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TB is a disease which *hides* in the body': Qualitative data on conceptualisations of tuberculosis recurrence among patients in Zambia and South Africa

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ABSTRACT

The WHO estimates 58 million people experienced one or more TB disease episodes between 2000 and 2018. These 'former TB patients' are at greater risk of future TB infection and death than TB naïve people. Additionally, former TB patients experience social, psychological, and physiological difficulties after microbiological cure. Drawing on semi-structured interviews collected with 28 people from communities in Zambia ($n = 8$) and South Africa ($n = 2$) between October 2018 and March 2019, we describe their perceptions of having two or more TB episodes. Utilising a discursive analytic approach, we interrogated how participants conceptualise their risk of disease recurrence. Despite being surprised by subsequent TB episodes, participants utilised their bodily experiences of TB signs and symptoms alongside their experiential knowledge of health systems processes to procure timely diagnosis and care. Yet, many participants were unable to resume social and economic participation. Experiences of multiple TB episodes and correlating social, economic, and physiological vulnerabilities, challenged participants biomedical understanding of TBs curability. Through notions of dirt and 'staining', participants conceptualise TB as a sinister, malicious presence they are bound to encounter time and again. Health providers should discuss the risk of TB recurrence with patients and promote prevention, early detection, and diagnosis of TB disease.

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Introduction

In 2018, tuberculosis (TB) was the leading infectious cause of death worldwide (WHO, 2019). Despite a global annual decline in TB incidence rates of 1.5% over the past decade (MacNeil et al., 2019), approximately 10 million people develop active TB each year (WHO, 2019). Between 2000 and 2018, an estimated 58 million people experienced TB diagnosis and treatment (WHO,

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2019). Yet, 18% of tuberculosis treatment episodes are estimated to be unsuccessful (Datta & Evans, 2019). People previously treated for TB are at increased risk of recurrent infection. TB recurrence increases the risk of developing multi-drug resistant (MDR) TB, experiencing treatment failure/relapse, chronic physiological impairment (Trauer, 2019), and contributes to approximately 75% of the global TB burden (Chin et al., 2019). Even people successfully treated for TB have a three times higher mortality rate than the general population (Romanowski et al., 2019).

Recurrent TB occurs in two primary ways; firstly, by relapse of the original TB infection and, secondly, by exogenous reinfection of a new strain (Shen et al., 2017). Most relapse occurs within the first year after treatment completion and reinfection after the first year likely equally common in high burden settings (Marx et al., 2014). Former TB patients are also at increased risk of long-term negative effects of TB disease, like chronic obstructive pulmonary disorder, bronchiectasis and overall poor lung health (Cohen et al., 2019; Osman et al., 2019). Part of the World Health Organisation's (WHO) strategy for 2020, is to prevent any catastrophic costs to people and their households as a result of TB disease (WHO, 2019). There has been a recent call to raise global awareness of and interest in people's lives, 'post-tuberculosis' (Allwood et al., 2019).

The global TB epidemic is concentrated in Africa and South-East Asia, which accounted for an estimated 70% of all TB cases in 2017 (WHO, 2019). In 2018, 2,22,350 TB case notifications (including recurrent cases) were reported in South Africa and 36,866 were reported in Zambia (WHO, 2020a, 2020b). The incident TB case notification rates in South Africa were 520 per 1,00,000 and 346 per 1,00,000 in Zambia, respectively (WHO, 2019). People who have had TB once are up to seven times greater risk of recurrence than TB naïve people (Crampin et al., 2010). TB recurrence ranged from 7.6% and 40% of all confirmed TB cases across the 52 South African districts in 2011 (Marx et al., 2019). South Africa and Zambia also exhibit high HIV co-infection rates amongst TB cases, estimated at approximately 60% (WHO, 2019). One effect of the co-occurring TB-HIV epidemics has been an increase in recurrent TB episodes (Marx et al., 2014; Trauer, 2019).

People living with TB also experience socio-economic barriers to uptake and adherence to treatment (de Vries et al., 2017; Shiotani & Hennink, 2014), including TB-related stigma (Murray et al., 2013; Nyblade et al., 2019), depression (Sweetland et al., 2017) and costs related to TB care (Foster et al., 2015; Onazi et al., 2015). How people perceive, understand and think about TB disease affects their utilisation of health services and treatment uptake and adherence (Skinner & Claassens, 2016). Despite representing an important group for understanding the long- and short-term impact of TB disease, little qualitative research has been conducted among people with recurrent TB. Specifically, there is a lack of data on contextual understandings of TB to better apprehend mis/conceptions about health and illness and push for culturally appropriate configurations of public health interventions (Hoddinott & Hesselning, 2018; Mason, Degeling, et al., 2015; Nyasulu et al., 2018). This paper speaks to emerging field of research into the quality of life of people, post-TB treatment completion (Kastien-Hilka et al., 2016; Zarova et al., 2018). We aim to contribute to this dearth in research by interrogating how people formerly having lived with TB, conceptualise TB disease and understand their risk of future TB infection.

