

High levels of vulnerability and anticipated stigma reduce the impetus for tuberculosis diagnosis in Cape Town, South Africa

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Prolonged diagnostic and treatment delays, particularly in settings experiencing concomitant human immunodeficiency virus (HIV) and tuberculosis (TB) epidemics, undermine global TB control efforts. Current TB control policy in South Africa, as organized through the National TB Control Programme (NTP), relies on the voluntary presentation of TB suspects to local clinics for diagnosis, i.e. passive case finding (PCF). In 2005 a participatory study suggested that popular interpretation and perception of TB within eight South African township sites in and around Cape Town, all carrying a high burden of HIV and undiagnosed TB, undermine PCF. Both people's association of TB with dirt and squalor, and the anticipation of HIV-related stigma, combine to impede TB diagnosis. Respondents conveyed TB as unavoidable; this perception is expressed in the context of vulnerability where so much—including dirt—is largely beyond the control of local residents. The lack of control has a disempowering effect, reducing the drive for seeking treatment. In addition, low confidence in patient confidentiality and anticipated HIV-related stigma act as direct deterrents to TB diagnosis and treatment. In conclusion, we wish to draw attention to high levels of disease stigma and vulnerability, and how these undermine PCF. Public health interventions that wish to improve case detection should aim to: (1) emphasize how early treatment improves outcome and can curb ongoing transmission; (2) combat a sense of communal vulnerability to TB; (3) address anticipated HIV–TB stigma; and (4) improve the quality of care provided at local diagnostic services, addressing low levels of patient confidentiality.

Keywords Tuberculosis, South Africa, vulnerability, stigma, diagnostic delay

KEY MESSAGES

- 'Bottom-up' evidence explains how anticipated HIV–TB stigma delays TB diagnosis and treatment.
- Respondents think about TB as an unavoidable symptom of their own socio-economic vulnerability.
- Disease stigma is likely to impede passive case finding.

Introduction

Undetected tuberculosis (TB) in settings experiencing concomitant human immunodeficiency virus (HIV) and TB epidemics substantially compromises TB control programmes in southern Africa (Wood *et al.* 2007; Ayles *et al.* 2009). Current TB control policy relies on passive case finding (PCF)—the voluntary presentation of individuals to local health services—for the diagnosis and treatment of TB, yet reluctance to access health care is a common problem prolonging diagnostic delay in many settings (dos Santos *et al.* 2005; Bassili *et al.* 2008; Lonroth *et al.* 2010). Previous research in a township community of Cape Town, South Africa, showed that despite a well-run treatment service which followed the internationally recommended control strategy of Directly Observed Treatment Short-course (DOTS), 63% of adult cases with TB remained undetected and the majority of these cases were co-infected with HIV (Wood *et al.* 2007). Multiple social factors have been identified as key contributors to this type of delay and include poverty, low educational levels, substance abuse, low awareness of TB, misconceptions about disease, age, gender, history of immigration, disease stigma, time to reach a diagnostic facility and a preference for alternative treatment options, i.e. traditional healers, self-treatment and the use of the private sector (Karim *et al.* 2007; Bassili *et al.* 2008; Gershon *et al.* 2008; Storla *et al.* 2008). Specifically within the South African context, past research suggests that the social stigma of and local misconceptions about TB are key factors that delay voluntary presentation (Metcalf *et al.* 1990; Westaway and Wolmarans 1994; Edginton *et al.* 2002; Promtussananon and Peltzer 2005).

The social impact of HIV and AIDS on TB is negatively affecting patient behaviour in areas experiencing concomitant epidemics (Ngamvithayapong *et al.* 2000; Bond and Nyblade 2006; Sengupta *et al.* 2006; Magazi 2008; Mavhu *et al.* 2010). Bond and Nyblade (2006) demonstrate that HIV and AIDS have not only shaped the epidemiology of TB, but also the social experiences and perceptions of TB. In areas where there is local confusion between the two diseases, they highlight the threat posed by the related manifestation of HIV–TB stigma to TB control.

We analysed a participatory study to investigate how popular perception and interpretation of TB within eight South African township sites of Cape Town, which all carry a high burden of undiagnosed TB and HIV, may impact on the success of PCF. Our findings show how anticipated HIV-related stigma and a popular sense of communal vulnerability to TB hamper PCF. In light of the urgent need to increase case detection and the call for social science to ‘promote understanding regarding the complex psycho-social interplay of TB and HIV/AIDS’ (Ngamvithayapong-Yanai and Ishikawa 2006), these findings are pertinent.

Background

This study makes retrospective use of qualitative data collected within the framework of a collaborative community-based clinical trial known as the Zambia and South Africa Tuberculosis and AIDS Reduction (ZAMSTAR) study. Data collected from fieldwork conducted in 2005 and 2006 in eight South African ZAMSTAR research sites is used for a textual analysis of discussions respondents held about TB.

The fieldwork was labelled Broad Brush Survey (BBS) and based on a set of participatory methods as used by Wallman to ‘freeze/fix’ communities under stress in Kampala, London and Turin (see Wallman 1996, 2003 and 2011). As a qualitative method, BBS, as used by ZAMSTAR, aimed to gather a broad and comparable understanding about the social context within each of the ZAMSTAR research sites in preparation for the implementation of public health interventions (Sismandis *et al.* 2008; Bond 2011). This analysis, therefore, draws only on parts of a substantial ZAMSTAR data set and is independent of the ZAMSTAR trial (see also Murray 2010).

