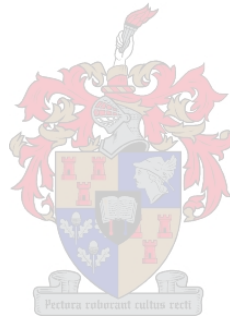


The Social Terrain of Endemic Tuberculosis in and around Cape Town

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Master of Philosophy in Communicable Diseases



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DECLARATION

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Date: 02 November 2010

ABSTRACT

Global control of the tuberculosis (TB) epidemic remains one of the greatest health challenges of the 21st century, despite the availability of effective treatment over the past 50 years. The rising incidence of transmitted (primary) drug resistant TB threatens the very fabric of conventional TB control efforts, which are already strained by a rampant human immunodeficiency virus (HIV) epidemic. Ongoing transmission of *Mycobacterium tuberculosis* is a key factor that sustains the TB epidemic in endemic areas such as the socio-economically deprived townships of Cape Town, South Africa. My research explores the disease context, or social terrain, of TB in this endemic setting. It is primarily concerned with how the social terrain of endemic TB may contribute to ongoing transmission and the potential that it holds for enhancing TB control efforts. Analyses of qualitative data from eight township research sites in and around Cape Town show that pragmatic and novel approaches are required to pierce through the enormity of TB as a political and economic problem. Broadening the current biomedical focus on treating individual patients, to include more holistic community-based interventions, can and should be developed.

Data were collected as part of qualitative pre-intervention community surveys conducted in 2005 and 2006 for a public health intervention trial (ZAMSTAR) performed in Zambia and South Africa. Twenty-four communities were selected as research sites and this study draws on the survey data collected in the trial's eight South African sites. Although the data were collected for the ZAMSTAR trial, the aims and analyses presented in this study - which seek to improve our understanding of how the social terrain is meaningful for TB control - remain independent of ZAMSTAR.

Through a retrospective analysis of the South African data, I inductively present three distinctive ways in which the social terrain is meaningful for TB control. First, the interaction between social cohesion and social diversity may be an important variable that predicts community response to public health interventions aimed at reducing the prevalence of TB in these endemic areas. This is demonstrated by triangulating ZAMSTAR'S adaptation of a social systems model with further analysis of the research sites. Second, the study identifies a common discourse running through the sites that stigmatizes TB as both a dirty and HIV-related disease. It is argued that this may be significantly contributing to TB diagnostic delay and I call for more holistic approaches to TB control that can reduce perceived marginalization and TB-HIV stigma. Third, congregate settings emerge as noteworthy visible features of social terrain that clearly have the potential to facilitate TB transmission within communities. The pre-intervention surveys qualitatively described public spaces within each research site and the use thereof. Basic principles of TB transmission are applied to these descriptions, developing a novel method of mapping the relative transmission risk possibly posed. Innovative use of similar approaches could identify likely transmission "hot spots" that may serve as focal points for targeted interventions, such as adjustments that increase ventilation or encourage TB suspects to seek urgent medical diagnosis and treatment.

OPSOMMING

Die beheer van tuberkulose (TB) bly steeds een van die grootste gesondheids uitdagings van die 21ste eeu, ten spyte van die beskikbaarheid van effektiewe behandeling vir die afgelope 50 jaar. Die stygende insidensie van oorgedraagde (primêre) middelweerstandige TB bedreig die wese van konvensionele TB kontrole programme, wat reeds gebuk gaan onder die oorweldigende impak van die menslike immuungebrek virus (MIV) epidemie. Ononderbroke oordrag van *Mycobacterium tuberculosis* is 'n kardinale faktor wat die epidemie onderhou in areas soos die sosio-ekonomies agtergeblewe dele van Kaapstad, Suid-Afrika. My navorsing ondersoek sosiale terrein (konteks) van TB in hierdie hiperendemiese konteks. Dit is primêr gemoeid met die moontlike bydrae van die sosiale terrein tot voortgaande TB oordrag en die potensiaal wat dit mag inhou om TB kontrole te verbeter. Analise van kwalitatiewe data van agt agtergeblewe gemeenskappe in en om Kaapstad wys dat nuwe en pragmatiese benaderings benodig word om die volle omvang van TB as 'n politieke en ekonomiese probleem aan te spreek.

Data is versamel as deel van kwalitatiewe pre-intervensie gemeenskapsopnames wat gedoen is gedurende 2005 en 2006 vir 'n publieke gesondheid intervensie studie (ZAMSTAR) in Zambië en Suid-Afrika. Die studie sou poog om die TB prevalensie betekenisvol te verlaag in gemeenskappe wat erg geaffekteer word deur MIV. Vir navorsings doeleindes is vier-en-twintig gemeenskappe geselekteer, waaronder agt Suid-Afrikaanse gemeenskappe. My studie analiseer kwalitatiewe data wat versamel is in hierdie agt gemeenskappe, wat verskeie observasie en deelnemende tegnieke ingespan het. Die studie poog om algemene begrip te verbeter van hoe die sosiale terrein betekenisvol kan wees in TB kontrole; dit is my eie werk en is totaal onafhanklik van die groter ZAMSTAR studie.

Induktiewe retrospektiewe analise van data identifiseer drie voorbeelde wat illustreer hoe die sosiale terrein betekenisvol mag wees vir TB kontrole. Eerstens, die interaksie tussens sosiale kohesie en sosiale diversiteit mag 'n belangrike veranderlike wees wat gemeenskapsrespons tot publieke gesondheidsintervensies voorspel. Dit word geïllustreer deur die toepassing van 'n sosiale sisteme model (soos aangepas deur ZAMSTAR) en analise van ander aanvullende data. Tweedens, identifiseer die studie 'n gemeenskaplike diskoers in alle navorsings gemeenskappe wat TB stigmatiseer as beide 'n vuil en MIV-verwante siekte. Dit word gearchiver en getoon dat hierdie verskynsel moontlik betekenisvol bydra tot vertraging van TB diagnose en die nodigheid vir meer holistiese benaderings wat marginalisasie en TB-HIV stigma kan verminder word uitgewys. Derdens blyk dit dat openbare vergaderplekke 'n belangrike deel van die sosiale terrein vorm en duidelik die potensiaal het om TB oordrag binne gemeenskappe te fasiliteer. Die pre-intervensie opnames het alle openbare vergaderplekke sorgvuldig beskryf en basiese beginsels van TB oordrag is gebruik om vergaderplekke geografies te kaart volgens die moontlike transmissie risiko wat dit mag inhou. Innoverende gebruik van GIS-gebaseerde benaderings, soortgelyk aan die metode wat gebruik is om potensiële "transmission hot spots" te kaart, mag bydra om intervensies beter te fokus, deur bv. verbeterde ventilasie te verskaf of mense met simptome van TB aan te moedig om dringend mediese hulp te soek.

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PREAMBLE

It is a Friday morning and the clinic is not as busy as I have seen it before. I assume this is because of the rain. As I sit in the 'TB room' of the clinic, together with the 'TB nurse' and an assistant to the nurse, several patients come in. They take their tablets at the sink and walk out. Their treatment card is filled in. Not much is said. One of the men to come in looks particularly thin, withdrawn and sickly. He waits for the nurse who has rushed out of the room in the meantime. The nurse comes back in and asks the patient to drop his trousers. I feel uncomfortable and that I ought to leave the room. The patient speedily turns around before I move and, placing his hands on the counter top, is injected. The nurse explains that these injections are very painful. I am unsure if this comment is directed at the patient or me - perhaps both of us. The man leaves as ghost-like as he arrived, slipping in and out of clinic. The nurse explains that he was previously on TB treatment which he completed but the TB "came back" and he was then also diagnosed with HIV. Accompanied by a young woman, the next patient to come in was struggling to walk. An adult man, he looked exceptionally drawn and had a yellow ashen pallor to his skin. As he sat down, the nurse explained to the couple that he had been diagnosed with MDR – "a very serious type of TB" – and that the clinic had booked a place in the hospital for him, but that the hospital was currently full. In the meantime, while he waited for a place, he needed to come everyday to the clinic to collect his medication and have an injection. The patient looked down into his lap and asked softly how long this would have to go on for [the treatment]. The nurse responded saying that it depended on whether he was willing to work with them [the clinic] to fight this TB or not. She asked whether he wanted to go on treatment or not. There was no response. The nurse then asked whether it is because of David¹. David is an MDR patient who was admitted to hospital and started medication, but failed to follow his treatment through. He is now living in his community with untreated MDR TB and the clinic suspects that David's two children have caught MDR TB from him. Three people who knew David have died from MDR TB. The nurse explains to the patient that the hole in his lung is too big for the current medication he is on and that is why he has to have the injections. She also says that if David has been speaking to him and telling him to refuse treatment, he must not listen because David has not taken responsibility for his health; he has not "worked with the medicine", has consequently not recovered and is now spreading the disease to others. If he wants to get better, the nurse explains, he must go on heavier treatment. The patient takes his pills and has his injection. Again, little is said. He leaves with a pair of shoes from a donation box that the nurse tries to match with his size as more patients arrive.

- Fieldnotes, Cape Town township clinic visit, 16/04/04.

¹ Pseudonyms are used throughout this dissertation when referring to patients and other respondents.

The above vignette is taken from one of my first visits to a 'TB clinic' after starting a job at the Desmond Tutu TB Research Centre (DTTC) as a fresh graduate. Prior to the job, I embarrassingly had very little understanding of why tuberculosis was still an issue for South Africa. I had been attracted to the position because of a brief introduction to medical anthropology which, in turn, had stimulated an interest in public health. At this time I understood a fair amount about the transmission and prevalence of HIV/AIDS in South Africa. HIV/AIDS was a popular subject amongst my peers and a wide range of media informed me about political, economic, social and medical aspects of the disease. I was aware of many studies and NGOs working on the topic and had also been interviewed, while at university, about my own perceptions regarding this powerful and deadly disease. I had come to fear it. In stark contrast, I knew very little about tuberculosis beyond that it could be 'cured'. It occupied a suspiciously silent space in my social circles.

When I started working for the research centre, I quickly realized the depth of tuberculosis as a complex public health problem for South Africa and the urgent need to bring attention to the disease as a societal problem. Unjustly plaguing the poor, TB continues to constrain the lives of many people like the patients I saw at the clinic. More than simply an infection, this 'curable' disease evidently still has the power not only to kill, but also to strip away hope and dignity from its victims, placing a substantial burden on impoverished patients as well as on over-stretched health services. Complicated by rampant HIV, re-infection and increasing drug resistance, it seemed so obvious when visiting 'TB clinics' that socio-economic vulnerability played a major role in the manifestation of disease in all of the TB patients that I saw. As one respondent in the field put it, "TB is made here". I became frustrated by this. Both the nurse and patients were trying their best, but everyone present in the 'TB room' could sense that things were not working. They were not working for the nurse, who was overwhelmed by the stream of unresponsive patients failing to shake off disease, nor for the majority of patients who seemed ominously pacified by their disease - having lost hope for the recovery of their health.

This study is driven by an acute awareness that novel ways of challenging the persistence of tuberculosis within hyperendemic South African communities are needed. It approaches the frustration I constantly felt in the field which was rooted in the dilemma

the political economy of tuberculosis presented. The role of socio-economic factors in sustaining the tuberculosis epidemic was simply glaringly obvious, but the complexity of addressing these seemed overwhelmingly out of reach. This study acknowledges that sub-standard socio-economic conditions play a key role in driving the susceptibility of endemic areas to tuberculosis, but aims to pinpoint pragmatic avenues within such a given context that may be particularly relevant to enhancing the epidemiological impact of curative therapy. To this end, I draw on my experience while working at the DTTC to carve out locally responsive ways of understanding the South African epidemic from a social perspective, with the hope that this may help lead to increasing the efficacy of current public health responses in high burden settings.

CHAPTER ONE

Background & Introduction to Study

TB and society

Tuberculosis (TB) has deep historic roots that predate written record and despite the advances of modern medicine, the disease persists as a major global public health problem (1, 2). Most cases of TB are caused by *Mycobacterium tuberculosis* (*M. tuberculosis*), a small bacillus which infects the lungs. *M.tuberculosis* can be transmitted from any one person to another when projected into the air by the infected person (usually through coughing, sneezing, talking or singing) and breathed in by another. Experts used to speculate that ancestral *M.tuberculosis* strains originally spread to humans from cattle (who harbour *Mycobacterium bovis*) during the Neolithic period, but recent genetic evidence suggests otherwise. *M.tuberculosis* seems to have a very ancient human origin predating the onset of farming and animal husbandry (3). Currently, TB kills more people than any other curable infectious disease worldwide, with at least 4500 people dying daily (4). The total number of reported incident TB cases continues to increase, although the number of cases per capita has reached a plateau since 2004. Although the TB burden in many regions has been reduced, in settings where the epidemic is complicated by one or a mixture of HIV/AIDS, diabetes and/or drug resistance, TB prevalence remains unacceptably high. (5) According to Comas and Gagneux: “HIV/AIDS and diabetes are important comorbidities that dramatically increase susceptibility to TB. The synergy between HIV/AIDS and TB is a particular problem in sub-Saharan Africa, while the impact of diabetes on TB is increasing in many of the rapidly growing world economies; it may already be a more important risk factor for TB than HIV/AIDS in places like India and Mexico. The strong association between HIV/AIDS and drug resistant TB has been well established, but whether similar interactions exist between drug resistant TB and diabetes needs to be explored further” (3).