Methods

Setting

The Tuberculosis (TB): Tuberculosis Reduction through Expanded Anti-Retroviral Treatment and Screening (TREATS) project builds on the HPTN 071 (PopART) (Hayes et al., 2014) trial. HPTN 071 (PopART) was a cluster-randomised trial implemented across three study arms in 9 study communities in South Africa and 12 in Zambia. The evaluated combination prevention intervention included TB screening with active linkage to care. The overall aim of the TREATS project is to measure the impact of the PopART intervention on TB disease incidence, prevalence, and incidence of TB infection. The population size of the communities ranged from approximately 14,500–

1,61,615, with Zambian communities having larger populations. Common features across the communities in South Africa and Zambia were population expansion and mobility (both daily and transient), with the majority of the population categorised as urban poor. HIV prevalence in all communities was high. The communities also exhibited high levels of unemployment, migrant or seasonal work, and a bustling informal economy. More distinctive features include racial segregation in South Africa and proximity to international borders in six Zambian communities (Bond et al., 2016). Nested in the TREATS project, we collected qualitative data to describe TB stigma, mental health, and popular understandings of TB.

The South African data were collected from two communities in the Western Cape, City of Cape Town Metropole. The study communities are part of an urban/peri-urban setting of ~1000 sqm/~2500 km², with ~4.5 million residents and >100 state-run primary care health facilities. The Western Cape has one of the highest burdens of TB worldwide, estimated at 681 notified cases per 1,00,000 population in 2015 (Vanleeuw et al., 2017). By comparison, the South African national prevalence of TB of all forms among all age groups was reported as 737 (95% CI 580-890) per 1,00,000 population in 2018 (van der Walt & Moyo, 2018, p. 17). Between 2017 and 2018 77.4% of TB patients in the Western Cape were also living with HIV and on anti-retroviral treatment (Mzobe & Loveday, 2019). Additionally, the Western Cape has experienced an annual increase in the proportion of TB retreatment cases, from 26% in 2012 to 35% in 2018 (Davies et al., 2020, p. 76).

Prevalence of TB in Zambia is estimated to be 455/10,000 and Zambia is considered a high burden TB country by the WHO (Kapata et al., 2016). The WHO reported that approximately 46% of TB patients in Zambia were also living with HIV, 97% of whom were on ART, in 2019 (WHO, 2020a). Common infrastructural features in the study communities included a government health facility, primary schools, police stations, churches and recreational facilities, market areas and transport depots (Bond et al., 2016). Despite free provision of TB treatment through government health services, individuals often face pre-diagnostic costs, user fees, and indirect cost incurred during treatment supervision such as transport costs (Aspler et al., 2008). Consequently, TB treatment and management may result in economically vulnerable households incurring costs owing to loss of productivity, selling of assets and an increase in debt (Chileshe & Bond, 2010). Formal employment options are very limited, and the main livelihood option for most residents includes trading in goods with many women selling in the local markets (Bond et al., 2016).

Sampling, recruitment, and data collection

Participants were identified through clinic registers and referrals of TB-symptomatic participants by the PopART intervention staff. The study is a cross-sectional qualitative research design, using semi-structured interviews. All data were collected between October 2018 and March 2019. Data were collected from two study communities in South Africa and eight in Zambia.

Participants for the interviews were ≥18-year-old TB patients identified as either smear positive or GeneXpert positive who had started treatment at any point between 1st September 2016 and 31st December 2017. Participants included in the sample had to have had TB at least once, and successfully completed their treatment regimen. All data were collected by experienced graduate socio-behavioural science researchers, led by authors Wademan and Mainga, supervised by authors Hodinott and Bond respectively. Interviews were conducted at a time and place convenient to participants. We conducted a total of 103 interviews, $N = 25$ in South Africa and $N = 78$ in Zambia. In these, 28 ($n = 12$ South Africa, $n = 16$ Zambia) participants reported more than one TB disease episode, with disproportionately more in South Africa. In this sample, 19 were men, 9 were women, and 13 of these participants also reported living with HIV.