Setting

All eight research sites are located in the Western Cape province of South Africa, which has one of the highest TB notification rates in the world. Worst hit are the densely populated socio-economically deprived township areas where annual TB notification rates exceed 1000/100 000 and were approaching 1500/100 000 at the time of this study (Cape Town TB Control 2004; Lawn *et al.* 2006). The TB epidemic is fuelled by a concomitant HIV epidemic in these areas; around 60% of TB patients are co-infected with HIV (World Health Organization 2011). The Western Cape has lower HIV prevalence rates than many of the other provinces in South Africa, but HIV infection rates are still high; among women attending public antenatal clinics, infection is estimated at 30% nationally, while estimation for the Western Cape is 18.5% (Department of Health 2011). Six of the sites can be classified as townships of greater Cape Town itself and the remaining two sites form townships of nearby towns.

As a result of overcrowding, crime, migration and relocation within and outside, the research sites are notoriously difficult to enumerate; the ZAMSTAR trial estimated that each site had an adult population of between 20 000 and 40 000 that was served by a single local health facility. Local health facilities as organized through the National Tuberculosis Control Programme (NTP) followed standard TB control practices according to the internationally recommended DOTS strategy. Socio-economically, the sites are well known to be marked by an informal economy, high levels of unemployment, high levels of violence and chronic poverty despite receiving various forms of social welfare from the state (Robins 2005; Norman *et al.* 2007). This was reiterated when synthesizing BBS data, which showed dependency on state welfare, unemployment, crime, violence, substance abuse, inadequate housing, poor municipal services as well as xenophobia to be common sociological features. Subtle differences included the nature and levels of collective initiatives and informal economic activity within each site (see Murray 2010).

Methods

Method of fieldwork

The ZAMSTAR BBS used a mixture of participatory research techniques to gain an understanding of social interaction, the local economy, the layout of the community, the mobility of individuals, how time is spent, perceptions of TB, TB treatment options, TB stigma and patients’ experiences of health services

within each of the eight study sites. Details of the relevant participatory techniques are provided in Table 1. After each activity took place, reports detailing the observations made and discussions held were written by the research assistants who had facilitated the activity. Textual content of these reports was generally structured under four topics: (1) the process of the activity, (2) information about the community, (3) information on people's daily activities, and (4) their knowledge and perceptions of TB and HIV. Our analysis focused on data gathered under topic (4) although activity reports were assessed in their entirety. Research work that focuses on other areas of the data set is published elsewhere (Murray *et al.* 2009).

Groups of community representatives were formed by the wider ZAMSTAR trial as a body through which to work in each township. These groups were labelled Community Advisory Boards (CABs) and consulted before and after BBS fieldwork; CABs are established as a widespread strategy for involving communities in clinical trials (Strauss *et al.* 2001). Participatory activities began with a CAB meeting and were facilitated by two research assistants who worked across all eight research sites. Both of these research assistants spoke dominant local languages and were accompanied by two local fieldworkers who worked in each site for the wider ZAMSTAR study. In the CAB meetings, one research assistant facilitated while the other took notes. In the majority of the other activities, one research assistant facilitated while a local fieldworker helped with note-taking. In instances where gendered spaces were being researched, we ensured that a team of women facilitated groups of women and a team of men facilitated groups of men.

With guidance from the second author, research assistants were trained over the course of a week using a participatory approach that familiarized them with techniques used in BBS and equipped them with qualitative research skills such as probing, reflexivity, observing, asking open-ended questions and the writing of textual data. Training also aimed to give research assistants an understanding of their role within the ZAMSTAR project and of ethical issues they may face whilst doing fieldwork. In particular, the team was prepared for circumstances where they may witness or experience a crime and for situations where they might be asked questions about TB and/or HIV or for social support. In addition, research assistants doing the bulk of the fieldwork were trained in Good Clinical Practices (GCP) as a result of ZAMSTAR being a clinical trial. The study was approved by the Ethics Review Board of Stellenbosch University.

Data analysis

Research assistants facilitating the participatory activities produced typed activity reports after each BBS activity. These were written drawing from field notes and flipchart work as appropriate. All content was translated into English by the research assistant when writing the activity reports. We prepared the activity reports for entry into the qualitative data software programme QSR N6 by restructuring them (in some cases this was done alongside the facilitators and note takers of the activities if clarity was needed). Once entered into QSR N6, the data were coded into 'parent' and 'child' themes. Before

Table 1 Participatory methods used in the ZAMSTAR BBS: fieldnotes were kept by fieldworkers during, and reports were written after, each activity