TB affects poorer countries. Socio-economic factors such as poverty, overcrowding, inequity and malnutrition have long been recognized as principle predisposing factors of TB (6). The global occurrence and distribution of TB has been historically shaped by

large processes that adversely affect the living conditions of populations such as industrialization, war and colonization (2). As put by John Huber in 1907: “The tubercle bacillus is an index by inversion of the real progress of the human race. By it the claim of civilisation to dominate human life may fairly be judged. Tuberculosis will decrease with the substantial advance of civilisation, and the disease will as surely increase as civilisation retrogrades” (6). TB incidence has peaked during phases of rapid industrialization, as occurred across Europe in the 18th and 19th centuries when the organization of societies around industrial manufacturing went hand-in-hand with urbanisation. Rapid growth of towns, poor living conditions and severe crowding increased exposure to *M.tuberculosis* and malnutrition simultaneously lowered people’s resistance to disease. Sustained declines in TB prevalence during the 19th century were linked mainly to improved living conditions. TB incidence and mortality rose again in parts of Europe during the first and second world wars. This increase was particularly evident in countries that experienced prolonged food shortages, reflecting again the impact of malnutrition on increasing the vulnerability of individuals to develop tuberculosis and sustain the epidemic. TB was also on the rise in Africa and Canada where colonialists had introduced new strains of *M.tuberculosis* to these areas through contact with indigenous populations. The susceptibility of indigenous populations to disease was not only increased by their lack of exposure to European strains of *M.tuberculosis*, but also compounded by the adverse changes in demography, lifestyle and environment brought about by the colonization process. Owing to loss of ancestral land and the emergence of wage labour, they became impoverished, living in overcrowded concentration camps or reserves with few substantial food sources. Many had to work in the mineral mines of South Africa where conditions were highly favourable for the development and spread of TB. (2)

TB continued its rapid decline in the ‘developed’ world following the two world wars. Improved living conditions across Europe and America reflected the convergence of political and economic interests in support of health reform and this helped to reduce TB prevalence and mortality rates. Prolonged exposure to the TB epidemic, which had been raging for centuries in Europe, probably also increased host resistance through natural selection, although no consistent markers of genetic susceptibility/resistance have been identified. The primary factor driving the prevalence of tuberculosis down at this time is widely understood to be socio-economic change. (7) The discovery of

streptomycin in 1947 and the use of isoniazid combination therapy shortly thereafter heralded the development of modern chemotherapy used to treat TB, which still offers a very cost-effective cure (8). Walt reports that by the 1960s “it is fair to say that most public health physicians assumed that TB control and treatment was a managerial problem”, and, “the fact that developing countries in the greatest need, with high prevalence rates, were least able to adopt the new ways of diagnosing and treating TB, became buried in the complacent belief that drugs and ambulatory care could cure those with disease and BCG [Bacillus Calmette-Guerin] vaccination could prevent further cases” (9). The limits of modern medicine and the complexity of TB eradication became painfully clear towards the end of the 20th century however. Rather than a decline in global TB prevalence, there was an escalation of the epidemic, fuelled and complicated by the arrival of HIV/AIDS and drug resistant TB.

The global resurgence of TB was attributed to the combined effects of the HIV epidemic and socio-economic factors linked to global population growth and industrialized capitalism including rising poverty, rapid urbanization, crowded living conditions and migration (10). TB control programmes were dysfunctional and suboptimal regimens were achieving poor cure rates. This together with an increasing concern from the international community over emergent drug resistance, brought the DOTS strategy into existence (11). Initially entitled ‘Framework for Effective Tuberculosis Control’, DOTS was developed as a five-point strategy by WHO and the International Union Against Tuberculosis and Lung Disease (IUATLD), an international TB technical non-government organization (NGO). It focused on attaining the following five points: (a) political commitment to TB control with increased and sustained financing, (b) detection of TB cases through sputum smear microscopy i.e. passive case finding, (c) regular and uninterrupted supply of anti-TB drugs, (d) six to eight months of regularly supervised treatment (including at least 2 months of directly observed of drug taking) with improved access to treatment, and (e) reporting systems to monitor treatment progress and program performance.

DOTS was internationally recommended shortly after TB was declared a global emergency in 1993 (12). The strategy was promoted by key actors in WHO and the World Bank as ‘the solution’ to TB control and transferred from the international arena to national governments on a global scale (13). Small explains how as the result of a

carefully planned and executed program of operational research, DOTS is to be lauded as the most significant advance in TB intervention over the past decades (14). By 2007 196 countries were using DOTS, the global case detection rate of sputum smear positive TB rose from 15% in 1995 to 63% and treatment success rates from 77% to 85% (15). Yet, despite the successes of DOTS and the millions of lives saved, control of the global TB epidemic remains elusive. Currently, over one third of the world's population is thought to be infected with MTB and more than 80 percent of these cases are found in impoverished areas of Africa and Asia (5, 16). Among the 15 countries with the highest estimated TB incidence rates, 13 are African, a phenomenon linked to global economic inequity and high rates of HIV co-infection (5). Countries in sub-Saharan Africa, where TB has re-emerged as the leading cause of death among adults (17), continue to fall alarmingly short of reaching prevalence and mortality targets (5).

Whilst DOTS helped unify the global response to TB and was successful in parts of the United States and China, in many other parts of the world, especially in settings with a high burden of HIV and/or drug-resistant TB, the success of the strategy has been questioned. A substantial amount of criticism leveled focuses on how the strategy, in practice, tends to disempower TB patients and divorce individual cases from their socio-economic context. It is argued that although the principles of DOTS were initially appealing, the emphasis that has been placed on sputum smear-microscopy and the directly observed therapy (DOT) component during its implementation - often through the way the strategy was branded and marketed – led to a dogmatic and restricted focus, while the other points of the broader strategy were often overlooked with disastrous consequences (13): “With the emphasis that is placed on directly observed therapy (DOT), there is a tendency for placing the focus on patient ‘failures’ while effectively masking the failures of the system to enable patients to comply” (11).

Although the shortcomings of DOTS are widely acknowledged and WHO has begun to emphasise that greater attention needs to be paid to social and health system factors affecting TB control, DOTS still remains the primary strategy for the prevention and control of TB worldwide (16). Current TB policies continue to be heavily criticized for treating individual patients without reference to the social conditions that frame his or her life and research from around the world has consistently highlighted socio-economic factors not only as determinants of disease but also as barriers to effective biomedical

control of TB. (11, 18-25) When highlighting the problem that migration poses for the DOTS strategy in China, Don Enarson expressed the need to develop the narrow DOTS focus as follows:

“The DOTS strategy is not an end to itself but only the front door to the fight against tuberculosis. The real hard work is yet to come...”

- Enarson: 2006 (25)

Following Robert Koch’s demonstration that MTB was the infectious agent causing tuberculosis, TB research focused primarily on the transmission dynamics, prevention and treatment of this “necessary cause”. The establishment of microbiology as a discipline in the late nineteenth century brought with it the discovery of vaccines and serum therapy for many diseases. Since these “new” sciences had succeeded in helping bring several infectious diseases under control with cures and vaccines, many researchers and government officials worldwide hoped they would do the same for TB (26). The fact that there are more TB patients today than ever before, more than 125 years after the discovery of *M.tuberculosis* and after the implementation of DOTS, provides substantial evidence that the biomedical lens through which tuberculosis control has been addressed is too narrow. Very little recognition has been given to the fact that *M.tuberculosis*, although a necessary cause, is not the sole cause for the development of TB and that the TB epidemic persists within vulnerable communities.

The South African perspective

“TB is like television – popular - you can find it in every house”
- Study respondent living in a Cape Town township, 28/06/2005.

South Africa is currently experiencing one of the most severe TB epidemics in the world, with TB incidence rates in excess of 1 000/100 000 in many places. It is characterized by growing levels of drug resistance and an increasing number of cases associated with a still rampant HIV epidemic (27). Estimates suggest that 70% of TB patients are co-infected with HIV and that TB notification rates have continued to rise steeply since 1995 despite the widespread implementation of DOTS in 1996. Although curative therapy has

been available for over fifty years, TB is the leading cause of mortality - responsible for 13% of all adult deaths (28). Moreover, ongoing transmission of drug resistant strains and a mature HIV epidemic that shows no sign of abating, threaten the very fabric of TB control efforts (29). Considering how poor urban planning, overcrowding and high levels of malnutrition dominate socio-economically deprived areas of South Africa previously marginalized under the Apartheid regime, it is unsurprising that TB remains largely endemic to these parts of the country and their populations. In poor settings that are predominantly black² and coloured TB can be found 'in every house', while in more affluent areas TB is typically absent.

TB emerged as an epidemic in southern Africa with the arrival European colonialists, although MTB was present in indigenous populations prior to this. It is recorded that Vasco de Gama's Portuguese expedition, the first to sail around the Cape of Good Hope, was plagued with TB and historical accounts suggest that the initial spread of TB disease amongst indigenous communities closely relates to their degree of European contact following formal colonization. South Africa was frequently marketed as a 'health resort' to Europeans who hoped to be cured of their TB from the country's sunny climate. This probably assisted to enlarge the local infectious pool towards the end of the 19th century, but the discovery of rich diamond and gold reserves around the same time created an extensive migrant labour system throughout southern Africa that fuelled the spread of the disease. (2)

Cheap labour was exploited from the indigenous South African population and other southern and central African colonies by European settlers who wanted to develop mineral mines. Mineworkers were employed on a contract basis and housed in very crowded and confined compounds which favoured the spread of TB. Mineworkers were not fed properly and forced to work long and physically demanding hours, so poor nutrition and health conditions lowered their resistance to disease. The lack of ventilation in the mines themselves also facilitated the development of lung silicosis, and the spread of TB. Alongside the growth of the mining industry, rapid urbanization and industrial development ensured that TB became a major cause of morbidity and mortality in

² Apartheid divided South Africa into population categories comprising Blacks, Coloureds, Asians, Indians and Whites. The use of these terms in this study reflects a history of constitutional racial segregation and does not imply support of this discriminatory ideology.

impoverished peri-urban areas of South Africa during the 20th century amongst the emergent working classes. TB was also spreading to more rural areas by this time, mainly through migrant mineworkers who had become diseased. Policy was that the contracts of TB sufferers were terminated and they were repatriated back to their areas of origin. This practice played a key role in spreading TB especially to black families in rural areas because migrancy was enforced solely on the black population and a hut tax had increased crowding in their family homes. Black workers could not relocate to the city and were forced to move back and forth between the mines and their rural homes. Other discriminatory practices such as differential wages perpetuated their poverty. TB had therefore begun to fall more heavily on the indigenous population as compared to the settler population well before Apartheid became an explicit national ideology. (2, 7) Many medical authorities, as well as some sectors of private business and the state, recognized the need for racial and urban environmental reforms in order to control TB, but this awareness became diluted by the Nationalist victory of 1948 and the discovery of curative therapy in 1943 which offered a medical bullet that many believed could eradicate TB. (7)

When curative TB treatment became available, tuberculosis control efforts became formalized on the South African mineral mines, but this public health response proved inadequate within the context of Apartheid. Case detection was low due to financial constraints and discriminatory legislation - factors that also complicated case management, often leading to inadequate and/or partial treatment. Black labourers often lost pay or employment if diagnosed with TB and the Group Areas Act limited access to well functioning clinics, with inequitable distribution of health services and social care. This increased the number of chronic cases who then acted as sources of infection to others, explaining why TB treatment programs ultimately had little impact on the prevalence of TB amongst the black population under Apartheid, while TB virtually disappeared amongst the white population by the 1980s. (7)

During the 1990s the legal machinery of Apartheid was dismantled. South Africa enlisted expert help from Dr Karel Styblo, ex-director of scientific activities of the IUATLD, to conduct a rapid appraisal of tuberculosis control efforts in 1995. Following Dr Styblo's visit, a new recording and reporting system was implemented and South Africa began to standardise the training of TB health workers based on his

recommendations. The DOTS strategy was officially adopted in 1996 but despite a reliable drug supply, relatively good commitment to TB control on many levels, adequate health infrastructure and substantial financial resources, drug resistance continued to increase and treatment interruption remained a problem. Alongside the need for further improvement in DOTS implementation, the need for community-based interventions became evident. The rapid emergence of the HIV epidemic also emphasized the urgent need for collaboration across TB and HIV programmes. (30)

The control of the concomitant HIV and TB epidemics remains one of the biggest challenges facing post-apartheid South Africa today (27). Despite the establishment of extensive (and growing) social welfare programmes, TB and HIV are thriving symbiotically alongside gross socio-economic inequalities, high rates of unemployment and increasing poverty - a “sobering recognition of the limited liberation achieved” (31-33). After years of mixed messages and poor focus, South Africa has developed a TB Strategic Plan (2007-2011), alongside a strategic plan for HIV/AIDS, to address the TB epidemic. In a recent speech³ Molefi Sefularo, the deputy health minister, spoke of the need for “a change of mind-set and more sense of urgency to confront the scourge of TB”. The health minister, Aaron Motsoaledi, has also explicitly recognized the importance of scaling up responses to the HIV and TB epidemics⁴. Dr Motsoaledi is expanding DOTS by increasing the number of lay health workers working as DOT supporters, training more health workers in TB management and has plans to initialize a social mobilisation campaign to try and strengthen TB control. (34) Against the backdrop of previous political failures to adequately respond to the HIV epidemic, there is hope that a recent shift in political leadership will facilitate a more effective response to HIV as well as TB, TB services having lagged behind the scaling up of antiretroviral therapy (ART) (27, 32).