Interviews ranged from 30 min to 2 h in duration and were conducted in the participants' preferred language (usually a mixture of English and a local language). Topic areas covered included: (1) perceptions about TB disease and risk of transmission (2) health seeking behaviours (3)

experiences of TB treatment (4) physical and psychosocial impact of TB (5) TB-related stigma and support and, (6) perceptions and/or experiences of TB-HIV co-infection. The participatory research activities included community and social network maps with which to describe ‘TB-hot-spots’ in each of the communities and to describe people relied on for knowledge about TB disease and treatment. The interview recordings were summarised and translated into English for analysis.

Ethical considerations

Ethical approval for all study procedures was obtained from the institutional review of the London School of Hygiene and Tropical Medicine (LSHTM) (#14985), the Bio-medical Ethics Committee of the University of Zambia (005/02/18), and the Pharma-Ethics Research Ethics Committee South Africa (180219727). All participants in the interviews signed written informed consent.

Data analysis process

Data analysis began by reading the transcripts of all 28 participants’ interactions with researchers to identify, capture and describe central themes, common experiences and/or patterns shared by participants. Divergent perceptions/experiences were also noted. Thereafter, we reread all the transcripts to identify exemplar cases with which to illustrate the themes. The exemplar cases provided both detailed descriptions of unique experiences and important patterns in participants’ experiences that cut across the data set. Finally, we conducted a discursive analysis of participants’ talk of TB episodes (Wetherell, 2007). The analytic process involved identifying metaphors and analogies participants use to explore and explain their experiences and conceptualisations of TB disease.

Findings

Below we describe people’s experiences of having more than one TB episode. We begin by describing how participants perceived ‘dirt’s’ role in exposure to and transmission of TB. Then we describe how participants reacted to having more than one TB episode. Next, we present some of the short- and long-term consequences participants linked to their experiences of TB. Finally, we describe participants’ perceptions of future risk of TB infection.

The role of ‘dirt’ in TB transmission

Participants described high levels of TB transmission, pointing to dirt or extreme cold. During our discussions with participants, they linked dirtiness to geographic/architectural and social contexts that involved exposure to dust, sewerage, dirty/contaminated water, and informal housing:

P1: [This community] has a high TB prevalence. [...] The conditions in [this community] are such that it’s very dusty, there’s shacks around, everything’s happening. There are many possibilities for someone to contract TB. [...] These are the shanty shacks—it’s very dusty and there are no full-flush toilets in this area, it’s only temporary toilets. Sometimes you will see sewerage spilling all over the show. (20190202, Man, South Africa)

Dirtiness, perceived to contribute to TB infection, went beyond socio-environmental factors and included morally sanctioned behaviours, like smoking, drinking, and having multiple sexual partners. Interestingly, in the extract below, the participant suggests health workers appeared to prohibit sex, rather than focus on exposing a close contact to TB. Messages of this kind may obscure understandings of the route of TB transmission and risk of infection, and further conflate HIV prevention messaging with TB prevention. Although the participant below narrated a unique interaction with health workers, other participants echoed a similar sentiment:

P2: Yes, they told me that since you're cured, you should avoid beer, smoking and ladies. I mean ladies at home hanging around its fine but not be with [have sex with] your lady, [...] and avoid being in crowded places and playing with a group because TB may occur again, and it would be unfortunate because [...] there may be complications in you surviving if it was to come again. (20181031, Man, Zambia)

Participants thus conflated having TB with being dirty. For instance, one participant referred to people living with TB as *vuil* (Afrikaans¹ for dirty) and saying, 'you might also get it because of their spit, dirty spit' (20190220, Woman, South Africa). These slippages contribute to the stigmatisation of people with TB. TB disease is being conceptualised as not only transmitted by dirt, but also altering the persons' identity, so that they are themselves dirty.

This same participant went on to reveal underlying tensions and linkages of 'dirt' between TB and HIV that might fuel stigmatisation. The participant recounted how the trial-employed community health workers 'were checking for AIDS [but] they found out then my blood is clean, meaning that I do not have it' (20190227, Woman, South Africa). Despite having equated having TB with being 'dirty', the participant appears suggest that people living with TB and HIV may experience a deepening sense of 'dirtiness'.

