. One miner explained how illness-related discrimination in families reflects misperceptions that weight loss, weakness, and coughing up blood are contagious and lead to death. As families noted, miners/ex-miners with these symptoms have died with a diagnosis of HIV and TB. While families have ample, direct experience that miners/ex-miners bring sickness and death from the mines, this sometimes led to assumptions and accusations rather than support. In one instance, a miner recalled being reproached that he 'coughs too much' and that he 'must still have TB'. Indicative of many miners/ex-miners' experiences, these micro-aggressions produced a feeling of severe isolation when ill. Consequently, many miners/ex-miners reported rarely sharing their experiences of living with, or surviving, TB with their families.

Miners/ex-miners felt negatively about their interactions with the health care system and clinicians. Several reported experiences that left them doubtful that hospitals were places for healing. One ex-miner stated:

> The hospital is a storeroom where you go to die.

Many of the men we spoke with would delay visiting a doctor out of fear and, potentially, a lack of perceived social and instrumental support. Some reported self-delaying access to TB care; others were eventually dragged to a clinic by their wives or transported by ambulance because their illness had progressed so far that they collapsed.

When we asked miners/ex-miners whom they trusted, they described the strong bonds they formed with their co-workers, and how, because of the dangerous working conditions, they literally placed their lives in their co-workers' hands. One ex-miner relayed:

> Anyone that I was working with, I took him as my friend because I was working along him….You know in the mines, if you don't cooperate with the

people that you are working with, you can easily be trapped.

This cooperation also led to shared experiences and friendships that provided support during difficult times, including illness. However, given the shared lack of knowledge about its cause and how to protect themselves from TB, often all miners could do was bear witness to others' suffering. As one ex-miner said:

> I was working with another guy, he was a miner. He was afraid to go to the hospital….He died underground, that one I can witness it, he died underground.

Seeing friends die from TB perpetuated miners/ex-miners' fear and sense of powerlessness.

The clinician's perspective: whose responsibility?

Most health care workers interviewed were unable to acknowledge the socio-economic and cultural determinants affecting their patients' understanding or perception of illness. Clinicians appeared to blame patients for poor treatment adherence. One nurse became very upset talking about her patients who interrupt their anti-tuberculosis treatment, saying, 'it's on your behavior' because the mine is 'putting a lot of energy in you' with health education campaigns and free medication. She said she felt like asking those who discontinued treatment, 'Why are you killing yourself?' We heard many clinicians shift the responsibility for managing TB from the clinician or system to the patient. One clinician in a district meeting said:

> …clients don't understand that they need to do their part for us to do our part.

Health care workers rarely recognized the challenges their patients face in accessing or adhering to treatment—challenges that include the social and medical dislocations of migration, stigma and mistrust, and economic hardship. Health care workers routinely blamed the habits of individual patients for the high rates of TB, without attributing any contribution from inadequate counsel or clinician behavior. This was most evident in discussions with stakeholders at the managerial level who spoke about difficult, uneducated, or non-compliant patients.

Policy makers/managers: issues too difficult to face

Policy makers/managers were generally interested in our research and admitted they had not previously collected such data. During a group interview, a policy maker stated that it was much easier to avoid seeing and hearing stories from the field because it affected her work. We were told:

> …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.

Such attitudes among these stakeholders contribute directly to the 'masking' of TB.

Policy makers/managers told us that stakeholders talk about the TB epidemic among miners and discuss possible solutions; however, accountability is diffuse and challenges in implementation remain unsolved. Conversations with policy makers/managers revealed a general sense of resignation due to the broad social factors (e.g., fear, stigma, apartheid legacy) that further complicate the problem. One interviewee described it as a collective malaise in addressing the TB epidemic. Some suggested that an analysis of the failed systemic approaches to TB among miners might reveal the origins of the fear and misinformation that masked TB and contributed to their poor outcomes. One mining organization manager was hopeful that:

> You can have a system that's supportive enough to actually get people to come on treatment.

Overall, administrators expressed motivation to address TB in miners, but felt overwhelmed by the bureaucracy and their ability to effect change.