Although political will, social mobilization and health system strengthening have been identified as ingredients of an effective response to the TB epidemic, there is also evidence that TB policies themselves need internal rejuvenation. In the Western Cape Province there is a notable disparity between the success of ART services and the TB

³ The speech was delivered in Cape Town to the meeting of the Consortium to Respond Effectively to the AIDS/TB epidemic (CREATE) and reported by the Independent Online 12 October 2009; South African Press Association.

⁴ See the health minister's address at the media launch of the Lancet Country Series on health in South Africa, Issued by South Africa's Department of Health, 24 August 2009. Access at <http://www.doh.gov.za>.

programme, the latter having more difficulty to deliver treatment successfully. Some argue that the relative success of ART services may be a result of its patient-centered approach, which aims to empower HIV patients with information and responsibility. Under the DOTS strategy TB control programmes failed to recognize the importance of treatment literacy and active patient involvement. (27)

It has also been argued that DOTS has failed in the Western Cape largely because it has not been designed as a strategy to curb the spread of tuberculosis through interrupting transmission, but rather as treatment guideline for tuberculosis (35). Whalen cites Lawn *et al.* (36) to show that despite reaching WHO's treatment goals, TB remains well out of control in a high burden community suffering a concomitant HIV epidemic, concluding that the main reason for the failure of DOTS is not a lack of proper implementation as has previously been argued. He explains that "epidemics result from the transmission of a micro-organism from infectious persons to at least one other susceptible individual. The force of this transmission is captured in the basic reproductive rate of an epidemic, a parameter that can be understood as the number of new infections among susceptible individuals during the infectious period of a case. Only three determinants underlie this important parameter: (1) the number of contacts (per unit time) between an infectious patient and susceptible contacts; (2) the probability of infection (or disease), given adequate contact for transmission from the patient to a susceptible individual; and (3) the duration of infectiousness of the index case." His argument is that DOTS does not sufficiently address the number and frequency of contacts or the likelihood of disease infection and therefore is inadequate as a control strategy in hyperendemic areas of South Africa.

Whatever the reason for the failure of current TB control efforts, it is clear that while gross economic disparities persist and treatment success remains low in comparison to other African countries that have considerably fewer resources (5), there is vast scope for innovative approaches that may help to amplify the efficacy of curative treatment, by both reducing TB transmission and vulnerability to develop disease at a community level.

Theoretical considerations

The overview of the TB epidemic in South Africa provides a tragic example of the tight relationship between a wider political economic context and infectious disease. Whilst the country tries to scale up control efforts, a historic path of social and economic inequality consistently ensures that disadvantaged South Africans struggle for health against “seemingly insuperable odds” (37). Alongside the earlier description of global tuberculosis, the description of South Africa also alludes to a difficulty in translating the wide recognition that TB remains a key symptom of “poverty consequential upon an unjust social and economic order” (38) into a workable alternative reality. Indeed, Rosenberg explained decades ago, that since at least the time of Rudolf Virchow (who founded the science of cellular pathology in the 1850’s), physicians and historians concerned with ‘social medicine’ have tended to view disease not as an alien visitation but rather as the consequence of social organisation and especially of social inequity (39). The control of TB in Europe and North-America emphasizes how macro change in socio-economic organization together with more focused control efforts has proved most effective at bringing tuberculosis under control. The case of the South African epidemic suggests that without mass socio-economic overhaul, the DOTS strategy alone will not bring TB under control.

The dominance of a biomedical perspective, rooted in individual autonomy, is often blamed for restricting successful social approaches to the control of TB. This is evident in the work of key figures such as Dubos and Dubos and Paul Farmer (40, 41) who criticise approaches that ignore the political economy of TB. The authors adopt a vulnerability perspective that shows how less emphasis should be placed on the individual and his/her agency and more emphasis needs to be placed on how surrounding contextual factors fuel the epidemic and the inability to control it. Emphasis is placed on how globe-spanning processes of dispossession – what Farmer refers to as “structural violence” - determine areas of suffering and disease. This theme is also seen in recent qualitative work on TB. For example, Munro et al. highlight that much research on adherence to medication indicates how factor’s outside of the individuals’ control are central to explaining poor adherence, yet current theories of health-seeking behaviour fail to address socio-cultural factors influencing patients adequately with far greater attention needed to be given to the structural barriers to patient adherence (42, 43).

Magazi's work emphasises that focusing on patient adherence itself is a biomedical construct, showing that this can mask the ways in which poverty constrains a patient's agency for health care (44). A further example is given by Bond and Nyblade who argue that: "The failure of the TB world to address stigma is a reflection of how implicit biomedical power and control is in TB history, discourse and practice, and consequently how TB research and practice often fails to address the complexities of people's lives" (45). Social scientists argue that multiple disciplines and specific key stakeholders need to collaborate for a more holistic and effective tuberculosis response (11, 46 - 48). Indeed, it has been shown that the role of social research in improving TB care is "oddly limited for such an old disease" with TB having received far less attention from social science researchers than HIV/AIDS (49). While biomedicine is making important strides in developing vaccines, diagnostic techniques and treatment, medics and social scientists alike tend to agree that the impact of biomedicine on the eradication of TB will remain limited unless the public health arena gathers greater contributions from a variety of disciplines, including the social sciences, to bring a smorgasbord of perspectives to TB prevention and control.

In light of the wide recognition that contextual/structural factors play a crucial part in sustaining the TB epidemic and that approaches to TB control need to be broadened, why current control policies have not developed more holistic approaches more readily, and the dominant biomedical perspective has remained so resilient, is less clear. One argument could be centered on the difficulty in addressing the broad socio-economic determinants of TB because structural factors that shape the epidemic are embedded in global and local political and economic systems - presenting a substantial challenge for policy programmers (50). Mann has explained how modern concepts of health recognize that underlying 'conditions' establish the foundation for realizing physical, mental and social well-being and that "the practical difficulty is that the socio-economic paradigm creates an overwhelming challenge. Therefore the identification of socio-economic status as the 'essential condition' for good health paradoxically may encourage complacency, apathy and even policy and programmatic paralysis" (51). Paul Farmer has also pointed this out: if the problem seems too complex, then often there is inaction (41).

There have been notable achievements for South Africa in terms of political freedom but poor health status of the general population continues to undermine its democratic potential. The understanding of TB as a socio-economic problem is undeniable, but there is also a need to ensure that emphasis on the socio-economic determinants of TB does not allow TB to fall into the 'background noise of society', obscuring the importance of developing novel and pragmatic socially informed approaches to its control. As Johnston has stated:

“Epidemics do not always elicit an immediate and widespread response. Epidemics of acute infectious diseases can themselves become part of the “background noise” of society”.

- William Johnston, 1995 (52)

Defining social terrain

“The microbe is nothing, the terrain everything”

- Louis Pasteur

Louis Pasteur (1822-1895) is famously said to have questioned the value of his own germ theory with the above quote on his deathbed. Pasteur actively promoted the germ theory of disease, linking different infectious diseases to specific pathogens. He argued that infectious organisms were the most important factor that led to disease. Contemporaries of Pasteur, Claude Bernard and Antoine Bechamp, argued otherwise. They believed that an imbalance within the internal terrain of the body was necessary for pathogens to cause disease, emphasising the context or environment in which bacteria lived rather than the bacteria themselves. On the one hand, if the terrain was balanced (homeostatic) then bacteria could not flourish. On the other hand, if the terrain was out of balance (vulnerable), then bacteria would thrive. Similarly, and central to this study, is the argument that the social terrain in which the TB epidemic is sustained is at least as significant for TB control as the treatment of individual patients. In South Africa, a definable place where human vulnerability and the TB bacillus meet is not only within the individual TB patient, but also within hyperendemic areas and basic infectious disease principles demonstrate that endemic areas, rather than individual cases, represent the central entity that sustains the TB epidemic (53). In an attempt to escape the problematic complexity and unbounded nature of a patient's socio-economic context,

whilst still heading calls for the broadening of the biomedical focus beyond individual patients, I turn to a type of meso-level qualitative analysis of endemic populations in this study; slotted between (but not removed from) the individual patient and political-economic structures.

In certain instances Pasteur's quote has been used to emphasise the relative significance of the socio-economic determinants of TB (44, 54). The use of 'terrain' in these cases remains loose, however, and shows little appreciation of the concept as it was used by Pasteur and his contemporaries. For Pasteur, Bernard and Bechamp, the boundary of terrain was the individual body. Arguably factors outside of the individual body impact on its 'balance', but key to their understanding of terrain are individual host characteristics that favour the pathogen, giving rise to the manifestation of disease. This study expands this idea outwards - away from the individual body to the communal body - arguing that a better understanding of endemic populations and the interactions and characteristics within them, as opposed to those found within individuals or the microbe, is crucial to enhancing the epidemiological impact of TB control efforts. My use of 'social terrain' therefore denotes the social landscape within communities; analytical boundaries are demarcated more by the unifying social features than the geographic coordinates of the disease context itself.

Study aim and objectives

I argue that what comes to the foreground when one qualitatively investigates the social terrain of TB is important because results are orientated towards collective phenomena emerging from the communal. Endemic populations are not simply random collections of individuals; they have a 'life' of their own that is more than the sum of its component (reductionist) parts (55). This study aims to 'tap' into the 'life' of hyperendemic communities in and around Cape Town in a way that marries people with place to explore the following core hypothesis:

In hyperendemic township areas in and around Cape Town, the TB epidemic is sustained by dimensions of its social terrain. An improved understanding of

which may offer locally relevant avenues for enhancing the epidemiological impact of TB control efforts.

The following key research objectives are derived from this core hypothesis:

- 1) To identify and compare sociological features potentially pertinent to the design and implementation of public health interventions by revisiting the application of a social systems model - used to explore the capability of eight townships to respond to public health intervention.
- 2) To identify characteristics and interactions within the social terrain of TB that may be compromising current TB control efforts across these eight townships.
- 3) To develop a “proof of concept” application that demonstrates how the social terrain of TB may guide public health intervention to enhance TB control.

Findings are presented in chapters three, four and five. In chapter two I provide an overview of study methods and setting. Chapter two also explains how the large ZAMSTAR public health intervention study provided a platform for this study, describing my involvement within it.

References

1. Daniel TM. The history of tuberculosis. *Respir Med* 2006; 100: 1862-70.
2. Metcalf C. A history of Tuberculosis. In: *A century of tuberculosis: South African Perspectives*. Cape Town: Oxford University Press, 1991.
3. Comas I, Gagneux S. The Past and Future of Tuberculosis Research. *PLoS Pathog* 2009; 5: e1000600.
4. World Health Organisation. *Tuberculosis Facts*. World Health Organisation, Geneva, Switzerland: WHO 2009.
5. World Health Organisation. *Global Tuberculosis Control: Epidemiology, Strategy and Financing*. Geneva, Switzerland: WHO 2009.
6. Zumla A, Grange J. Tuberculosis and the Poverty-Disease Cycle. *J Royal Soc Med* 1999; 92: 105-07.
7. Packard RM. Holding Back the Tide: TB Control Efforts in South Africa. In: *A century of tuberculosis: South African Perspectives*. Cape Town: Oxford University Press, 1991.
8. Porter JDH, Grange JM, eds. *Tuberculosis: An Interdisciplinary Perspective*. London: Imperial College Press, 1999.
9. Walt G. The politics of Tuberculosis: The Role of Process and Power. In: *Tuberculosis: An Interdisciplinary Perspective*; Porter JDH, Grange JM, eds. London: Imperial College Press, 1999.
10. Leinhardt C, Ogden JA. Tuberculosis control in resource-poor countries: Have we reached the limits of the universal paradigm? *Trop Med Int Health* 2004; 9: 833-41.
11. Hurtig AK, Porter JDH, Ogden JA. Tuberculosis control and directly observed therapy from a public health/human rights perspective. *Int J Tuberc Lung Dis* 1999; 3: 553-60.
12. Rusen ID, Enarson DA. Fidelis – Innovative approaches to increasing case detection of tuberculosis. *Am J Public Health* 2006; 96:14-6.
13. Ogden J, Walt G, Lush L. The Politics of 'branding' in policy transfer: the case of DOTS for tuberculosis control. *Soc Sci & Med* 2003; 57: 179-188.
14. Small, PM. Tuberculosis in the 21st century: DOTS and SPOTS. *Int J Tuberc Lung Dis* 1999; 3: 949-55.
15. Marais BJ, Raviglione MC, Donald PR *et al*. Scale-up of services and research priorities for diagnosis, management and control of tuberculosis – Call to action. *Lancet* 2010; 375: 2179-91.
16. World Health Organisation. *Tuberculosis Fact Sheet no. 104*. World Health Organisation, Geneva, Switzerland: WHO March 2010.
17. Jamison DT, Feachem RG, Makgoba MW, Bos ER, Baingana FK, Hofman KJ, Rogo KR eds. *Disease and Mortality in Sub-Saharan Africa: Second Edition*. Washington D.C.: World Bank, 2006.
18. Bam TS, Gunneberg C, Chmroomsawasdi K, Bam DS, Aalberg O, Kasland O, Shiyalap K, Srisorrachtr S. Factors affecting patient adherence to DOTS in urban Kathmandu, Nepal. *Int J Tuberc Lung Dis* 2006; 10: 270-6.
19. Luhailima TR, Netshandama VO, Davhana-Maselesele M. An Evaluation of the Implementation of Tuberculosis Policies at a Regional Hospital in the Limpopo Province. *Curationis* 2008 Dec; 31: 31-8.
20. Ogden J, Rangan S, Uplekar M, Porter J, Brugha R, Zwi A, Nyheim D. Shifting the paradigm in tuberculosis control: Illustrations from India. *Int J Tuberc Lung Dis* 1999; 3: 855-861.