Reaction to subsequent TB episode compared to first TB episode

Participants reported that they were better able to symptomatically identify TB at subsequent episodes. This often resulted in earlier diagnosis. In the extract below, the participant describes how he struggled to receive his first TB diagnosis. Other participants described similar delays to being diagnosed. After his initial TB episode, however, the symptoms did not abate. Almost a decade after his first TB episode, he began to experience severe TB symptoms again:

P4: I would come [to the clinic] but I would just be given Panadol and told that its malaria. I became worse. So, I came here, and they referred me to the [local] central hospital in 2009. [...] I stayed there for one week and was discharged. I came home and was still very sick; bedridden, and I was taken back to the hospital. [...] The second x-ray they found [TB] in my ribs.

I: Okay, what about in 2017; how did you know [you had TB again]?

P4: I knew because I had TB before. The first time I took [treatment] for 8 months and I knew that this TB isn't cured. [...] I knew it was TB. So now I came here and asked for a referral [...] to the hospital. [...] I was admitted for three days, and they discharged me. I went home and was worse. [...] The TB nurse then referred me again to the hospital we did an x-ray again and [TB] was found. (20181102, Man, Zambia)

Not only does this case describe the physiological awareness participants gained from a first TB episode, but also the institutional knowledge to know which health facilities and workers to seek out in order to receive optimal care and a timely diagnosis.

Another participant contrasted her experiences of two TB disease episodes. While this participant's experience is unique it helps highlight how participants use their tacit knowledge of TB to receive an earlier diagnosis for her second TB episode compared to her first. The first time was in 2013. Then she developed TB again in 2017 with her husband. They completed treatment together. She commented on the emotional and physical toll of her first disease episode. The participant notes that she feared a second TB episode might be as bad as the first. But her actual experience of her second TB episode was not as difficult as she expected it to be. She attributes the difficulties experienced during the first TB episode to it being discovered later:

P5: [During my first TB episode] I felt uncomfortable and thought I could die at any time if it could get any worse [...]. I couldn't breathe. I thought that if it could be like that again then it's going to be difficult. [But] I didn't have problems with the second episode it's the first one that was difficult. It was discovered later. (20190307, Woman, South Africa)

However, despite their prior experience and the apparent biological and tacit knowledge of TB, some participants were worse off during their second TB episodes, having to undergo longer

treatment periods, sometimes with injectables for up to three months. Apart from the personal-biological knowledge garnered through prior TB experiences, participants shared how subsequent TB episodes were alarming and depressing:

P6: The second time, I came to see the doctor at the ART clinic. I explained that I was coughing, then he referred me to the TB corner. I also didn't expect that I will be told I have TB because I have had TB before. So, I wasn't expecting it to come back. (20181113, Woman, Zambia)

Another Zambian participant said, 'I was very sad [at diagnosis], especially the second time' (20181107, Male, Zambia). Overall, there appeared to be a shift in participants' responses after the first through subsequent TB episodes – from acute alarm to resilience and, finally, resigned acceptance. So, while surprise predominated participants' accounts of their first bout of TB, resignation appeared to creep into participants' accounts of their second, or as is illustrated by the unique experience of a woman participant in South Africa, a third and potentially fourth TB episode. When we met her, the participant had already had three TB episodes, and claimed to be experiencing symptoms like those she had during prior TB episodes. When asked how she felt about a fourth TB episode, the participant simply said, 'All I can do is go for a test, and if they say I have TB then start my treatment and finish it. Then you will get better' (2019220, Woman, South Africa). The participant had presumably come to accept TB as an imminent but treatable threat, in stark contrast to the participant's reaction to her first TB diagnosis in which she experienced anger, distress and irritation:

I: And how did you feel the first time you had TB? How old were you?

P7: Look, the first time you get TB, you're angry, you're not really angry, but you don't want to be disturbed [you want to be left alone], you're so distressed, you don't want to have anything to do with anyone. [...] It's not that people ask questions, really, it's more that they nag you or provoke/aggravate you—everyday they come and say the same thing over and over again [...]. Now I don't really get angry. I don't feel well, my chest—it's like a cold won't leave me alone. And this cough isn't going away—if only it would go then I would feel better. (2019220, Woman, South Africa)

While the participant spoke about having already had three TB episodes, when asked about the possibility of another TB episode, she reverted to what seemed like a 'clinically' rehearsed answer 'they say you can get it again' (2019220, Woman, South Africa).