Participatory method	Description of activity	No. per site*	Community participants per activity	No. reports analysed from 8 sites
Community free-listing and mapping	Meeting with community representatives. Free-listing exercise identifying where TB is thought to be spread, where TB is coming from and where people seek treatment. Mapping exercise to discuss the layout of the community.	1	5–10	7
Transect walks	Walks through each community. Recorded activities taking place, variety of treatment options available, and held informal interviews with a cross-section of the community about TB.	2	> 40	16
Daily time charts	2–3 hr activities with men, women and youth. Time charts were used to discuss daily living patterns. Open-ended discussions about TB were held alongside.	4	4–15	28
Structured observations	2–3 hr observations in gathering places. Women's spaces, men's spaces and mixed spaces were explored. Recorded open-ended discussions about TB.	4	4–20	29
NTP clinic observation	3 hr observation at the local clinic. Informal interviews about TB were held with staff and patients while a checklist detailing waiting time and attendance frequency was completed.	1	>30	7
Evening observation	1 x 1–2 hr observation in the evening, usually at a drinking place, to discuss TB.	1	>10	6

Notes: *This is an indication of the number we aimed to complete in each of the eight research sites. For logistical or safety reasons, in some instances the target number was not met. This is reflected in the number of total reports analysed.

BBS = Broad Brush Survey; NTP = National TB Control Programme.

coding was finalized electronically, each activity report was coded manually by two different research assistants (usually by the facilitator of the activity and an office-based research assistant) using a standardized thematic coding map developed from an initial assessment of the data. Final codes were entered into QSR N6 by comparing the two manual sets of codes and merging them. This system reduced the chance of textual misinterpretation, as discrepancies were discussed within the research team when comparing the two coding sets. We drew on the coded data as completed by the ZAMSTAR team and completed further manual analysis of activity reports to inductively identify iterative themes.

Findings

Two dominant themes emerged from the data: (1) the association of TB with dirt and squalor, and (2) the anticipation of HIV-related stigma and how it impedes HIV and TB diagnosis. Findings are presented in three parts linked to these two themes. The first part uncovers how TB is primarily defined as a 'dirty' disease, exploring popular ideas about the causes of TB. Both the second and third parts show how the experience of TB is linked to suspicion of HIV. Whilst the second part draws attention to factors that are said to generate HIV suspicion, the third focuses on the navigation of this suspicion.

Popular definition and understanding of TB

While many respondents in all research sites connected overcrowding, poverty and malnutrition to TB, in only two of the sites was there a general understanding that TB can be cured. Respondents in these two sites also linked the spread of TB to coughing, spitting and talking closely more consistently. Dominant across all research sites was people's explanation that TB results from contact with dirt and squalor. Bewitchment beliefs were also evident, although these were more prominent amongst the elderly and included TB as a result of being kicked in the chest by *impundulu* (the lightning bird of Xhosa folklore) or *idliso* (poisoning through witchcraft). Less pervasive explanations about the transmission of TB included the sharing of food and utensils with TB patients, exposure to damp or extreme temperatures and kissing. In one research site, TB was deemed a genetic disposition, and, in another, men claimed that women were more vulnerable to TB and HIV as a result of weak blood.

The dirty disease

"People who have toilets lock them for safety and cleanliness and those who don't have toilets relieve themselves in the open or in plastic bags. Stray dogs break open the plastic bags and the contents spills out all over the place. People breathe these germs [including TB] everyday." (Respondent during an observation at a market area, 25 October 2005)

TB was heavily associated with filth, blocked drains, poor sanitation and inadequate housing. Many blamed the poorest

areas of their communities for the spread of the disease. These areas were often referred to locally as *ezimbacwini* (translated as refugee camps with strong connotations of neglect), and residents explained that levels of excrement and household waste stagnating in streets and across open spaces were highest in these areas due to a lack of municipal services. Field teams felt that in some sites levels of uncollected waste were worse than in others, but all the townships faced problems with waste disposal and saw this as a source of disease. Some respondents felt that flies were attracted by waste and spread TB through the community, others felt that breathing in the bad smell generated by waste (including animal carcasses), or coming into direct contact with waste, might cause TB. Eating dirty food—either collected from rubbish bins or not prepared hygienically—was also often mentioned as a cause of TB. In one township, where racial tensions were apparent, racial groups were blamed for the spread of TB because they were believed not to prepare food hygienically. Often a certain sector or particular individuals within a research site were blamed for the spread of TB because they or their living conditions were viewed as dirty. For example, during an observation at a hair salon, the owner pointed out a homeless man wearing soiled clothes and a blanket exclaiming, *"How can [we] be safe from contracting TB if there are people like that in here?"* (7 October 2005). Often locals living in more derelict conditions within a research site were blamed, but in some instances blame was also placed on outsiders from more dirt-ridden townships for bringing disease to a community.

Beyond the more general way local communities viewed their (or other) populations to be susceptible to disease as a result of unhygienic or dirty living conditions, ideas of personal pollution as a result of performing dirty work or drug abuse also emerged. Exposure to dust and chemical or industrial pollution during employment was strongly linked to the development of TB. Often those who had experience of employment blamed weak occupational health and safety procedures for causing disease. Inhaling substances including paint fumes, building materials on construction sites, smoke from electric train cables, chemicals used to clean buildings (for example, schools or hospitals), particles from fabric and wool in textile industries, and pesticides when working on farms were also mentioned as causing TB. Smoking, drinking (in particular cheap wine and local commercial *ijuba* beer which is seen to have more chemicals than traditionally brewed beer) and breathing steam from asbestos (evaporation from houses in the morning sun) were also commonly said to lead to TB because they polluted the body.