DISCUSSION

Our novel qualitative findings are the first to examine social and behavioral determinants of TB and care delivery among miners/ex-miners, their families/communities, health care providers, and policy makers/managers in South Africa. Our structured observations reveal a widespread lack of knowledge and understanding that contribute to the 'masking of TB', despite health promotion activities in mines and clinics. The further exacerbation of stigma and fear associated with TB manifests in miners/ex-miners as a denial of symptoms, delays in care seeking, and a distrust of the health care system. Among families it appears as misinformation and incomplete understanding of TB risk, treatment, and prevention. Longstanding stigma and discrimination in the TB care pathway has been well documented.[30–35]

Stigma and the association of TB with HIV and what health care providers and policy makers labeled 'negative behaviors' can reduce patients' willingness to be evaluated for TB and cause them to interrupt their treatment.[30–35] However, this masking extends beyond knowledge gaps and stigma; it is an articulation of symbolic and structural violence. Masking TB brings new forms of risk and vulnerability, as well as the possibility for health care workers and policy makers to place the onus on patients and avoid dealing with entrenched health inequalities and the need for structural changes to current health care delivery systems.[36,37] Our data also suggest that local

experiences of living with and surviving TB were unknown to the clinicians, managers, and policy makers we interviewed. This limits public awareness and the potential for adapting health care services to the miners' context.

Interventions responsive to these findings would include shifting to community-based education to improve care-seeking behaviors among miners and to provide families/communities with a chance to collectively respond to reduce stigma. Giving more attention to lay health education and promotion among local support systems will further benefit family and community care giving. Studies in rural Ethiopia and Nicaragua have shown that interventions to improve knowledge and address stigma, such as the initiation of local TB support groups, can improve care-seeking behavior, clinic attendance, and treatment completion among TB patients.[38–40] Furthermore, such patient-based groups can improve patients' understanding of TB, including initial reactions to diagnosis, and build better attitudes towards TB in the community.[38–40]

Clinicians serving miners adhered to the prevailing biomedical model that tends to hold TB patients responsible for contracting their disease and for treatment adherence.[41] Nevertheless, many clinicians were eager to learn new approaches to better serve their patients. Under a co-designed delivery model, clinicians trained in shared decision making and motivational interviewing would learn to address their patients' shame and guilt about having TB and engage them in their care and treatment. Blaming patients fails to recognize the interdependence of providers and patients, and to account for broader socio-ecological factors that influence people's health behaviors and preferences, and ability to get the necessary support to adhere to treatment.[40]

Among policy makers/managers, the masking of TB articulates, in part, as poor communication with patients, families, and clinicians, which has resulted in implementation challenges for TB management and treatment. Furthermore, the longstanding, socially complex nature of TB in the mining sector has caused policy makers/managers to feel overwhelmed, constraining them in effectively identifying problems and seeking and implementing solutions with others, including miners/ex-miners and their families/communities.

Several approaches to overcoming this masking of TB can be derived from our findings. First, it is time to move beyond patient-centered care—which is often based on assumptions about patients' needs—to a patient co-designed model that will provide preference-sensitive care delivery. Miners and their families clearly articulated their needs and preferences for how, from whom and where they would like to receive care. Furthermore, miners must receive health education and employment informa-

tion regarding TB in ways that are accessible and meaningful to them, and from people they know and trust. Our research suggests that current or former miners are an untapped resource and the ideal cohort to conduct health education and what the public health system calls 'case management', but what might be reframed by miners as 'patient support'. Despite their diverse backgrounds, ex-miners bring the shared culture of the mine to their interactions; this, in turn, fosters trust and credibility. Ex-miners should be recruited into existing community health worker programs in South Africa. A study in a rural district of KwaZulu-Natal showed that well-trained community care workers reduced stigma and discrimination and enhanced TB and HIV care, including improved case finding, TB contact tracing, and linkages to care.[42] Although mining communities differ from rural villages, the success of this program is promising for similar interventions among miners. This approach would also promote employment after mining and build stronger relationships between mining communities and the health care system.

At the health system level, the health care delivery redesign process should improve clinician and manager accountability and emphasize patient priorities and satisfaction. This could be done by collecting and disseminating patient-reported outcome data and allocating resources to those interventions with the greatest success. Sharing TB case finding and treatment outcomes data among care teams may encourage competition towards improvement and support best practices. In addition, health care delivery should use measures and tools that empower clinicians to deliver, and patients to receive, care that is responsive to individual and population preferences. These measures and tools should be co-developed with miners to help clinicians and policy makers/managers better meet the miners' needs.

Educational programs for health care workers may prove beneficial. A Cape Town study of a health care worker educational program found that poor patient-provider communication adversely affects patients' treatment adherence.[43] The educational program encouraged health care providers to consider what patients wanted to know about TB, and the problems and difficulties of anti-tuberculosis treatment from patient perspectives. Overall, health care providers found the intervention useful and thought it helped them work better as a team and with their patients, although there were many structural barriers to long-term change.[43]

A limitation of our study was that we had minimal access to current miners due to mining company restrictions; we interviewed only one employed miner and 29 former miners. It is possible that the experiences of ex-miners might differ from those

presently mining. However, as the range of time since mine employment was 5–10 years and the data supporting the dominant theme were consistent and reinforced by triangulation, it seems unlikely that circumstances were significantly different. Another limitation is that most of our interviewees were South African. Our findings may not be generalizable to the miners and/or families of labor-sending countries. While it is unlikely that the concerns identified by our interviewees are South African-specific, a broader study that includes participants from the labor-sending communities would clarify regional differences.