21. Bond V, Chileshe M, Sullivan C, Magazi B. The Converging Impact of Tuberculosis, HIV/AIDS, and Food Insecurity in Zambia and South Africa. Final Working Report 2009. Renewal Programme. <http://programs.ifpri.org/renewal/pdf/ZambiaSAFinalReport.pdf>. Accessed October 2009.
22. Rubin AJ, Garro LC. Social and Cultural Factors in the successful control of tuberculosis. *Pub Health Rep* 1992; 107: 626-636.
23. Dimitrova B, Balabanova D, Atun R, Drobniowski F, Levicheva V, Coker R. Health service providers' perceptions of barriers to tuberculosis care in Russia. *Health Policy and Planning* 2006; 21: 265-274.
24. Naidoo P, Dick J, Cooper D. Exploring Tuberculosis Patients' Adherence to Treatment Regimens and Prevention Programs at a Public Health Site. *Qualitative Health Research* 2009; 19: 55-70
25. Enarson DA. Migrant tuberculosis: a moving target. *Int J Tuberc Lung Dis* 2006; 10(9): 945.
26. Johnston, W. *The Modern Epidemic: A History of Tuberculosis in Japan*. Cambridge (Massachusetts) and London: Harvard University Press, 1995.
27. Abdool Karim SS, Churchyard GJ, Abdool Karim Q, Lawn SD. HIV infection and tuberculosis in South Africa: an urgent need to escalate the public health response. *Lancet* 2009; 374: 921-33.
28. Statistics South Africa. Mortality and Causes of Death in South Africa: Findings from death notification 2007. STATSSA: 2009. www.statssa.gov.za/publications/statsdownload.asp?ppn=P0309.3&SCH=4507. Accessed November 2009.
29. Gandhi NR, Moll AM, Sturm AW, Pawinski R, Govender T, Lalloo U, Zeller K, Andrews J, Friedland G. Extensively drug-resistant tuberculosis as a cause of death in patients co-infected with tuberculosis and HIV in a rural area of South Africa. *Lancet* 2006; 368: 1575-1580.
30. Edginton M. *TB: Past, present and future - HST Update (56)*. Durban: Health Systems Trust, Healthlink Programme, 2000.
31. Colvin CL, Leavens J, Robins S. Seeing like a 'PWA': A study of therapeutic citizens and welfare subjects in Cape Town, South Africa. Working Paper 144. Chronic Poverty Research Centre, 2009. <http://www.chronicpoverty.org/publications/details/seeing-like-a-pwa-a-study-of-therapeutic-citizens-and-welfare-subjects-in-cape-town-south-africa>. Accessed November 2009.
32. Kleinert S, Horton R. South Africa's health: departing for a better future? *Lancet* 2009; 374: 759-760.
33. Mooney G, Gilson L. The Economic situation in South Africa and health inequities. *Lancet* 2009; 374: 858-859.
34. AllAfrica.com. South Africa: TB Management Training for Health Workers. <http://allafrica.com>. Accessed April 2010.
35. Whalen CC. Failure of Directly Observed Treatment for Tuberculosis in Africa: A Call for New Approaches. *Clin Infect Dis* 2006; 42: 1048-50.
36. Lawn SD, Bekker LG, Middelkoop K, Myer L, Wood R. Impact of HIV infection on the epidemiology of tuberculosis in a peri-urban community in South Africa: the need for age-specific interventions. *Clin Infect Dis* 2005; 42:1040-7.
37. Unterhalter B. The Health of the Urban Black in the South African Context. *Soc Sci & Med* 1982; 16:1111-7.
38. Zumla A, Granje J. Establishing a united front against the injustice of tuberculosis. *Int J Tuberc Lung Dis* 1998; 2:179-81.
39. Rosenberg, C. Cholera in Nineteenth-century Europe: A tool for social and economic analysis. *Comparative Studies of Society and History* 1965; 8:452-463.

40. Dubos R, Dubos J. *The White plague; tuberculosis, man and society*. Boston: Little, Brown and Company; Canada: McClelland and Stewart Limited, 1952.
41. Farmer, P. Social Scientists and the New Tuberculosis. *Soc Sci & Med* 1997; 44: 347-358.
42. Munro S, Lewin S, Swart T, Volmink J. A Review of health behaviour theories: How useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Pub Health* 2007; 7:104. doi:10.1186/1471-2458-7-104.
43. Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient Adherence to Tuberculosis Treatment: A Systematic Review of Qualitative Research. *PLoS Med* 2007; 4: e238. doi:10.1371/journal.pmed.0040238.
44. Magazi B. *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, 2008.
45. Bond V, Nyblade L. The Importance of Addressing the Unfolding TB-HIV Stigma in High HIV Prevalence Settings. *J Comm App Soc Psych* 2006; 16: 452-461.
46. Porter JDH, Grange JM, eds. *Tuberculosis: An Interdisciplinary Perspective*. London: Imperial College Press, 1999.
47. Pronyck P. *The Political Economy of HIV/AIDS and Tuberculosis –thinking outside the DOTS*. Presentation to the South African National Tuberculosis Association, Rural AIDS & Development Action Research Programme: School of Public Health, University of the Witwatersrand, South Africa, June 1999.
48. Gandy M, Zumla A. The resurgence of disease: social and historical perspectives on the 'new' tuberculosis. *Soc Sci & Med* 2002; 55: 385-396.
49. Ngamvithayapong – Yanai J, Ishikawa N. The role of social science research in reducing the burden of tuberculosis in high HIV-prevalence settings. *Trop Med & Health* 2006; 34: 7-13.
50. Lonroth K, Jaramillo E, Williams BG, Dye C, Raviglione M. Drivers of tuberculosis epidemics: The role of risk factors and social determinants. *Soc Sci & Med* 2009; 68: 2240-2256.
51. Mann JM, Gruskin, S, Grodkin MA, Annas GJ, (eds). *Health and Human Rights. A Reader*. New York: Routledge, 1999.
52. Johnston, W. *The Modern Epidemic: A History of Tuberculosis in Japan*. Cambridge (Massachusetts) and London: Harvard University Press, 1995.
53. Marais BJ, Obihara CC, Warren RM, Schaaf HS, Gie RP, Donald PR. The burden of childhood tuberculosis: a public health perspective. *Int J of Tuberc Lung Dis* 2005; 9: 1-9.
54. Porter JDH, Ogden JA. Commentary on the resurgence of disease: social and historical perspectives on the 'new' tuberculosis. *Soc Sci & Med* 2002. 55: 397-398.
55. M. Pearce N, Merletti F. Complexity, simplicity, and epidemiology. *Int J Epidem* 2006; 35(5):515-519.

CHAPTER TWO

Study Setting and Methods

This study makes retrospective use of data collected within the framework of a large collaborative community-based trial known as the Zambia and South Africa Tuberculosis and AIDS Reduction (ZAMSTAR) study. ZAMSTAR is a seven-year community-based clinical trial (2004-2011) working within government health systems across sixteen communities in Zambia and eight in Cape Town, South Africa. It aims to measure the efficacy of public health interventions to reduce TB prevalence in impoverished communities with a high prevalence of both TB and HIV. The public health interventions being evaluated include strategies for enhanced active case finding, efforts to improve community health education and improved integration of TB and HIV services. The trial is being carried out by the Desmond Tutu TB Centre (DTTC) at Stellenbosch University and the Zambia Aids Related TB Project (ZAMBART), with support from the London School of Hygiene and Tropical Medicine (LSHTM)⁵.

Data were collected from fieldwork conducted in 2005 and 2006. The fieldwork sought to gather a broad comparable understanding about the social context within each of the 24 ZAMSTAR research sites in preparation for the implementation of interventions. Data collection was focused on generating insight into how communities perceived TB and identifying social factors that may influence TB prevalence, TB exposure and the uptake of public health interventions. This fieldwork preceded the intervention component of the trial and was designed to initiate contact and build trust; establish functional research structures; and better understand the social dynamics within each community in order to develop optimal intervention strategies. The social anthropologist, Dr Virginia Bond, coordinated the social science research team, and I was placed in charge of conducting the South African component of this pre-intervention fieldwork for ZAMSTAR. Dr Bond was largely responsible for the design of the fieldwork method which was labelled “Broad Brush Surveys” (BBS) and based on previous work done in Kampala (Uganda), London and Turin (Italy) by her mentor, Professor Sandra Wallman; social anthropologist and professor emeritus at University College London.

⁵ With support from John Hopkins under the Consortium to Respond Effectively to the AIDS TB Epidemic (CREATE).

As a qualitative method, BBS aims to gather a “wide and shallow” understanding of place, as opposed to the type of depth long-term ethnographies or in-depth interviews offer to understanding people. As Wallman explains, she uses BBS to help “freeze-frame” communities under different types of stress in order to assess the contextual “chaos” of place holistically. (1) This was particularly attractive for the ZAMSTAR project because it needed to be able to compare and holistically grasp the social context of 24 different places, across two countries, making this legible in a relatively short period of time. In Kampala, Wallman successfully used BBS (in conjunction with other methods) to identify social problems and opportunities for health care in Kamwokya, a densely populated area on the outskirts of the Ugandan capital suffering an HIV/AIDS epidemic. (1) In London, the BBS approach has been used to focus on the differences in social system between two urban communities considering what makes for ‘good’ diversity. (2) ZAMSTAR adopted the BBS approach to describe and understand key sociological differences between study communities. Comparative analysis of social context drawn from BBS influenced the intervention randomization process of the 24 research communities. (3)

This study uses the ZAMSTAR BBS data but the aims, analyses, discussions and conclusions drawn are my own work, independent of ZAMSTAR and any of its other ancillary studies. The following sections further clarify the methods employed together with my role within ZAMSTAR, which generated the data for this study. Following this I provide a short description of the research sites and outline the analyses performed.

Method of fieldwork

Background to BBS and its participatory techniques

The ZAMSTAR BBS employed a mix of participatory and observational research techniques to gain an understanding of social interaction, the local economy, the mobility of individuals, how time is spent, perceptions of TB, TB treatment options, TB stigma and patients’ experiences of health services within each community. The specific techniques used comprise a community meeting, community mapping, transect walks, daily time charts, structured observations and informal interviews. Employing a medley of these types of techniques broadly falls under a mode of participatory research which

gained popularity within a postmodern wave of enthusiasm for community-based analyses of social problems. In the 1970s, at a time when the expanding aid industry also needed rapid access to socio-economic data, participatory research emerged as a response to western perceptions concerning 'top down' development that was being pursued in the absence of adequate knowledge about and consultation with local communities (4). Participatory research became associated with social transformation in the "Third World" through its orientation towards community action and shared ownership of research projects. It is typically responsive to the needs of local people and committed to social, economic and political development. As Kemmis and McTaggart have put it, "proponents of participatory research have highlighted the politics of conventional social research, arguing that orthodox social science, despite its claim to value neutrality, normally serves the ideological function of justifying the position and interests of the wealthy and powerful". (5)

Many different processes and approaches fall under the umbrella of participatory research. The most common are Rapid Rural Appraisal (RRA), Participatory Rural Appraisal (PRA) and Participatory Learning and Action (PLA). According to a report prepared by the Department of International Health at Johns Hopkins University, RRA is often seen as the first generation of participatory techniques. In a typical RRA study, a team of researchers spends four to eight days in a community, involving community members in all aspects of data collection and analysis, from which a report is generated. Whilst this type of an approach is far more participatory than orthodox styles of social research, many participatory research practitioners feel that RRA still leaves a lot to be desired because participation is an isolated event rather than an ongoing process. The central objective of PRA, on the other hand, is to empower the community, not simply involve the community in collecting data. So while PRA employs the same research techniques as RRA, it has a long-term vision to enable the community to analyze its own problems, determine its own priorities, and to develop a plan for addressing these problems. The role of outside 'experts' in PRA is to facilitate the process and to provide technical assistance in response to needs articulated by the community. PLA is used as a collective term to describe a growing body of participatory approaches and methodologies that include not only approaches to data collection such as RRA and PRA, but also other processes and activities for establishing, strengthening, and

sustaining local participation and control such as participatory theater. It focuses on taking action as a result of findings, rather than collecting data as an end in itself. (6)

BBS as used by the ZAMSTAR project falls short of some of the more emancipatory notions of participatory research. Like RRA, it has a short time horizon and focuses on participation as a means for data generation rather than as a way of enabling empowerment. Indeed, BBS was also less flexible than many recent forms of participatory research because of it being a function of the ZAMSTAR trial and because of the need to compare data across communities. Yet, it retains many participatory features and the wider ZAMSTAR project aimed to establish a more long term enabling presence in research communities by implementing interventions within the framework of local health facilities. The trial employed local people and hopes that successful interventions will be absorbed and sustained by communities and their health services. To give a sense of the participatory features of the BBS, the next section outlines exactly what it involved and how it was implemented.