Life after TB, again

During our discussions with participants, we asked them how they had physically, emotionally, or socially been affected by TB. Changes to participants' lives following subsequent TB episodes ranged from little to no impact, to major changes in lifestyle, family arrangements and physiological functioning. These modifications in lifestyle often stemmed from either an internal desire or external pressure on participants to stop immoral/dirty behaviour perceived as increasing the risk of TB. When asked about how TB affected his life, one participant said,

P8: I told them [at work] that I'm sick and can't work for them. They said I should stop working and come back when I've recovered. But I decided not to return because I'm killing my future. [...] I don't drink anymore. [not since] I was attacked by TB in 2015. [...] My relatives told me to stop drinking after I got TB in 2015. If you see my relatives, you'll see that they are all big but I'm skinny. (20190122, Man, South Africa)

The participant presents several 'moral' positions in this extract. For example, emphasising health and life over work saying, 'I decided not to return because I'm killing my future'. He also stopped drinking because his family attributed his ill-health and being skinny to drinking, where being plump is considered healthy. While the participant above was hesitant to return to work for fear of contracting TB again, other participants described how their bodies had been damaged by TB, and they were unable to work at all anymore.

Another participant described how he believed TB had become asthma, after completing his TB treatment four years prior to our interview. According to the participant, TB caused irreparable damage to his lungs, inhibiting his ability to work and perform other routine chores, like shopping. During our interview with the participant, he showed us three different asthma pumps – one of which he must always keep on his person in case of an asthmatic attack. Thus, for some of the participants, the inability to return to work appears to be a recurring notion linked not just to ill health (current TB/post TB sequelae), but fear of perceived higher occupational risk in their workplace.

In the extract below, the participant speaks about his ‘countless’ TB episodes. When asked why he believes he has had TB so many times, he mentioned being exposed to construction and plastering material at work. However, earlier in the discussion he explicitly linked HIV with increased vulnerability of future TB infection: ‘when you have HIV you are likely to have TB [...] these things are associated’ (20190222, Man South Africa). His HIV status and knowledge of an increased risk of TB infection did not appear to change his understanding of the underlying route of TB infection which he attributed to working in cold weather. The participant goes on to describe how his need to care for his health rubs up against his need to financially provide for his family, and that this dilemma has been the cause of tension between him and his wife. Ultimately, the participant chose his health over his career and no longer works when feeling ill or weak.

P10: I’ve had TB countless times, starting from 2006 to 2007. I have even lost a job because of it. Let me say I have had TB four times, it skips years. [...]. I have stopped working; I’m sitting at home. [...]. Sometimes I’m forced by the household situation. I’m forced to go look for a job and get a job. My wife would think I’ve quit the job intentionally, but I fell sick. When it is raining, in winter, my body becomes weak from the TB I’ve had before. Sometimes I tell [my wife] straight that my health is more important than the job. (20190222, Man, South Africa)

For some participants, TB marked a rupture in their financial and social lives, requiring them to significantly alter their work and home lives. A Zambian participant shared how he was fired from his work on medical grounds and evicted from his house because of having TB, forcing him to move to his mother’s house and sell some household assets to survive. His employer’s insistence that he needed to stop work in case ‘TB comes back, [and] you die at work’, made him wonder, in turn, ‘how I will survive, because when I try to find work the TB comes back’ (20181031, Man, Zambia). Unfortunately, being fired and unable to secure future work opportunities was not unique to this participant.

As with the participant above, others found life during and after TB lonely. They blamed TB for causing ruptures in interpersonal relationships. In exceptional cases, participants told us that their wives, siblings, friends, or other family members abandoned them while they were on TB treatment – and occasionally, indefinitely. Other participants struggled for social support and were heavily stigmatised for having TB a second time, undoubtedly increasing anxiety, and negatively impacting their overall wellbeing.

P11: I would talk to my brother. I had concerns of dying but he would always tell me you will be fine, finish your medication. Even now he tells me the same thing [...] [Other people] would not visit me or check on me and when I meet them, they would say just quit the medication you have been taking it for too long just stop taking it so you can die and stop bothering us. I felt bad. (20181107, Man, Zambia)

While not all participants experienced social ostracisation of this kind, almost all participants noted a disruption to the things that used to define their identities. The inability to perform every day, menial tasks led to a serious disruption in participants’ identities, not to mention the impact their need for additional care had on their immediate and extended family members:

P9: My niece [...] was very tired of me, even when I would ask her to prepare water to take a bath, she would be angry. I will not lie to you; she used to be very tired of me. She is a girl, but she was very tired, and she is only twenty-three years old. She was old enough. [...] I used to feel very bad, as if this child did not like me. (20190227, Woman, South Africa)

The disruption in the participant's identity is evident in the fact that she used to feel 'very bad', at having to rely on her niece and sister to do everything for her. Being an older woman, and used to fulfilling the role as carer, the participants' self- and social- identity came under pressure while being cared for. Although hers is a unique story, many other participants described how TB had come to change or shape their identities. Indeed, participants recounted how TB robbed them of vitality, personality and, potentially, their lives. In the extract below, the participant describes himself as a 'skeleton in the flesh.' The participant goes on to inscribe TB with the power to negatively 'change who you are,'