The link to HIV

Redefinitions of TB as a result of HIV and AIDS were evident similar to those described by Mavhu *et al.* (2010) and Bond and Nyblade (2006). Respondents distinguished between old/fat TB and new/thin TB (or TB-plus), the latter understood as incurable and strongly associated with HIV and/or weight loss, the former often understood as curable and associated with weight gain. Talk that TB is a precursor of HIV or AIDS also emerged. Some thought that if one is irresponsible whilst undergoing TB treatment (e.g. by drinking or taking drugs) one can develop HIV or AIDS, and others thought that AIDS results

if TB medication fails. Some assumed that if one contracts TB a second time one has HIV, and a few thought that TB necessarily leads to HIV or that they are one and the same disease. Themes emerging from BBS data highlight that TB is linked most prominently with HIV suspicion. Respondents consistently argued that TB patients are likely to be judged as HIV-infected by their community, showing that perceived levels of HIV–TB stigma are very high:

“It’s all the same, because people treat you the same.” (Woman during evening observation, 7 October 2005)

“It’s easy for people with TB to talk about having TB when they are at the clinic for treatment, but it is not so easy to talk about having TB in the community to people who don’t have the disease or don’t know you have TB, because TB is associated with AIDS.” (Relapse TB patient during an NTP clinic observation, 19 July 2005)

Factors fuelling HIV suspicion

Symptoms

Most townships exhibited detailed and bio-medically sound knowledge of TB symptoms, with two being the exception. Persistent coughing, back pains, low appetite, fatigue, weight loss, sweating and vomiting blood were frequently mentioned as signs of TB. Importantly, weight loss was also heavily associated with HIV or AIDS; respondents consistently reported that if a person loses and then does not regain their weight, they are suspected of having HIV or AIDS. The following extract from an activity report provides an example of how loudly weight loss speaks within the townships:

“An adult man, the patient had been recently diagnosed with TB at his local clinic. He had overheard his neighbours saying he had AIDS because he was very thin. He was so thin that he himself started to believe he might have AIDS, concluding that either there must be a way unknown to him of contracting AIDS other than sexual intercourse or that condoms do not work because he always used condoms.” (Respondent during clinic observation, 19 July 2005)

Thinness has been regarded as a sign of HIV or AIDS in previous studies conducted by Magazi (2008) and by Matoti-Mvalo (2006) in townships near Cape Town. Matoti-Mvalo highlights that respondents were conscious about a thin body as signalling the presence of HIV or AIDS to the point that those who understood obesity as a risk factor for non-communicable diseases would rather be overweight and obese than lose weight to improve their health because others may suspect that they have HIV or AIDS. Magazi’s anthropological study of TB patients shows that her informants began to move more freely around their community once they gained weight after initiating treatment as this dispelled any suspicions of HIV infection within the wider community. In all eight of our study townships, levels of perceived HIV stigma are extremely high and weight loss arouses deep suspicion of HIV. Further, weight loss complicates TB treatment-seeking behaviour. For example, during an observation outside a hair salon (8 September 2005), a woman who had previously been cured from an episode of TB showed how the urgency of seeking

treatment from her local NTP clinic was lost because she retained her weight. The woman worried her TB had returned because she was coughing heavily and always felt cold. She explained that she had been to the clinic and was asked to bring her sputum sample back the following day, but failed to do so because she did not want to return and meet with the TB patients there. She elaborated saying that TB patients all looked “ugly” when they are very ill and that she “liked her TB” because the symptoms did not show—she had not lost any weight.

While weight loss speaks loudly to communities about whether a particular individual has TB or HIV, in some instances the behaviour of an individual also appears to shape community identification of disease. On the whole, patients with TB are not expected to feel weak or be antisocial, and if they do display these symptoms, HIV infection is often assumed. During a daily time chart activity with youth who were playing pool (2 August 2005), it was said that one could tell if someone had TB or HIV because the latter made people shy, weak and passive while the former made its victims assertive, stubborn and angry. The manner in which TB and HIV are seen to evoke different emotional performances suggests that TB is understood as a more demonstrative disease than HIV. This is also reflected in community ideas that TB patients disclose their disease, while HIV patients conceal theirs.

Non-disclosure and disclosure

“When someone says ‘I have TB’ others will say that the person has three words [HIV].” (Woman during an observation at a water point, 27 June 2005)

Indeed, a strong negative correlation exists between positive community ideas about disease disclosure and the social stigma of disease across the research sites. In five research sites respondents often explained that if individuals “hide” a disease and do not disclose their disease “status” they are likely to suffer more than they need. Respondents also suggested that disclosing ones status could help a patient to heal. Those who “hide” their disease were thought to die sooner because of the stress and pain of experiencing illness in isolation; it was claimed that patients who did not reveal their TB faced the added burden of community suspicion of HIV. As a group of street sweepers explained after a daily time chart activity: *“People who hide their illness are those who are suffering from the big TB [i.e. HIV or AIDS]”* (7 October 2005).