The ZAMSTAR BBS process

Before BBS officially began, groups of community representatives were formed by the wider ZAMSTAR trial as a representative body through which to work in each community. These groups were labeled Community Advisory Boards (CABs). The initial idea behind the CABs was to build a relationship between research communities and the ZAMSTAR project, providing an arena where community issues and researcher issues could be addressed: In medical research, particularly in clinical trials, the use of a Community Advisory Board (CAB) is frequently called for in order to facilitate a more participatory public health approach (7). This is often seen as a way to avoid risks such as exploitation, disempowerment, community harm and disturbance of employment. I presented and discussed an outline of our fieldwork proposal to the ZAMSTAR CABs prior to data collection, asking permission for and guidance with fieldwork. At the end of fieldwork, findings were fed back in a meeting with CABs in the form of a flyer and oral presentation by fieldworkers. At both the meetings before and after fieldwork, CABs had the opportunity to ask questions.

In reality, the establishment of functional and constructive CABs in South Africa was fraught with difficulty as a result of local political wrangling and conflicting agendas between researchers and CAB members. Many of the research communities lacked a widely representative body of their own, and it proved difficult to identify community members who were willing to be actively involved in such a set up without a clear sense of financial or political gain. In many cases the group of individual CAB members to whom we presented fieldwork differed from that to which we presented our findings, members changed frequently during the initial ZAMSTAR baseline studies. During the BBS process, which lasted just under two weeks in each community, locals were trained to help research assistants with data collection, guiding research assistants through their respective communities. In each community the local assistant fieldworkers were financially remunerated by the ZAMSTAR trial and held other responsibilities within wider operations of trial. The selection of the local fieldworkers resulted in a difference of opinion between ZAMSTAR and some of the CABs. The ZAMSTAR trial wanted to advertise openly throughout the research communities and let the research team appoint candidates to the position after they had assessed the suitability of the applicants. The CAB, on the other hand, wanted to appoint people to the position independently. While ZAMSTAR did not want to compromise on its own principles of fairness and equality (insisting on advertising openly for these positions) it also didn't want to undermine the views of the CAB. After much discussion it was agreed that advertisements would be placed throughout the communities concerned. An initial selection of possible candidates was made by ZAMSTAR and a final selection was made by a panel made up of CAB and ZAMSTAR members, after interviews were held with short-listed candidates. The root of the internal conflict transpired to be about financial reward. At the time of advertising for local fieldworkers, members of the CAB were not receiving any financial incentive. In some instances unemployed CAB members wanted to become fieldworkers because of the financial gain this move implied. This provides an example of the difficulty in reconciling the values of researchers with those of CABs to protect the best interests of the communities at large.

Actual BBS fieldwork began in each community with an informal meeting with the respective CAB to obtain an overview of the community. Research assistants facilitated a free-listing exercise where members of the group were asked to identify where people congregated in the community, where they believed TB was commonly spread, where

they believed TB was coming from and where people seek treatment. Research assistants also led a mapping exercise in which they discussed socio-economic boundaries, significant places, the location of gathering places as well as entry and exit points of the community. After the meeting, research assistants completed activity reports detailing the outcome of the meeting. True to participatory research, the insight shared by the CAB then shaped the following transect walks, which were conducted through the main hub of the community from boundary to boundary, passing through sub-areas and typical gathering places within the community. In most sites the participatory emphasis of the CAB meetings worked well - discussions were lively and informative. Participation was poor in one site where CAB members were not interested to collaborate without remuneration. Members contributed very little to the joint planning session. They also arrived and left as they wished during the meeting. According to the activity report, “the group was not really working together and listening to one another”. When fieldworkers began to discuss transect walks, the CAB explained that they “didn’t want to crack their skulls about it” and the team followed their advice to let local fieldworkers guide the transect walks.

Transect walks gave research assistants an opportunity to begin to understand the layout of the community, patterns of activities taking place, the variety of treatment options available and options for livelihood. They took photos, wrote field notes and held informal conversations with a random cross-section of community members about TB, livelihoods and the community along their way. Two sets of walks took place in each community. For safety reasons, one transect was conducted by a female research assistant and a male local fieldworker and another one, which followed a different route, by a male research assistant and a female local fieldworker. We felt that two females walking alone through these typically violent communities were too vulnerable. The field teams took GPS readings of public gathering places and provided qualitative descriptions of each. Again, activity reports were written by the teams after completing the walks. Out of the gathering places identified along the walks, field teams identified key places for further structured observations over the following days.

While the transect walks explored community discourse and the use of space in a general fashion, structured observations aimed to add a closer assessment of specific congregate settings within the community. Two to three hour observations were

scheduled at various locations and at various times. Again, there were two field teams. As opposed to the transect walks, however, the female research assistant worked alongside the local female fieldworker and the male research assistant alongside the local male fieldworker. This was because some observations aimed to explore gendered spaces. We ensured that a male driver shadowed the female team as a safety precaution. In each site the observations began with an early morning observation. The female team preferably identified a space used by women and/or children to observe and discuss who spent time there, whether people were local or not, what happened there, opinions about TB and physical features of the space relevant to TB transmission, such as the degree of ventilation. The male team went to an entry/exit point (typically a taxi rank) to observe the 'who and why' of mobility in and out of the community, repeating the observation in the evening. They counted the number of men and women coming and going and held informal discussions with many respondents. Informal discussions were more limited during this observation because often respondents were in a rush to get to wherever they were going. The female team then went on to spend time in a hair salon and a typically female gathering space identified along the transect walk. The male team went to places where male youth and adult males tended to gather for further observations. Both teams facilitated daily time charts during these observations. Daily time charts were used as a time-related participatory data collection tool that explored daily living patterns and other activities. Charts were drawn up with the assistance of key informants and then refined following discussion amongst the wider group.

The remaining participatory activities were made up of a health centre observation and a night walk. The female group conducted the health centre observation at local clinics where they spoke with staff and patients to gather general opinions about TB, patients and the service provided by the clinics. During this observation, research assistants filled in checklists with as many respondents who were willing. The checklist focused on how long patients waited at the clinic, the frequency with which they attended the clinic, the distance traveled to get to the clinic and the cost of the visit for the patient. During the night walk, the male team made a brief observation of the community during the evening. Accompanied at all times by a driver for safety reasons, they explored how busy the community was as compared to during the day and what was happening at local bars - who gathered there and how crowded they were. Again, informal discussions

about TB and the community in general were held. After each individual observation, research assistants wrote activity reports detailing their discussions and observations. These activity reports, together with those from the CAB meeting and the transect walks formed the textual data analyzed in this study.

The South African social science research team

I was responsible, amongst other ZAMSTAR functions, for the collection of the South African BBS data. This meant that I had to establish a social science research team to partner with an equivalent team in Zambia. Key to this role was to work with both the CABs and other South African ZAMSTAR team leaders to arrange fieldwork that was considerate of the South African communities and the broader ZAMSTAR objectives. I also had to collaborate closely with Virginia Bond to ensure that fieldwork in both countries applied the same methodology and principles. To this end, I was responsible for creating a fieldwork guide that aimed to standardize BBS fieldwork across Zambia and South Africa as much as possible. The guide stipulated where and how the logistics and/or methods would differ (see appendix I).

My core team consisted of three other research assistants who had specific, but not exclusive, roles. Two members were primarily responsible for conducting the fieldwork; one member tackled the logistics of fieldwork and data entry into QSR N6, acting as my deputy; and I managed the team as it worked through the eight South African research sites, monitoring the data collection through debriefing sessions held at the end of fieldwork in each site and re-working activity reports with research assistants to ensure clarity and detail of content. In each of the research sites, two local fieldworkers joined the team for the duration of fieldwork in a particular site. These fieldworkers also held responsibilities within the wider ZAMSTAR trial, but generally worked with the 'BBS' team first as we were one of the initial teams from the trial to enter the ZAMSTAR research sites. My primary concerns as team leader were to establish good rapport in the field - especially considering the relatively short periods of fieldwork in each site, to protect the safety of the field team and to ensure that the data collected for the trial were of consistent quality.

After my deputy and I received training in Zambia in how to train research assistants in BBS, we jointly trained the two research assistants who were to do the majority of the actual fieldwork. Following this, these research assistants helped us to train the 2 local fieldworkers recruited to assist with data collection in each of the eight sites before fieldwork commenced. Both research assistant and fieldworker training was structured over the course of a week and had a strong participatory emphasis that aimed to familiarize fieldworkers with the techniques used in BBS and equip 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 fieldworkers 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, for the event that they would be asked questions about TB and/or HIV, and for situations where they might be asked for social support. The core team (three research assistants and I) also underwent training in QSR N6, the software package we used for entering our data, and, I supervised the initial data-entering process.

It was important for me that research assistants conducting the bulk of the fieldwork were able to speak both Xhosa and Afrikaans as these languages were likely to be needed in the field and I did not want language to be a barrier in establishing good rapport with locals. My experience while visiting similar endemic communities with the DTTC had made me feel that my own lack of proficiency in Xhosa and Afrikaans had been a significant stumbling block on previous occasions in gathering data and in this instance we needed communities to speak as freely as possible to fieldworkers. Also of concern was a general mistrust of researchers. The following excerpt from an introductory synopsis of an observation highlights the suspicion respondents can have. It is written up by a member of the BBS field team after an observation at a beer-brewing shebeen:

We introduced ourselves, the study and the purpose of our visit. The owner asked other women in the room if they were willing to participate. They all agreed and said they were just relaxing there. We did the daily time chart with four women aged between 45 and 53 years. Three women were unemployed and the fourth woman, the owner, sells African beer. We also spoke to two men who came to the shebeen. We discussed livelihood options, TB and respondents' personal experiences of TB. At the end of the observation the

owner wanted to be sure that we were not going to report her business to the police. We reassured her that the observation is for research purposes to see how some women spend their time and we wanted to know how people live. We told her that we did not even take her name and home address.

-Activity report, 23/08/05.

As highlighted earlier, the research sites in this study represent 'structurally violated' communities by definition; they are communities pre-selected by ZAMSTAR as poor and suffering from a high burden of TB and HIV/AIDS. Alongside poverty and disease, high levels of unemployment and violence meant that the field teams needed to be prepared to conduct research in a context where the chance of witnessing and/or experiencing violence was very real. As leader of the team I had to (a) maximise the safety of fieldworkers and study participants; (b) maintain the representivity and integrity of data; and (c) reduce the risk of socially disturbing communities. To try and maximize the safety of research assistants and local fieldworkers, I made it clear that individuals always needed to be accompanied by at least one other member of the ZAMSTAR team and that a local fieldworker needed to accompany research assistants in the field at all times. Field teams were also directed to be in constant contact with a driver from the DTTC, who had to shadow them relatively closely. Field teams were supplied with airtime for their cellular phones in case they needed to call for support and debriefing sessions were held at the end of fieldwork in each community, so that issues arising could be addressed. Often debriefing sessions ensured that fieldworkers avoided certain areas that were particularly notorious for crime and violence. In one community the police were informed of the BBS night-time observation as fieldworkers had heard rumours during fieldwork that they were planning raids on some of the *shebeens*. Movement during the nighttime observations was quite heavily restricted in all communities as a safety precaution. It should be noted that while fieldworkers completed BBS fieldwork without being the subject of an attack, they did witness criminal and violent activity which future researchers doing any form of participatory research in these areas need to take into account. Although witnessing violence had been discussed during fieldwork training, I felt that more should have been done to prepare the team for the violent setting. We had prepared ourselves with contact numbers for local emergency services, but had not considered the complexity of settings where street justice prevails. I include an extract from an activity report written after a transect walk to illustrate the extent to which crime and violence shapes the social landscape in the research communities:

People raised the issue of the incidence of murder and violent robbery, and mentioned that serious criminals, when released from prison, return to live in [their community]. During our fieldwork we witnessed three young people being beaten up, almost to death, at the taxi rank by taxi drivers. Some passers-by supported the beating and some were concerned, but did not intervene. Another taxi owner eventually stopped the beating. In response to the high crime rate, the taxi owners and drivers have taken the law into their own hands, using violence themselves. Due to disillusionment with the police services, the taxi owners have become an accepted authority in the township and a powerful instrument of law enforcement. There are also no-go areas where the delinquent youth are operating.