P1: But, once you lose weight—I was some sort of a skeleton in the body, in the flesh [...]. It affected me because I had no energy. I couldn't work. I usually read a lot, but while I had TB, I was a completely different person. I was always in bed. Sometimes I would get chills, sometimes I would get sweats, I wouldn't eat. It changes who you are, you become a different person. (20190202, Man, South Africa)

Later in the discussion, the participant described how the physiological impact and changes in his personality affected his identity as a lawyer, father, husband, and active community member while living with TB:

P1: You don't perform. You're constantly thinking about your spouse—that other people might be asking her why she's staying with this man, whose ailing, lying in bed, no longer providing. But my wife was so supportive, and my children were worried that I might pass away. (20190202, Man, South Africa)

Ill health after TB came to limit some participants' future choices. In one participant's case, he owned land with housing and cattle in a rural area approximately four hours from where he currently lives. While living on his ancestral land would be a far more luxurious life than the two by four-meter shack in which he currently lives, he feared not being able to access care should he need it:

P12: You see, now, I have house in the Eastern Cape. It's my house. My father and my grandfather passed away and left everything to me. So, there is a person staying there looking after the sheep and the goats. [...]. If I went there, I would suffer because if I were to get sick during the night, there wouldn't be any transport to take me to the hospital, even the ambulance would take a long time to come fetch me. Hours, you see. So, that is why I've decided to stay here. (20190122, Man, South Africa)

Like this participant, other participants had to weigh the costs of a particular lifestyle against their risk of TB infection, social ostracisation and their general wellbeing. Thus, life after TB involves realigning one's life with perceived moral behaviour that will prevent exposure to future TB infection. It also requires readjusting one's individual and social identity to the incapacities that come with post-tuberculosis sequelae, and resources that are and may be required to ensure good health.

Former TB patients' perceptions of future TB infection

For some participants, the potentiality of subsequent TB episodes provoked fear. Some participants expressed fear that another TB disease episode might dramatically reduce their life expectancy, while others expressed fear of being on treatment again, or developing a drug-resistant strain of TB that requires longer, more arduous treatment regimens. Other participants, had begun to question whether TB was in fact curable, doubting whether the treatment worked, or if the disease ever left their bodies in the first place.

In our discussion with a Zambian man, he described how he increasingly came to doubt that TB was treatable following his first and second TB episodes, and wondered whether he presently had a third TB episode.

P13: I just used to think I will never get cured. I even started believing it especially when TB came back for the second time [...]

I: Now do you believe that you have been cured?

P13: No because the TB is back.

I: Ok so are you sure you will get cured now?

P13: I am still doubting. (20181107, Man, Zambia)

Persistent misconceptions about the risks of reinfection or relapse in places of high-burden TB areas appeared to influence participants' decisions about future employment. In one instance, a participant believed that changing his lifestyle and workplace would guarantee he would not be infected again.

I: Do you sometimes worry that you might have TB again?

P14: No, because I no longer work in that place I used to work in, I now work in a different place.

I: So, there is no other way which you think you can get TB?

P14: No. (20190209, Male, South Africa)

Those participants with an understanding of the risk of TB infection/transmission relied on isolation/separation tactics, or with avoidant behaviour. Often, however, these kinds of public health efforts contribute to stigmatisation. Further, a lack of understanding of the increased risk of relapse and/or reinfection may contribute to the scepticism illustrated in many participants' narratives around TB being curable. Few participants were aware of their increased risk of future infection while other participants used knowledge gained from their prior TB episode to appease any fears about future TB infection.

P9: If [TB] comes back again, I will have to go to the clinic again. I will not waste any time with anything. The minute I feel that there is something wrong, I will definitely go [to the clinic]. (20190227, Woman, South Africa)

While positively constructed, in the sense that this participant says she will act quickly at the hint of another TB episode, her account harks back to other participants' resigned acceptance of future TB infection. Thus, participants' experiences of multiple TB disease episodes clashed with knowledge they are provided with by health workers. They are told that TB can be cured, but a second, third or fourth TB episode throws doubt over this knowledge. One of our participants, a middle-aged man living in South Africa, made sense of this predicament by explaining that he believes the TB bacteria had merely been put to sleep, or was hiding in the body and could therefore resurface at any time.