CONCLUSION

These findings contribute new understanding of the long-term effects of the masking of TB in Southern Africa on perpetuating disempowerment, stigma, and inadequate care among miners/ex-miners and their families/communities. Health care workers' and managers' efforts to address TB among miners are constrained by the limitations of the current care system. New approaches are urgently needed. Engaging miners in redesigning care delivery could be a game-changer to address the unacceptable TB burden in this population.

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RESUME

CONTEXTE : Les mineurs d'Afrique du Sud souffrent du taux le plus élevé de tuberculose (TB) dans le monde. Les efforts actuels visant à enrayer l'épidémie sont insuffisants. L'héritage du passé et la persistance du fardeau de la maladie exigent des approches innovantes afin de restructurer la fourniture de soins de santé pour mieux servir cette population.

OBJECTIF : Caractériser les déterminants sociaux et comportementaux en matière de santé d'une prestation réussie de prise en charge de la TB selon la perspective des mineurs et ex-mineurs, du personnel de santé et des décideurs et gestionnaires.

SCHÉMA : Nous avons réalisé une enquête ethnographique appliquée avec 30 mineurs/ex-mineurs, 13 membres de leurs familles et communautés, 14 prestataires de soins de santé et 47 décideurs et gestionnaires locaux en Afrique du Sud.

RÉSULTATS : Les mineurs et ex-mineurs ont déclaré que l'offre de soins de santé ne répondait pas à leurs besoins.

Beaucoup d'entre eux ont souffert inutilement, sur le plan physique et psychologique, en raison des informations limitées qu'ils ont reçues à propos de la TB, du peu d'engagement dans leurs propres soins, de leur manque de confiance dans les prestataires de soins et d'un système qui ne valorise pas leur expérience. La stigmatisation et la crainte associées à la TB ont pour conséquence un déni des symptômes et un retard dans la recherche de soins. Le personnel de santé et les décideurs et gestionnaires ont exprimé leur découragement lié aux contraintes du système entravant des soins optimaux.

CONCLUSION : Nos résultats décrivent les effets à long terme d'une perpétuelle désinformation et d'une stigmatisation de la TB résultant de la peur et de la déresponsabilisation des mineurs et de leurs familles et communautés. Si l'on veut réduire le poids de la TB, il est urgent de concevoir en collaboration avec les mineurs un système de prestations de soins de santé qui réponde mieux à leurs besoins.

RESUMEN

MARCO DE REFERENCIA: Los mineros surafricanos adolecen de las tasas más altas de tuberculosis (TB) en el mundo. Las iniciativas actuales encaminadas a contener la epidemia son insuficientes. Los legados históricos y la carga de morbilidad persistente exigen enfoques innovadores que permitan remodelar la prestación de atención sanitaria, con el fin de aportar mejores servicios a la población.

OBJETIVO: Caracterizar los determinantes sociales y comportamentales de la salud que pueden contribuir a una prestación eficaz de la atención y el tratamiento de la TB, desde la perspectiva de los mineros actuales y antiguos, los profesionales de salud, los encargados de las políticas y los administradores.

MÉTODO: Se llevó a cabo en Suráfrica un estudio etnográfico con 30 mineros actuales y antiguos, 13 familiares o miembros de la comunidad, 14 profesionales de salud y 47 responsables de políticas locales y administradores.

RESULTADOS: Los mineros actuales y antiguos afirmaron que los sistemas de prestación de atención

de salud no respondían a sus necesidades. Muchos refirieron sufrir perjuicios físicos y psicológicos innecesarios por causa de su escasa educación sanitaria en materia de TB, una vinculación mínima con su propia atención de salud, la falta de confianza en los profesionales de salud y un sistema que no valora sus experiencias. Los estigmas y el temor asociados con la TB dan lugar a la negación de los síntomas y a retrasos en la búsqueda de atención. Los profesionales de salud, los encargados de políticas y los administradores refirieron sentirse desmotivados para prestar una atención óptima por causa de las restricciones del sistema.

CONCLUSIÓN: Los resultados del estudio describen los efectos a largo plazo de la desinformación permanente y los estigmas en materia de TB originados en los temores y la pérdida de capacidad decisoria de los mineros, sus familias y las comunidades. Existe una necesidad urgente de definir, en conjunto con los mineros, un sistema de prestación de servicios de salud que responda mejor a las necesidades de la población.