- Activity report, 29/07/05

The information I received about the aftermath of the beating mentioned in this vignette was sketchy. It appeared that fieldworkers had begun to call emergency services, but had heeded the recommendations and examples made by locals not to get involved in any way as the consequences of their actions were unpredictable. They feared upsetting vigilantes and were not sure if the victims themselves wanted them to seek medical attention on their behalf. I was initially shocked that research assistants had not contacted emergency services or called for support immediately, as they had been trained to respond to witnessed violence of this scale. I realized, however, that their decisions had taken place in the context of street justice and were theirs to make given I had not been in the field at the time. The incident reflects the tough ethical dilemmas that may need to be faced during community-based fieldwork in settings where local codes of justice are unfamiliar, violent and unregulated. It also highlights the demands placed on individual fieldworkers, emphasizing the need for teamwork and strong links with local organizations that can offer forms of support and advice.

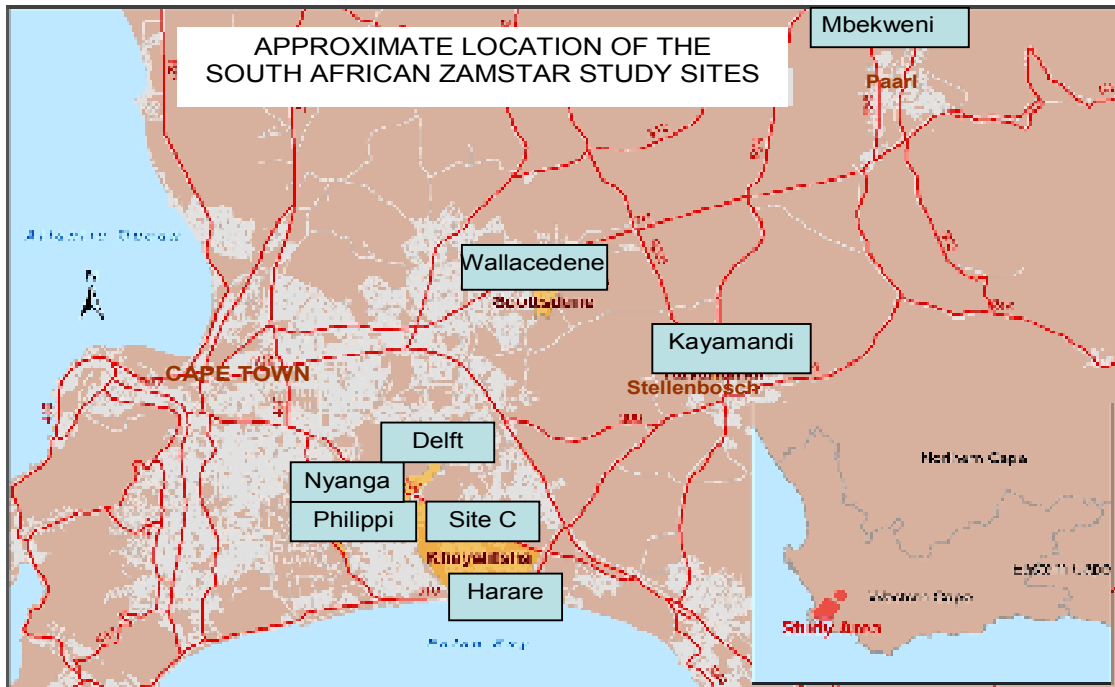
Most of my own time in the field was spent with members from the wider ZAMSTAR study to help form CABs, to discuss and ask permission for BBS fieldwork with CABs, and to help appoint local fieldworkers. Once BBS fieldwork had started, textual data began to accumulate in the form of activity reports. My deputy and I 'cleaned' the data by editing and restructuring it (in some cases this was done alongside fieldworkers if more clarity was needed) before it was coded and entered into QSR N6. We used the data to construct a common coding 'tree' of subject categories into which data were coded (see appendix II). Before coding was finalised in QSR N6, each activity report was coded manually by two different people from the core team using a visual poster

'map' of the coding tree that we displayed on the wall. I began the data coding process in QSR N6 by comparing these two manual sets of codes, inputting final codes by merging the manual ones. I left the data entry process before it was complete and consequently the manually coded data from the remaining sites were entered by another member of the ZAMSTAR team. For the purposes of this study, I used coded QSR N6 data (as completed by the ZAMSTAR team) supplemented by my own further manual analysis of activity reports to identify iterative themes following principles of grounded theory (8). Owing to the fact that I left the coding process prematurely I felt more secure with a manual revision of the 'raw' data to complement and triangulate the coded information; I also find it easier to analyze hard copies of text rather than digital versions.

Study setting

All eight of the South African ZAMSTAR research communities are located within the Western Cape Province of the country. Six of these communities - Nyanga, Philippi, Site C, Harare, Delft and Wallacedene - can be classified as township areas of greater Cape Town itself. Two communities - Kayamandi and Mbekweni - are peri-urban areas surrounding Stellenbosch and Paarl (see map below). The Western Cape has one of the highest TB notification rates in the world (9), with rates exceeding 1500 per 100 000 of the population in some of the areas included in the study. Worst hit are densely populated socio-economically deprived areas where rates of HIV infection are also very high.

FIGURE 2.1:
Map of greater Cape Town, showing the location of the 8 study sites.



Qualitative baseline data from all eight South African communities, selected for the ZAMSTAR intervention study, were included in the analysis. In 2004, these communities had an estimated adult population of between 20 and 40 thousand. Local diagnostic health facilities in the communities followed standard TB control practices according to the internationally recommended DOTS strategy. Socio-economically, all 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 (10, 11). This was reiterated when synthesising the BBS data, which showed the following broad sociological features to be common to the eight communities:

- Xenophobia
- Dependency on state welfare
- Unemployment
- Crime

- Violence
- Substance abuse
- Inadequate housing and poor municipal services

Subtle differences across the sites included the nature and levels of collective initiative and informal economic activity. To provide a brief overview of these similarities and differences I include community descriptions of each research community, as summarized from the available BBS data.

1. Nyanga

Nyanga was one of the busiest townships by day, but relatively quiet by night. A transport hub for many surrounding areas, Nyanga is a large established urban township found adjacent to Cape Town International Airport and approximately 12 kilometers southeast of Cape Town's city centre. The residents of Nyanga are black Africans and predominantly Xhosa speaking. A large proportion of residents, especially those living in poorer and more crowded areas of Nyanga, are originally from the Eastern Cape Province. As in other parts of Cape Town, distinctions are drawn between the "Cape-borners" (*"I was born here – I didn't get here in a bus"*) and "amaGoduka" (meaning 'those who go home' and referring to residents who have strong ties to the more rural Eastern Cape). There are a fair number of permanent residents from other African countries such as Zimbabwe, Burundi, Congo, Malawi, Nigeria, Tanzania and Kenya, many of whom run businesses in Nyanga. There are striking differences in living conditions in different parts of Nyanga. Certain areas are relatively clean, spacious and well serviced by the state, while others areas are densely populated with no toilets, water taps or waste collection services. While high levels of unemployment were evident and many are supported by state welfare (often in the form of 'disability grants'), a lively informal economy suggested that there are more job opportunities for locals than in other communities. Many women own and run small businesses and local men earn incomes as owners/drivers of taxis, carpenters or builders. High levels of alcohol abuse were apparent and some unemployed men explained that they drink "out of boredom". In some instances individuals were remunerated in alcohol for doing odd jobs for local businesses. There was also evidence of a thriving drug trade with the use of marijuana and mandrax particularly evident. Certain parts of the community are notorious gangster areas and the community has a reputation for crime, violence and serious criminals.

Fieldworkers themselves witnessed acts of violence and locals spoke of gang related conflicts in schools. Many CBOs and NGOs are present and fieldworkers felt that levels of social support were relatively high.

2. Harare

Harare is a township area of Cape Town's metropole that is semi-serviced. It is situated along the coastline on the periphery of Khayelitsha (a large established township) and emerged in the early 1990s. It is primarily inhabited by Xhosa speaking black Africans, with a few residents from other African countries living and running businesses there. Residents live in makeshift shacks or brick houses and fieldworkers felt that it was relatively clean and spacious, although pockets of the area were filled with uncollected waste. The community is isolated and far from town centers, but there are several NGOs and churches that play a significant role in community development. Fieldworkers documented that it was relatively quiet there during the day, with many leaving in the mornings to go to work in and around Cape Town or to look for employment. Local businesses often belonged to people from outside of the community and local facilities, such as churches, were being used by outsiders. Locals reported high levels of unemployment and many seemed to rely on state disability grants as a form of income. Community savings clubs were common; a group would pool money together and pay a member of the club out on a rotational basis. Levels of theft, marijuana use and teen pregnancies were said to be high.

3. Site C

Site C, like Harare, is part of greater Khayelitsha. According to locals, Site C has been slow in responding to urban renewal programmes compared to other surrounding township areas. The majority of homes in Site C are shacks made from wood, cardboard, hardboard and corrugated iron. An area called Section A in Site C has, however, been developed recently with permanent brick houses. It has been renamed Buffer Zone. The population is exclusively black African but as in Nyanga, there is tension between those born in the Cape and those who have moved to Site C from the more rural Eastern Cape. For example, a group of youth explained to research assistants that they are 'Cape-Borners' arguing that there is a difference between the youth who are born in Cape Town vis-à-vis those who are from the Eastern Cape. They said that they walk, talk, dress and wear hairstyles differently, suggesting that 'Cape-

Borners' are more sophisticated. Site C is a busy area with a train station and taxi rank. Locals reported mass unemployment and many resort to gambling on card games as a source of income. Women admitted to shoplifting in Cape Town and reported high levels of prostitution. Some local business options were apparent: Spaza shops and formal shops were generally owned by men and African beer shops by women. The youth in the area were very opinionated and keen to discuss issues such as crime, employment and HIV/AIDS. Many talked openly about theft and vandalism as part of their daily activities. Other locals reported high levels of crime, violence, hunger, alcohol abuse and a lack of family structures. Locals appeared judgmental of outsiders and, as in Harare, came together to form savings clubs.

4. Delft

Delft was formed as one of the first official multi-racial communities after the dismantling of Apartheid. It is a fairly isolated township, lying near to Cape Town International airport and home to predominantly a mix of black African and Cape Coloured people. Fieldworkers noted a lack of community leadership and a strong socio-economic divide between what is known as 'Delft South' and 'Voorbrug', with the latter relatively better off. Delft has many recreational facilities, but these are poorly utilized. Many home owners prefer to lease their houses and live somewhere else. Locals also tend to try and escape their community over weekends by visiting friends or family in other areas. Housing structures are very mixed in terms of size and construction. Some are private and some public, and many are extended with shacks. Issues around inadequate housing were often raised by respondents. Fieldworkers felt that the community as a whole was relatively clean and less compact than other communities. Locals reported high levels of unemployment, burglaries, beatings and alcoholism. Some are involved in running small local business but many look for employment outside of Delft, in and around Cape Town.

5. Wallacedene

Wallacedene is found near Kraaifontein in the Oostenberg municipal area. It lies near to farmland beyond the northern suburbs of Cape Town, approximately 30 km outside of the city's centre, and is expanding northwards towards Bloekombos, a settlement of mixed ethnicity (largely black African) and where one finds serviced RDP (Reconstruction and Development) housing as well as makeshift housing (shacks).

Wallacedene itself is largely an unserviced area comprising makeshift housing (there are sporadic large brick houses, but these are often used as business premises by outsiders). Clusters of families are found residing around single toilets and sinks; houses are very overcrowded and it is difficult to distinguish one household from the next. Its population is a mix of black African people - mostly Sotho, Xhosa and Pedi – and Cape Coloured people. Foreigners from countries such as Somalia, Nigeria, Namibia and Zimbabwe are also living in Wallacedene and fieldworkers reported a visible sense of racial and ethnic integration as well as little evidence of class or socio-economic divide. Wallacedene was described as the dirtiest and most overcrowded of all the communities. Respondents were often notably concerned about child health in the area and many felt that their own community was a hotspot for disease, gangsters, rape and murder. Locals reported high levels of prostitution and under-aged drinking was very visible to fieldworkers. Although Wallacedene is a major source of cheap casual labour for nearby farms and industries, unemployment is rife. Elderly men were seen collecting scrap metal and selling this to a nearby scrap yard and many women resort to sex work as a means of getting by. The male youth often turn to shoplifting, robbery, pick pocketing or car hijacking. A taxi driver claimed that “crime has become a modern way of life”. Others survive off of welfare grants from the state or hand-outs from NGOs.

6. Philippi

Philippi is a predominantly Xhosa-speaking township found approximately 17 kilometers outside of Cape Town’s city centre in Cape Town’s metropole. Most residents are black Africans who originated from the Eastern Cape, although there are others, such as Cape Coloureds and foreign nationals who moved to Philippi from other places. It has a relatively young population; the CAB mentioned that the majority of residents are middle aged or younger. Residents are generally low-income earners or unemployed, although there is a slightly wealthier set also living within the community. There is a uniform mix of housing – mostly comprising RDP houses, RDP flats and shacks – with pockets of larger privately owned houses. As in Nyanga, some areas are visibly poorer and ‘dirtier’ than others, with a greater lack of services. There has been a large amount of resettlement and construction within the community with new residential areas and RDP houses being built. These new homes have attracted people from other communities and fieldworkers felt that a broad feeling of mistrust amongst locals could be attributed to the relocations that had been taking place as well as high levels of crime. High levels of

gangsterism, murder, drug trafficking and robbery were reported by locals who described certain parts of Philippi as 'no-go' areas, explaining that it is difficult to sleep at night because of the sound of gun-shooting. The community is well-known for the amount of weapons that can be found there. Philippi has two nearby train stations and a big bus terminus. Many left the community in the mornings to work or go to school in and around Cape Town. Young adults seemed relatively well educated but graduates claimed they couldn't find employment. There is a local economy of small businesses, but this is much weaker than that of Nyanga and lies mostly in the hands of foreigners. Many are unemployed and hungry, relying on state welfare and support offered by NGOs.