P16: I didn't notice that it might be TB again. But now I know because TB is a disease which hides in the body. I've noticed this now, because this is the second time. [...] But actually, it's not finished, it's just disappeared. I think I could put it that way. [...] It disappeared and came back [...] Joh! To get TB a third time, I am scared [...] What can you do? You walk around and you catch it. Because, the people, [spit on the ground] and then you pass it and catch it. (20190122, Man, South Africa)

Although the participant believes that once someone has TB, it never leaves them, he also describes how it will only manifest again if one is exposed to TB again, e.g. through someone else's spit. Returning to our notion of dirt, we could say that the disease leaves a stain in the body. Here again, our participant's narratives present the tension between an individual's ability to avoid TB and living in a high-burden context where TB is everywhere.

Discussion

Similar to previous research, our participants were well-informed about TB, but understanding its 'route of spread' and 'misguidance regarding treatment compliance' remain treatment gaps (Nyassulu et al., 2018, pp. 387; 385). Participants located risk of exposure to TB, infection, and transmission within the context of their respective community, work, and home lives. As is well-

established in literature, our participants' descriptions show how various socio-environmental risk factors combine with high HIV and TB prevalence rates to increase their exposure to TB recurrence (Crampin et al., 2010; Datta & Evans, 2019; Packard, 1989). Given their prior experience of TB disease, participants were able to identify signs and symptoms of subsequent TB infections earlier and sought care promptly, compared to their first diagnosis. Yet, the subsequent TB diagnosis led some participants to believe that their original TB episode had not been cured. Other participants questioned whether TB was curable at all. Consistent with other research, our research indicates people in high burden, low resource settings show a general lack of understanding of the biomedical constructs underlying TB risk and transmission. Fewer still showed knowledge of the risk of TB relapse and/or reinfection (Ngamvithayapong-Yanai et al., 2019). Instead, risk of TB infection and transmission is caught up in local associations between disease and dirt.

We found that TB leaves an enduring mark on individuals' lives. This mark reaches simultaneously inward and outward impacting participants' individual and social identities, as well as marking spaces, places, and people that may expose them to TB. For example, both men and women experienced psychological and social shifts in terms of their caregiving roles. For men, the shift revolved primarily around their inability to remain household breadwinners, both when sick with TB as well as afterwards when incumbered by TB-related sequelae. Women on the other hand, struggled to contend with the shifts in their role as caregiver because of TB. Not only did TB limit their capacity to care for others, but also cast them as needing care themselves. Men and women thus suffered damage to their social standings that required renegotiating with family and friends as they became well again, or renegotiated support structures because of ongoing care needs. We have limited data on women's perspectives and experiences more generally, probably a reflection of the overall burden of TB which is higher in men than women in these contexts.

Participants' narratives about their individual, household, and social exposures to TB, suggested they had little control over these circumstances, and therefore ability to avoid future TB infections. Thus, while participants' understanding of TB transmission informed their decision-making regarding choices, like returning to or not returning to work, they felt unable to exercise enough freedom to escape future TB episodes. TB has long been considered a disease of poverty (Packard, 1989), and has more recently been understood as a result of structural violence (Farmer, 2000, 2003). Structural violence captures the complex mix of large- and small-scale social forces that contribute to the loss of life from preventable and treatable diseases, such as TB, in times of peace (Mason, Roy, et al., 2015). One such social force is the cyclical nature of risk for people living in poverty exposed to TB with access to under resourced health systems. People living in these conditions are more likely to have poor health outcomes, reducing productivity, deepening poverty, and thus increasing risk of future TB infection (Benatar & Upshur, 2010). This was reiterated in our participants' comparisons of their first with subsequent TB episodes that were seemingly unavoidable and is probably more pronounced among PLHIV who already experience social disruption and economic constraints.

Many participants noted linkages between TB and HIV. Like previous research, our participants noted obscurities in identifying and distinguishing TB from HIV; and how correlating associations may deepen their sense of 'dirtiness'. Managing the double-stigma of TB and HIV remains a key challenge to healthcare access, social support and disease management (Bond & Nyblade, 2006; Daftary, 2012). Although we did not explicitly ask participants about their experience of TB-HIV coinfection, some alluded to the increased vulnerability to (future) TB infection due to living with HIV. However, our research reveals a need to reconsider health workers' TB prevention messaging. Clarifying the differences between TB and HIV prevention measures may help to reduce stigma, and improve patients' understanding of the underlying route of TB (and HIV) transmission.