The notion of disease disclosure as a positive step for TB patients to take is juxtaposed against HIV–TB stigma. TB patients face a dilemma: both disclosing and not disclosing their disease can lead to stigmatization. Many respondents themselves appeared to be supportive and compassionate towards people with HIV or TB, often speaking of friends or relatives who were sick, but there was also evidence of a lack of social support for HIV and TB patients, with some respondents blaming individuals for their disease:

“People with AIDS deserve it because they are isifebe [translated as whores].” (Woman during transect walk, 21 July 2006)

"TB is a person's own fault because they live in dirty places, don't dress warmly and drink." (Hair salon owner during an observation, 22 July 2005)

Owing to how interchangeable TB and HIV have become, residents of one particularly marginalized research site were hesitant to talk about TB at all. HIV was largely seen as a taboo subject associated with promiscuity or abandonment and respondents feared talking about TB because others may humiliate and isolate them assuming that they were infected with HIV. Those who did enter into discussions said that people with TB hide their disease in fear of being stigmatized. This was re-iterated in other sites where it was explained that TB patients faced isolation, a loss of popularity and/or ridicule. In all sites there was evidence of extensive name-calling of TB and HIV patients.

Expressions of stigma appeared to be linked to disease knowledge in some instances. During one observation with youth (2 September 2005), for example, it was suggested that people with TB were seen to suffer more discrimination than those with HIV because TB patients cough germs. They felt that it was easier to socialize with an HIV-positive person because the virus would not spread unless they engaged in sexual intercourse. Socializing with a TB patient was viewed as more risky because the disease is airborne. In instances where the sharing of utensils, cigarettes and drinks were understood as a common way to contract TB, TB patients were made to use separate utensils, smoke a shared cigarette last and drink a shared drink last. In some instances, respondents suggested that nobody shares at all with a TB patient.

The navigation of HIV suspicion

Avoiding diagnostic services

A noteworthy number of respondents thought that they probably had contracted TB but did not want to attend their local NTP clinic. Many explained that they only seek care when they are *"really sick"* as others may insult or blame them for spreading disease and this adds to an individual's suffering. Across all of the townships, respondents claimed that a reluctance to test for TB at NTP clinics resulted from a fear of breached confidentiality. Attending this type of diagnostic service was simply viewed as too risky because the community could easily identify a patient and suspect him/her to be an HIV patient. Similarly, respondents also feared attending a community-based DOTS supporter (lay health workers used to supervise TB treatment). Confidentiality of patients at clinics was said to be compromised by long waiting times, designated waiting areas, doors that are left open in consultation rooms and a colour-coded card system used by clinic staff. In one research site, many did not want to attend the NTP clinic because it was too near a busy taxi rank and this increased the chance of being identified by their community. Patients waiting at the clinic avoided certain benches that they said indicated an HIV-positive status to others. In another site, locals complained of a single door that is used for both HIV and TB patients, commenting that if you go to the clinic for TB treatment, others might easily conclude that you have HIV or AIDS.

Turning to alternative treatment providers

Fear of being identified by their community and dissatisfaction with local NTP services not only made people delay seeking treatment from their local clinic, but were also common factors driving people experiencing TB symptoms to turn to NTP clinics in other areas and alternative treatment providers. A general lack of sympathy (from nurses), patient neglect and long waiting times (of up to 6 hours) were described as factors that pushed TB suspects away from NTP services. A few respondents also had a lack of faith in sputum diagnosis, saying that it was not reliable and therefore not worthwhile. They thought chest X-rays were more conclusive. Most claimed that they would turn to a private doctor first if they could afford this as a private doctor was most likely to maintain patient confidentiality. Others preferred to turn to traditional healers, faith healing or herbalists as a way of either avoiding HIV suspicion or supplementing allopathic treatment. This is consistent with findings from Van Wyk *et al.* (2011) who show that a significant proportion of TB patients receiving treatment from local NTP clinics first attended non-NTP health-care practitioners.

Those turning to traditional healers seek privacy through a diagnosis that does not define them as HIV/TB positive or negative—traditional healers typically diagnose *idliso* or *impundulu*. Although traditional healers are operating across all of the research townships, many respondents felt that they were not used that widely for treating TB, with the youth in particular often rejecting bewitchment theories. Respondents who did use traditional healers often ended up having their TB treated by the local NTP clinic, and in discussions held along transect walks, traditional healers explained how they often refer patients directly to NTP clinics if they are displaying symptoms of TB. Faith healing has previously been identified as a treatment option (Magazi 2008) and data showed evidence of this in most townships. During one transect walk (7 September 2005), respondents who told research assistants that they were undergoing faith healing explained that the church can address a range of problems somebody might be suffering from such as arthritis, sterility and stomach pains. Faith healing usually involves a process of prayer, purging and cleansing with holy water.