7. Mbekweni

Mbekweni is a largely Xhosa speaking peri-urban community found in the Paarl district of the Western Cape. It is also home to Sotho and Cape Coloured people. Many residents moved to Mbekweni from the more rural Eastern Cape seeking contract employment on surrounding farms and industries. Over the last few years there has been mass retrenchment in the surrounding industries which are also locally accused of tribalism. Allegations were often made that employers prefer to employ Cape Coloureds as opposed to Black Africans. High levels of unemployment were visible to research assistants while conducting fieldwork; a strong presence of men during the day (often seen playing dominos) as compared to other research sites was noted. Accompanying high levels of unemployment are high levels of alcohol abuse, drug abuse (particularly that of mandrax), rape and prostitution. One male respondent suggested that substance abuse and sex were a result of unemployment, saying that "the problem with poverty is boredom". Many men admitted to acts of robbery and research assistants felt that men had fewer options for employment as compared to women who were often sole breadwinners within a household. As in Nyanga and Site C, locals made distinctions between those born in Mbekweni (insiders) and those originating from the Eastern Cape Province (outsiders). They also described the community as small and close-knit – one that was vigilant of 'inkomers' (new-comers).

8. Kayamandi

Kayamandi is a relatively well-developed and serviced township community of Stellenbosch. It is densely populated and like many of the other communities, has strong ties with the Eastern Cape Province. The majority of residents are black Africans

of either Xhosa or Basotho ethnicity, but it is also home to a diverse group of people from different racial and ethnic backgrounds. There is a wide range of housing including brick houses, flats and shacks. Tensions within local community leadership run across deep political lines which appear to cut through the community. This was evident when the local fieldworker assisting with data collection raised concerns about the research team's safety because of potential tension between community members' and his own political alliance. It was also said that political alliances affect the allocation of housing and services within the community. NGOs that focus on upliftment projects were present and although unemployment appeared to be high, diverse options for employment were also apparent. Local businesses were busy in the evenings and the youth were involved in soccer and netball. Locals reported high-levels of domestic violence, marijuana use, theft and fistfights. However, unlike in Wallacedene, there was a sense of pride in the community amongst many residents who spoke about Kayamandi being a peaceful area in which levels of crime are low.

Ethics

This study makes innovative use of existing data without subjecting research communities to further fieldwork. It attempts to maximize the delivery of data that emerged from communities vulnerable to research. Written consent was given from the South African ZAMSTAR principal investigator, Prof. Nulda Beyers, to draw on data that was collected for the ZAMSTAR trial for the purposes of my own degree. Prof. Beyers as well as the study's other principal investigators, Prof. Peter Godfrey-Faussett and Dr. Helen Ayles received formal feedback on the study findings. I obtained ethical clearance for the BBS fieldwork conducted within the framework of the ZAMSTAR trial from Stellenbosch University's Committee for Human Research in January of 2005 as part of the baseline research of the ZAMSTAR trial. Additional clearance for this particular analysis (Masters study) was obtained in May of 2007, with a full progress report submitted in 2009.

Before the qualitative baseline data used in this study was collected, all researchers involved underwent training in Good Clinical Practice and Research Ethics. Any evidence that the qualitative fieldwork conducted in these communities presented any direct harm to individuals was closely monitored and none detected. There is a potential risk that study findings may lead to the stigmatization of the participating communities, but I

believe many findings are representative of conditions in many townships in the vicinity of Cape Town and not unique to the study communities. With sensitivity to the structural determinants of socio-economic conditions within the research sites, I have consciously tried to avoid pathologising the communities themselves, rather focusing on avenues to reduce suffering within them. After deliberation with my supervisors, it was decided to include the site names within this MPhil, since the risk of any adverse ramifications seems minimal and findings from each site may be very valuable to other researchers who may be able to build on this specific study, ultimately for the benefit of the research communities and other communities with similar profiles.

Outline of study results

It is argued that there is an urgent need to explore the relevance of social terrain for improving TB control in the background and introduction to this study. Three distinct ways in which it may be meaningful are presented in the following three chapters which draw on the BBS data in individual ways. Each of the three chapters is presented as an individual piece (one is published in a peer reviewed journal and the remaining two are being prepared for submission). This means that in some instances there is limited repetition regarding the ZAMSTAR trial and the BBS method. A synopsis of each is given:

1) Sociological variation is central to chapter three. ZAMSTAR applied an urban systems model to the BBS data in order to feed a comparison of the research communities into the constrained randomisation process of the trial. This chapter revisits the application of this model to the BBS to emphasise that endemic populations do indeed have a 'life' of their own, requiring locally specific interventions. I first explain how the model was used by the trial to reduce the complexity of social context. I then triangulate the results used by ZAMSTAR with my interpretation of the BBS data and with feedback made by my field team. I suggest that the interaction between social diversity and social cohesion within the research sites is a significant variable that predicts their individual response to public health interventions aimed at reducing TB prevalence. Four out of eight sites showed an exceedingly high degree of social fragmentation, which implies they are socially ill equipped to receive a public health intervention that does not address this.

2) Against the common backdrop of insecurity detailed by the community descriptions earlier, chapter four analyses the BBS data by focusing on popular perceptions and interpretations of TB. It emphasises the marginalization of the eight communities and shows that they self-doubt their own community support of TB patients. It identifies a popular discourse that stigmatizes TB as both a dirty and HIV-related disease. The association of TB with pollution suggests endemic communities feel overwhelmed by TB and I argue that this complicates passive case-finding. Perceived HIV-TB stigma is likely to be directly contributing to treatment delay as communities describe how there is an attempt to escape community suspicion of HIV/AIDS by avoiding local clinics or by seeking alternative treatment options.

3) Chapter five assesses the relevance of social spaces for TB control. In this chapter I present an assessment of Nyanga, for which there was sufficient secondary data to develop a novel multidisciplinary method to identify, map and compare potential public TB transmission 'hotspots' across the community. Components of the BBS are creatively combined with basic principles of TB transmission and GIS technology in a way that visually grades the potential transmission risk posed by congregate settings in the community. The likely role of public gathering places in fueling TB transmission is highlighted and the potential value of replacing 'case-finding' with 'place-finding' as a control strategy is discussed. This Chapter has already been published in a peer-reviewed journal, demonstrating how existing qualitative data was successfully reworked to deliver an innovative and pragmatic public health approach that makes the social terrain of endemic TB meaningful for addressing TB transmission at the community level (for a copy of the publication please see appendix III).

References

1. Wallman S. *Kampala Women Getting By: Wellbeing in the time of AIDS*. London, UK: James Currey, 1996.
2. Wallman S. 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, UK: University College London, 2003. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=464686. Accessed September 2008.
3. Sismandis C, Moulton LH, Ayles H et al. Restricted Randomization of ZAMSTAR: a 2 x 2 factorial cluster randomized trial, *Clinical Trials* 2008; 5: 316-327.
4. Campbell J. A critical appraisal of participatory methods in development research. *Int J Soc Res Method* 2002. 5:19-20.
5. Kemmis S, McTaggart R. 'Participatory Action Research: Communicative Action and the Public Sphere' in *Strategies of Qualitative Inquiry*. Third Edition. Denzin NK & Lincoln YS (eds). Los Angeles, London, New Delhi, Singapore: Sage Publications, 2008.
6. Winch PJ, Wagman JA, Malouin RA, Mehl GL. *Qualitative Research for Improved Health Programs: A Guide to Manuals for Qualitative and Participatory Research on Child Health, Nutrition and Reproductive Health*. Prepared by Department of International Health, Johns Hopkins University, School of Hygiene and Public Health. For USAID, Bureau for Africa, Office of Sustainable Development, 2000.
7. Strauss RP, Sengupta S, Crouse Quinn S, Goepfing J, Spaulding C, Kegeles SM, Millet G. The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process. *Am J Pub Health* 2001; 91: 1938 -1943.
8. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine Publishing Company, 1967.
9. World Health Organisation. WHO Report 2009. Global Tuberculosis Control. Country Profile: South Africa. Geneva, Switzerland: WHO 2009.
10. Robins S, ed. *Limits to liberation after Apartheid: Citizenship, governance and culture*. Oxford, UK : James Currey Publishers; Athens, OH: Ohio University Press; Cape Town: David Philip, 2005.
11. Norman Rosana, Matzopoulos Richard, Groenewald Pam, Bradshaw Debbie. The high burden of injuries in South Africa. *WHO bulletin* 2007; 85: 695-702. http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862007. Accessed November 2009.

CHAPTER THREE

Social Fragmentation and Public Health Intervention

“Tuberculosis research requires a combination of advances in biomedical knowledge with a broader understanding of the evolving relationship between disease and modern societies”

- Gandy & Zumla (1)

Tuberculosis (TB) has been declared a national emergency in South Africa. Despite the availability of free curative therapy, it is the leading cause of natural notified death in adults (2, 3). A thick contextual web of chronic poverty, hunger, inequity, violence and Human Immunodeficiency virus (HIV) reduces the ability of patients to cope successfully with the disease (4); and a variety of social factors contribute to high default and death rates, compromising the efficacy of current TB control efforts (2,5). Standard TB control practice primarily focuses on detecting the most infectious cases, providing access to treatment and encouraging adherence to a prolonged course of curative therapy. TB services are decentralized to a ‘community’ level, and public health interventions target populations that are served by a specific TB diagnostic health facility, regarded by the municipal health services to be a ‘community’. There are multiple and complex factors that potentially impact on the success of a particular public health intervention. These are linked to the characteristics of the intervention, how the intervention is implemented, and to the target community receiving the intervention (6). Little is understood about how the social terrain⁶ within target communities, as a whole, may affect the uptake of public health interventions aimed at reducing TB prevalence; or how to characterize contextual social differences that may be relevant to improving treatment outcomes.

Currently, a community-randomized trial named ZAMSTAR⁷ is evaluating different public health interventions aimed at reducing TB prevalence in Zambia and South Africa. The trial is one of the first of its kind to feed local social context, or terrain, into a constrained

⁶ Social terrain denotes the immediate internal socio-physical environment of endemic TB

⁷ The Zambia and South Africa Tuberculosis and AIDS Reduction Study (ZAMSTAR) is a seven year trial (2004-2011) working within government health systems across 24 communities in Zambia and South Africa. It aims to measure the efficacy of three different public health interventions to reduce TB prevalence in impoverished communities with a high HIV prevalence. The study is being carried out by the Desmond Tutu TB Centre, University of Stellenbosch, the ZAMBART project and the London School of Hygiene and Tropical Medicine, with support from John Hopkins, under the Consortium to Respond Effectively to the AIDS TB Epidemic (CREATE).

randomization process of its research sites, anticipating that it may have an effect on TB prevalence and the uptake of public health intervention (7). A social system's model developed by Wallman within the social sciences was adapted by the trial to do this. The model classifies urban systems in terms of their capability to absorb change and intervention i.e. their relative open-ness to people and influence from the outside. Key to the model is making sense of the extent to which the degree of heterogeneity within a social system affects a collective response to influence from outside of the system. Theoretically, the model implies that the more heterogeneous a social system is, the more adaptive and open it is to change and vice versa: less heterogeneity implies greater resistance to change and intervention - a system socially 'closed' to the outside and hard to access by an outsider (8). This paper draws on the application of the Wallman model to the South African ZAMSTAR research 'communities' in order to explore the capacity of urban township areas to absorb public health interventions aimed at reducing TB prevalence.

The weight of this chapter describes how we used the Wallman model to draw a qualitative comparison across the eight South African ZAMSTAR communities. Six visible and measurable indicators of social diversity - namely: livelihood; topography; interest groups; population mixing; population movement; and housing options - were developed to grade the communities along an open-closed continuum in terms of their predicted responsiveness to intervention. In this way, differences in social terrain were considered for the ZAMSTAR trial. Following from this, a participatory exercise is used to triangulate these findings with auxiliary knowledge from the field which further assesses the 'open-ness' of the high-burden townships, considering how social fragmentation and social cohesion might be at play. It is important to note that the set of ZAMSTAR interventions comprises enhanced case-finding and the integration of TB and HIV services. These interventions incorporate non-biomedical aspects such as household counseling, social mobilization and the strengthening of community networks. The effect non-biomedical components of these interventions might have on social cohesion within the research sites is unclear. For purposes of simplification, this paper theorises in terms of interventions that do not affect social cohesion within a target community, as this is a central variable in the argument.

Findings refract the notion of 'community' for TB control, highlighting that this is not necessarily a homogenous entity socially equipped to receive and sustain public health intervention.