Our research expands on extensive literatures on more numinous conceptualisations of TB than found in biomedicine; where infection is variously attributed to contaminated food products, genetics, dirt, poverty and immoral behaviour (particularly in settings with a high HIV burden) (Abney, 2011; Adams et al., 2017; Cremers et al., 2018; Dixon & Tameris, 2018a; Murray et al.,

2013; Versfeld, 2017). By considering the long-term impact of a TB disease episode on people's sense of well-being, social standing, and economic position, we suggest a re-consideration of why and how people affected by TB conceptualise it as staining 'dirt'. Our research echoes previous research that describes how people living with TB are construed as contagious, to be feared and treated (both personally and within the health system) with caution (Ascuntar et al., 2010; Dodor & Kelly, 2009). In one sense, dirt – both physical but also metaphysical/moral – is perceived to be the source of TB (Dixon & Tameris, 2018b; Masuku et al., 2018). This resonates with literatures on health beliefs in southern Africa more generally where disease is considered to exist on parallel biomedical and metaphysical levels (Feierman, 1985; Thornton, 2017).

More than this, we found that TB is conceptualised as a cause of dirtying people; this dirtying is more like a stain that can only be hidden/covered and never truly removed. This brings the conceptualisation of TB disease among former TB patients to be much more closely aligned with stigma literatures where the disease is a mark of inferiority/judgement (Christodoulou, 2011; Cremers et al., 2015). Importantly, the notion of this mark as a stain has significant implications for internal and anticipated stigma. For these former TB patients, the possibility of recurrence became an ever-present spectre that might again reveal their stain to the world. This patient experience also resonates with broader public health responses, where TB and its control has variously been described as a complex and illusive moving target (Bowker & Star, 1999); a conniving, non-wimpy bug and persistent pathogen (Macdonald et al., 2020); a disease without boundaries (Fogel, 2015); and as a disease beyond reach (Dixon & Tameris, 2018a) that continues to stifle global health efforts (Boire et al., 2013).

Frick et al. (2015) have critiqued the individualised stigmatisation and responsabilisation of TB patients through language, policy and practice. Lambert and Van Der Stuyft (2005) argued that patients are blamed for TB treatment initiation delays, absolving healthcare providers of delays along the TB continuum of care. Møller et al. (2010) further suggest that people who engage in immoral behaviours (namely, drinking and smoking) may serve as scapegoats carrying the stigma associated with being contagions of TB and HIV. We were surprised not to find similar levels of individualisation in the way our participants spoke. This may have been a consequence of the data collection process and is therefore a potential limitation. This analysis is an early exploratory step toward understanding these dynamics. Strengths of the analysis are that it was conducted in two settings (South Africa and Zambia) and underwent multiple steps of data analysis. Limitations to transferability of the findings include that we did not specifically sample for former TB patients, therefore those identified may not be adequately representative of the wider former TB patient population. Additionally, the cross-sectional design limits our ability to consider participants experiences over time – though the data included participants who had recent and more distant TB disease episodes.

Conclusion

People living with TB in South Africa and Zambia attribute susceptibility to TB infection and transmission to dirt. In these spaces, 'dirt/dirtiness' is both a literal indication towards their socio-environmental circumstances as well as a heuristic device indicating towards moralised behaviours. Most participants were able to receive a timely diagnosis after their first TB episode. This is in part due to a biological sensitivity to TB signs and symptoms, and in part due to their experiential knowledge of health systems. However, neither their biological sensitivity nor their experiential knowledge of health systems could prevent the psychological, social, economic, and physiological consequences of numerous TB episodes. Our participants' experience of subsequent TB episodes undercut their belief that TB is curable.

We believe this paper is a timely contribution to the increasing concern around recurrent TB that 'accounts for up to 75% of the total global burden of disease attributable to TB' (Chin et al., 2019, p. 203). Despite research from southern Africa suggesting former TB patients constitute an

important population for targeted TB control and prevention measures (Marx et al., 2016), current WHO-recommendations do not encourage long-term follow-up of former TB patients. Our findings suggest that more research is urgently needed among former TB patients, and on how recurrent TB is managed and conceptualised by both health workers and patients in high-burden contexts (Wanner et al., 2018). The global health fight against TB appears slow to gain traction. Achieving a sustained reduction in TB incidence worldwide must address enduring physical and psychosocial consequences beyond a treatment episode. This paper provides further impetus to the recent clarion call made by Harries et al. (2019) to initiate a ‘fourth 90’ to support and ameliorate the long-term impact of TB post-treatment completion.

Note

1. Afrikaans is one of the eleven official languages spoken in South Africa.

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