Discussion

Associations of TB with squalor and the resultant stigmatization of TB as a dirty disease have been well documented within other endemic parts of South Africa (Westaway 1989; Westaway and Wolmarans 1994; Edginton *et al.* 2002). How this affects TB control is less clear, although some advocate that correcting misconceptions through educational interventions may help reduce the stigmatization of TB and therefore improve PCF. In our findings, the association of TB with dirt does not fit comfortably with the idea that there is simply a gap in disease knowledge. There are variable levels of understanding of the symptoms of TB and its social determinants. Respondents connected overcrowding, poverty and malnutrition to TB and many considered TB an airborne disease. There was evidence that the concept of increased host susceptibility to disease is understood in many instances—smoking and drug abuse

(as well as other factors that weaken the body's ability to resist disease after becoming infected) were commonly linked to TB. Communities consistently described how TB, like the waste that is symptomatic of their marginalization, is omnipresent within their communities. As one respondent put it during a transect walk (21 October 2005), "*TB is made here*", and another during a daily time chart activity (28 October 2005), "*it's dished out here*". When the dominant idea that TB is caused by exposure to dirt and squalor is placed in the context of this understanding—that TB is unavoidable—the association of TB with dirt and squalor can be understood as an expression of communal vulnerability. Further, it reflects that having TB is an indication of being polluted, and it follows then that TB itself should be linked with pollution.

The urgency of seeking health care or a TB diagnosis appears, therefore, to be more diluted by the popular understanding that there is a communal vulnerability to TB and disease, than by a lack of bio-medical knowledge. Reflecting the way in which townships feel overwhelmed by the disease, TB, like the dirt-ridden environment of their townships, is understood as commonplace and inescapable. The strong sense of communal vulnerability and fatalism suggests that the perceived power of individual agency is low. The latter is problematic for the current reliance on PCF because PCF relies on the individual to self present at diagnostic and treatment services. A similar observation is put forward by a qualitative study of patient adherence to TB treatment (Naidoo *et al.* 2009) that explains how "*the complex interrelationships between environmental, social, cultural and personality factors are evident in the way participants constructed causal explanations of TB*". The authors describe how the inability to control the factors that caused the onset of TB was one of the dominant themes to emerge, with TB patients frequently assigning climatic and poor living conditions as the causes of TB. They argue that blaming external factors that are beyond individual control is disempowering, since individuals are less likely to be self-motivated to seek treatment or stimulate change within their communities. Ford *et al.* (2009) have also argued that the perception of TB as a common (inevitable) disease can be directly associated with treatment delay.

The inconsistency between control efforts that rely on self-motivation of TB suspects to present at health facilities and the way in which TB is perceived to overwhelm individual agency within the townships highlights the urgency of addressing this dichotomy through community-based interventions that can locally awaken a sense of self-determination. This could be done directly through emphasis on how early treatment improves outcome and curbs ongoing transmission within the township. It could also be done more indirectly, through broader interventions which may help communities to feel less marginalized, such as improved waste removal and service delivery, as these may reduce the sense of fatalism and encourage communities not to simply accept TB as part of their lot.

While the interpretation of TB as a dirty disease may be implicitly contributing to treatment delay, a fear of HIV suspicion is a significant explicit factor negatively impacting on treatment-seeking behaviour that also places a substantial psychosocial burden on individuals. Although actual

treatment-seeking behaviour of individuals was not investigated in this study, findings show that levels of anticipated HIV–TB stigma are extremely high across all eight of the research sites and that popular perceptions are very influential. Further research needs to validate the actual behavioural effect of anticipated stigma on seeking TB treatment as our findings strongly suggest TB suspects avoid seeking diagnosis in order to escape the gaze of their local community. While some studies support the claim of our respondents that HIV–TB stigma is contributing to treatment delay, others have doubted whether this delay is clinically significant (Godfrey-Faussett *et al.* 2002; Pungrassami *et al.* 2010). Findings from Godfrey-Faussett *et al.* (2002) challenge qualitative observations that HIV stigma is likely to increase TB diagnostic delay in Thailand (Ngamvithayapong *et al.* 2000), although results from the quantitative study are likely to be highly context specific and the understanding of what constitutes stigma is limited. Our method investigated popular perceptions in an open-ended fashion, showing that levels of anticipated disease stigma can be alarmingly high in settings where TB and HIV epidemics are concomitant.

All eight townships doubt their own social support of TB patients because of the association between TB and HIV. In light of our study's participatory emphasis and calls for more bottom-up research, our findings, which show how communities themselves believe anticipated stigma to be a driver of diagnostic delay, deserve urgent attention regardless of the fact that actual individual treatment-seeking behaviour has not been studied. According to what the respondents had to say, reducing levels of anticipated HIV-related stigma may have a significant ripple effect in encouraging voluntary presentation and this should be heard by policy makers. Interventions designed to reduce disease stigma in health care settings and within the wider community are therefore relevant (Macq *et al.* 2008; Nyblade *et al.* 2009). Improving services at NTP clinics and addressing low levels of patient privacy could have a significant impact on reducing diagnostic delay. The integration of TB and HIV services more generally into health services could increase confidence in patient confidentiality. Changes in practice to ensure consulting doors are closed, patient records are more discrete and waiting areas are less discriminating should be considered. While other studies have highlighted provider delay as a significant contributor to diagnostic delay (Meintjies *et al.* 2008; Skordis-Worrall *et al.* 2010), we did not explore this component given the unsuitability of our methods for this purpose. While our results cannot be widely generalized because factors contributing to diagnostic delay are potentially numerous and likely to vary considerably in relative importance between different populations and settings (Pronyk *et al.* 2001), striking similarities in popular perception were evident across all eight research sites.

Conclusion

Popular discourse stigmatizes TB as both a dirty and a HIV-related disease in the hyperendemic townships of Cape Town. A lack of control over their immediate environment engenders a passive response to TB amongst residents, who view TB as an inevitable outcome of living in poverty and

squalor. Coupled with the strength of anticipated HIV stigma, this exposes PCF as an inappropriate strategy in such environments, where interrupting the spread of TB through early case detection and effective treatment is essential to bringing the epidemic under control (Whalen 2006; Bekker and Wood 2010). To improve case detection, PCF should be reconsidered and public health interventions should aim to: (1) emphasize how early treatment improves outcome and curbs ongoing transmission; (2) combat a sense of communal vulnerability to TB; (3) address anticipated HIV–TB stigma; and (4) improve the quality of care provided at local diagnostic services, addressing low levels of patient confidentiality.

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Conflict of interest

None declared.

References

- Ayles H, Schaap A, Nota A *et al.* 2009. Prevalence of tuberculosis, HIV and respiratory symptoms in two Zambian communities: implications for tuberculosis control in the era of HIV. *PLoS ONE* **4**: e5602.
- Bassili A, Seita A, Baghdadi S *et al.* 2008. Diagnostic and treatment delay in tuberculosis in 7 countries of the Eastern Mediterranean region. *Infectious Diseases in Clinical Practice* **16**: 23–35.
- Bekker L-G, Wood R. 2010. The changing natural history of tuberculosis and HIV coinfection in an urban area of hyperendemicity. *Clinical Infectious Diseases* **50**: S208–14.
- Bond V. 2011. Terrains and tuberculosis: the model applied in urgent public health settings. In: Wallman S (ed). *The Capability of Places: Methods for Modelling Community Response to Intrusion and Change*. London: Pluto Press, pp. 80–110.
- Bond V, Nyblade L. 2006. The importance of addressing the unfolding TB-HIV stigma in high HIV prevalence settings. *Journal of Community & Applied Social Psychology* **16**: 452–61.
- Cape Town TB Control. 2004. *Progress Report 1997–2003*. Cape Town, South Africa: Health Systems Trust.
- Department of Health, Republic of South Africa. 2011. National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa, 2010. Pretoria, South Africa: National Department of Health.
- Dos Santos MAPS, Albuquerque MFP, Ximenes RAA *et al.* 2005. Risk factors for treatment delay in pulmonary tuberculosis in Recife, Brazil. *BMC Public Health* **5**: 25.
- Edginton ME, Sekatane CS, Goldstein SJ. 2002. Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. *International Journal of Tuberculosis & Lung Disease* **6**: 1075–82.
- Ford CM, Bayer AM, Gilman RH *et al.* 2009. Factors associated with delayed tuberculosis test-seeking behaviour in the Peruvian Amazon. *American Journal of Tropical Medicine & Hygiene* **81**: 1097–102.
- Gershon AS, Wobeser W, Tu JV. 2008. Delayed tuberculosis treatment in urban and suburban Ontario. *Canadian Respiratory Journal* **15**: 244–8.
- Godfrey-Faussett P, Kuanda H, Kamanga J *et al.* 2002. Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *International Journal of Tuberculosis & Lung Disease* **6**: 796–805.
- Karim F, Islam A, Chowdhury AMR, Johansson E, Diwan VK. 2007. Gender differences in delays in diagnosis and treatment of tuberculosis. *Health Policy and Planning* **22**: 329–34.
- Lawn SD, Bekker LG, Middelkoop K, Meyer L, Wood R. 2006. Impact of HIV on the epidemiology of tuberculosis in a peri-urban community in South Africa: the need for age specific interventions. *Clin Infect Dis* **42**: 1040–47.
- Lonnroth K, Castro KG, Chakaya JM *et al.* 2010. Tuberculosis control and elimination 2010–50: cure, care and social development. *The Lancet* **375**: 1814–29.
- Macq J, Solis A, Martinez G, Martiny P. 2008. Tackling tuberculosis patients' internalised stigma through patient centred care: An intervention study in rural Nicaragua. *BMC Public Health* **8**: 154.
- Magazi B. 2008. The spoilt blood that needs nourishment: Managing TB in the context of HIV/AIDS, food insecurity and social inequalities in Mbekweni, Paarl. MPhil dissertation, Department of Social Anthropology, University of Cape Town.
- Matoti-Mvalo T. 2006. An exploration of the perceptions about being thin, HIV/AIDS and body image in black South African women. MPH thesis, School of Public Health, University of the Western Cape.
- Mavhu W, Dauya E, Bandason T *et al.* 2010. Chronic cough and its association with TB-HIV co-infection: factors affecting help-seeking behaviour in Harare, Zimbabwe. *Tropical Medicine & International Health* **15**: 574–79.
- Meintjies G, Schoeman H, Morroni C, Wilson D, Maartens G. 2008. Patient and provider delay in tuberculosis suspects from communities with a high HIV prevalence in South Africa: a cross-sectional study. *BMC Infectious Diseases* **8**: 72.
- Metcalfe CA, Bradshaw D, Stindt WW. 1990. Knowledge and beliefs about tuberculosis among non-working women in Ravensmead, Cape Town. *South African Medical Journal* **77**: 408–11.
- Murray EJ, Marais BJ, Mans G *et al.* 2009. A multidisciplinary method to map potential tuberculosis transmission 'hot spots' in high-burden communities. *International Journal of Tuberculosis & Lung Disease* **13**: 767–74.
- Murray EJ. 2010. The Social Terrain of Endemic Tuberculosis in and around Cape Town. MPhil Dissertation, Faculty of Health Sciences: Stellenbosch University. Online at: <http://scholar.sun.ac.za/handle/10019.1/3492>.
- Naidoo P, Dick J, Cooper D. 2009. Exploring tuberculosis patients' adherence to treatment regimens and prevention programs at a public health site. *Qualitative Health Research* **19**: 55–70.

- Ngamvithayapong J, Winkvist A, Diwan V. 2000. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS* **14**: 1413–9.
- Ngamvithayapong-Yanai J, Ishikawa N. 2006. The role of social science research in reducing the burden of tuberculosis in high HIV-prevalence settings. *Tropical Medicine & International Health* **34**: 7–13.
- Norman R, Matzopoulos R, Groenewald P, Bradshaw D. 2007. The high burden of injuries in South Africa. *Bulletin of the World Health Organization* **85**: 695–702.
- Nyblade L, Stangl A, Weiss E, Ashburn K. 2009. Combating HIV stigma in health care settings: what works? *Journal of the International AIDS Society* **12**: 15.
- Promptussananon S, Peltzer K. 2005. Perceptions of tuberculosis: attributions of cause, suggested means of risk reduction, and preferred treatment in the Limpopo Province, South Africa. *Journal of Health, Population and Nutrition* **23**: 74–81.
- Pronyk PM, Makhubele MB, Hargreaves JR, Tollman SM, Hausler HP. 2001. Assessing health seeking behaviour among tuberculosis patients in rural South Africa. *International Journal of Tuberculosis & Lung Disease* **5**: 619–27.
- Pungrassami P, Kipp AM, Stewart PW *et al.* 2010. Tuberculosis and AIDS stigma among patients who delay seeking care for TB symptoms. *International Journal of Tuberculosis & Lung Disease* **14**: 181–7.
- Robins S (ed). 2005. *Limits to Liberation after Apartheid: Citizenship, Governance and Culture*. Oxford: James Currey Publishers; Athens, OH: Ohio University Press; Cape Town: David Phillip.
- Sengupta S, Pungrassami P, Balhithip Q *et al.* 2006. Social impact of tuberculosis in southern Thailand: views from patients, care providers and the community. *International Journal of Tuberculosis & Lung Disease* **10**: 1008–12.
- Sismandis C, Moulton LH, Ayles H *et al.* 2008. Restricted Randomisation of ZAMSTAR: a 2 x 2 factorial cluster randomised trial. *Clinical Trials* **5**: 316–27.
- Skordis-Worrall J, Hanson K, Mills A. 2010. Confusion, caring and tuberculosis diagnostic delay in Cape Town, South Africa. *International Journal of Tuberculosis & Lung Disease* **14**: 171–80.
- Storla DG, Yimer S, Bjune GA. 2008. A systematic review of delay in the diagnosis and treatment of tuberculosis. *BMC Public Health* **8**: 15.
- Strauss RP, Sengupta S, Crouse Quinn S *et al.* 2001. The role of community advisory boards: involving communities in the informed consent process. *American Journal of Public Health* **91**: 1938–43.
- Van Wyk SS, Enarson DA, Beyers N, Lombard C, Hesselning AC. 2011. Consulting private health care providers aggravates treatment delay in urban South African tuberculosis patients. *International Journal of Tuberculosis & Lung Disease* **15**: 1069–76.
- Wallman S. 1996. *Kampala Women Getting By: Wellbeing in the time of AIDS*. London: James Currey.
- Wallman S. 2003. The diversity of diversity: implications of the form and process of localized urban systems. Presentation at the second ENGIME (Economic Growth and Innovation in Multicultural Environments) workshop: communication across cultures in multicultural cities. FEEM working paper 2003.75. London: University College London. Online at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=464686, accessed September 2008.
- Wallman S (ed) in association with Bond V, Lo Conte R, Montuori A, Vidali M. 2011. *The Capability of Places: Methods for Modelling Community Response to Intrusion and Change*. London: Pluto Press.
- Westaway MS. 1989. Knowledge, beliefs and feelings about tuberculosis. *Health Education Research* **4**: 205–11.
- Westaway MS, Wolmarans L. 1994. Cognitive and affective reactions of black urban South Africans towards tuberculosis. *International Journal of Tuberculosis & Lung Disease* **75**: 447–53.
- Whalen CC. 2006. Failure of directly observed treatment for tuberculosis in Africa: a call for new approaches. *Clinical Infectious Diseases* **42**: 1048–50.
- Wood R, Middelkoop K, Myer L *et al.* 2007. Undiagnosed tuberculosis in a community with high HIV prevalence: implications for tuberculosis control. *American Journal of Respiratory and Critical Care Medicine* **175**: 87–93.
- World Health Organization. 2011. *Global Tuberculosis Control 2011*. Geneva: World Health Organization.