Setting

Fieldwork was conducted in eight township areas in and around Cape Town in the Western Cape Province of South Africa: Delft, Kayamandi, Mbekweni, Site C, Wallacedene, Philippi, Nyanga and Harare. The Western Cape has one of the highest TB notification rates in the world, reported to be between 773 and 1008 per 100 000 of the population (2). Worst hit are areas that were marginalized under the discriminatory Apartheid regime, such as the study sites. The social and economic conditions of Apartheid created an impoverished and overcrowded environment that was unjustly susceptible to disease (9). After the dismantling of Apartheid's legal machinery, these areas remain constrained by poverty and disease, currently experiencing incredibly high rates of HIV infection and tuberculosis disease as well as the rise of drug resistant TB.

The research sites used in this study include all of the South African sites that were pre-selected by the ZAMSTAR trial as a unit of randomization. A unit of randomization was defined as a population that is served by one diagnostic centre and was initially referred to by the trial as a 'community'. In 2004, the eight South African communities had an adult population of between 20 and 40 thousand and concomitant HIV and TB epidemics. Local diagnostic health facilities follow standard TB control practice - the internationally recommended DOTS strategy. Socio-economically all the sites appear superficially similar; they are 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 (10,11).

Method

During 2005 and 2006 a qualitative baseline study was conducted in the 24 ZAMSTAR research communities across Zambia and South Africa. The baseline study was completed before the implementation of any of the trial's interventions and was labeled

“Broad Brush Survey” (BBS). The BBS is a participatory approach to gathering a wide understanding about a local social system (12). Fieldwork for the BBS comprised community meetings, transect walks and structured observations carried out in each research community over a period of 5 days. Raw data collected from the BBS was written up into community profiles which focused on the following topics:

- Topography
- Environment
- Population
- Movement
- Places where people congregate
- Local economy
- Housing
- Schools
- Space and daily activities
- Women’s space and time
- Men’s space and time
- Youth’s space and time
- Children’s space and time
- Religion
- Health Services
- HIV/AIDS
- Tuberculosis hotspots
- Transmission and Causes of TB (local perceptions)
- Treatment Options and Care
- TB Stigma
- TB Knowledge
- Leadership and Mobilisation
- Stability of Community
- Unique characteristics

With these profiles at hand, the Social Science Team from the ZAMSTAR trial was facilitated by Professor Sandra Wallman⁸ to define and score indicators of diversity across the 8 South African communities in a workshop.

Without further ethnographic research, some of the less visible indicators of diversity suggested by the data and research team as relevant to TB control, such as community identity, tuberculosis perceptions, tuberculosis stigma and treatment options, were unable to be scored. Team response to these indicators was less unanimous than the response to more tangible and observable indicators. This highlighted limits to the BBS data which were most reliable for evaluating observable aspects of social life within the research communities. Dropping the less visible indicators because of this meant that six visible indicators which could be qualitatively measured by observation were grouped together and applied to the Wallman model. This set of visible indicators comprised livelihood, topography, interest groups, population mixing, population movement and housing options.

Researchers who had conducted fieldwork used the BBS data and the community profiles to score each of the indicators in each of the eight research communities comparatively. Scores aimed to give a sense of how diverse a community was in terms of each particular indicator. Guided by the social system's model which argues an urban system's capacity to respond to influence from outside of the system is largely governed by its heterogeneity, each indicator was first typed as either 'open' (Heterogeneous and open to change/ influence/ outsiders) or 'closed' (Homogenous and resistant to change/ influence/ outsiders). The six indicators were then enumerated on a scale of -3 to +3 (-3 being extremely closed; +3 being extremely open) to give a finer grading of open and closed. If a distinction between 'open' and 'closed' could not be made, a score of zero was given. Table 3.1 provides further description of the indicators and their 'open' and 'closed' features (see below).

Scores of the indicators were entered onto a grid and totaled with a possible maximum of 18 and minimum of -18. This crude agglomeration of scores did not reflect differences within communities nor did they mean that communities with the same score were the same on the ground i.e. a matching score on any indicator between sites meant that they

⁸ Professor Sandra Wallman is currently developing the 'open-closed' systems model that we adapted

had the same degree of diversity, although the components and mix of diversity may be different. The totaled result allowed the 8 communities to be graded along a continuum of open and closed in terms of their predicted responsiveness to biomedical intervention i.e. of their relative ‘open-ness’ to people and influence from outside.

TABLE 3.1
Six visible (able to be counted and mapped) indicators of social diversity with a description of ‘open’ and ‘closed’ features.

	DIVERSITY INDICATOR	‘OPEN’ FEATURES (emphasizing heterogeneity and flexibility)	‘CLOSED’ FEATURES (emphasizing homogeneity and inflexibility)
A	Livelihood	Many different ways to earn a living, informal (including sex work and criminal activity) and formal options of employment, evidence of extreme coping strategies.	Limited number of ways to get by, history of retrenchment from industry, no thriving informal economy.
B	Topography (a “Bird’s Eye View”)	A diverse range of transport hubs within the community. Many different collision spaces, public gathering places, access paths and roads. Options for expansion and development.	Limited and small transport hubs, Few exit and entry points and a small number of similar types of gathering places. Restrictive physical barriers and little room for development and expansion.
C	Interest Groups	Wide range of very active stakeholders religious denominations political parties, Community Based Organisations (CBOs), Non Governmental Organisations (NGOs) and other associations.	Limited range of stakeholders, religious denominations and political parties. Few CBOs and NGOs.
D	Interaction	Mixing and integration between a diverse range of social categories including sex, age, class, race and ethnicity	Limited mixing and integration between social categories including sex, age, class, race and ethnicity.
E	Mobility	Population movement evident. Daily and weekly mobility patterns are diverse and traveling in and out of the community is easy.	Limited population movement, common daily and weekly mobility patterns with limited traveling beyond the boundaries of the community
F	Housing Options	Mix of housing types. Both public and private housing available, Serviced and unserviced housing, various sizes evident and many different types of construction materials used.	Limited housing options, similar constructions with a similar value.

The visible indicator set used to grade communities along the continuum lacked significant indicators that were less observable and less tangible. To counteract this, an alternative experimental ranking of communities used a more intuitive assessment. This was a participatory ranking exercise that focused on community identity as an indicator of ‘open’ or ‘closed’ and was done after the initial scoring exercise. The intuitive ranking was not enumerated and represented the gut feeling of fieldworkers, who had spent time

researching the social terrain of each of the communities, of how less visible issues of stability, trust, social cohesion and a sense of commitment to place refracted the ‘open-ness’ and ‘closed-ness’ of communities. Without further ethnographic data, it presented a preliminary estimate as to whether more in-depth research would alter the position of any of the communities along the continuum.

Feedback from the BBS fieldwork has been delivered to research communities via a meeting with local community advisory boards (CABs) in each research site. Findings were written up and handed out in flyer format to members of the CAB within the framework of ZAMSTAR.

Results

After scoring and totaling the initial set of visible indicators, all eight township communities were classified as relatively open to outsiders and change. Some closed features were evident in all the sites except for in Philippi and Nyanga which were typed ‘open’ on all of the diversity indicators (see Table 3.2).

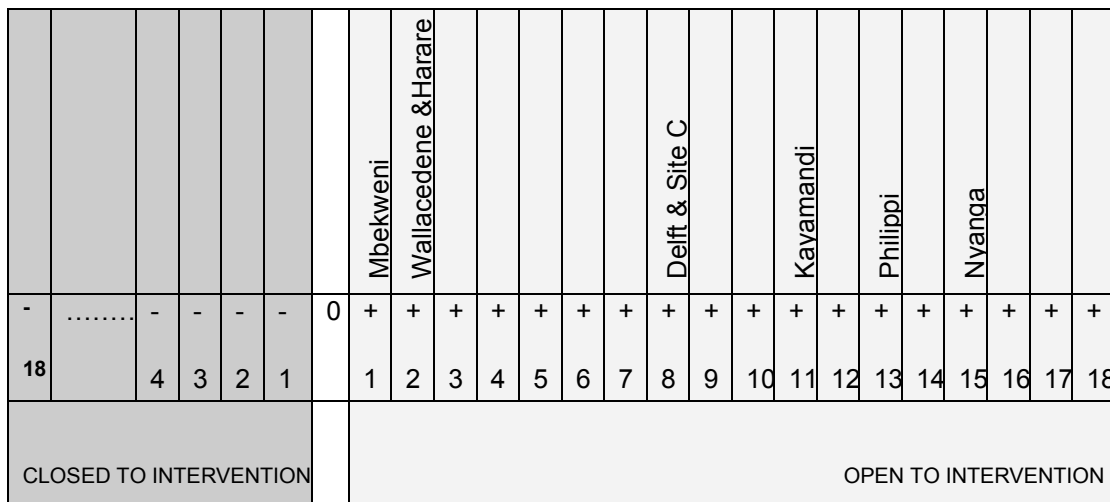
TABLE 3.2: Qualitative classification and scoring of social diversity

RESEARCH COMMUNITY	INDICATOR OF DIVERSITY					
	A Livelihood	B Topography	C Interest Groups	D Interaction	E Mobility	F Housing Option
DELFT (8)	+3	0	+3	-2	+3	+1
KAYAMANDI (11)	+2	-2	+3	+3	+2	+3
MBEKWENI (1)	-1	-1	0	+2	-1	+2
SITE C (8)	+3	+1	+1	+2	+3	-2
WALLACEDENE (2)	+1	0	-2	+3	+2	-2
PHILIPPI (13)	+2	+3	+2	+2	+2	+2
NYANGA (15)	+3	+1	+3	+2	+3	+3
HARARE (2)	-2	+2	+2	+1	-2	+1

+1 to +3 = open grading (light grey); -1 to -3 = closed grading (dark grey);
0 = both open and closed features (white)

Each indicator was weighted equally when collapsing the scores and the open-closed scale of sites that emerged showed five sites – Philippi, Nyanga, Kayamandi, Delft and Site C - to be relatively more socially heterogeneous places and therefore more ‘open’ to public health intervention than Wallacedene, Harare and Mbekweni (see Figure 3.1).

FIGURE 3.1:
Collapsing scores to place communities on a continuum of responsiveness to intervention

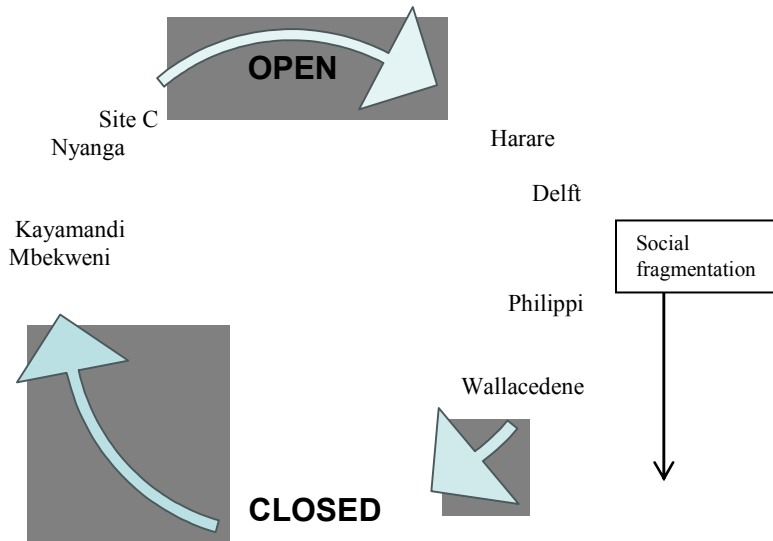


Interestingly, the participatory ranking exercise that graded communities using community identity as an indicator of ‘open’ and closed’, significantly moved the relative ‘open’ position of some of the research communities. Moreover, the exercise forced the research team to reshape the original Wallman model, converting it from a polar continuum to a circular model (see Figure 3.2).

Part of the problem with the polar continuum was that when community identity was assessed, such high levels of social fragmentation, mistrust and marginalization were evident in some communities that very little or no sense of social cohesion was apparent. Diverse representations of social phenomena felt meaningless as there seemed little evidence of a social system; an intervention from outside would struggle to find any kind of social grip, or foothold, within the research community, making it extremely difficult to initiate and sustain an intervention. Theoretically, this suggested that if a particular social system became so extremely fragmented, an ‘open’ community (in terms of social

diversity) could tip over into being 'closed' to intervention from outside, albeit a more passive form of resistance.

FIGURE 3.2:
Intuitive 'open' and 'closed' positioning of communities by fieldworkers based on community identity.



Results from this model suggest that a place like Mbekweni, although classified as relatively closed in terms of social diversity, is tending towards being able to sustain an intervention from outside because it shows relatively high degrees of social cohesion and stability. On the other hand, Wallacedene is shown to be essentially 'closed' to intervention as a result of extreme social fragmentation and instability. The following brief synopsis of the BBS data collected from Wallacedene grounds this abstraction.

According to locals, the first people to relocate to Wallacedene came from compounds that were occupied by migrant workers who worked for an asbestos company in a nearby town. In the early 1990s, because of the impossibility of family life in the compounds, men moved with their families to an area which had previously been farm owned but had become abandoned. Those moving from the asbestos factory's compounds (mostly

Xhosa from the Eastern Cape⁹) merged with former farm workers (largely a Cape Coloured community) who had become unemployed when the farm stopped operating. The initial informal settlement that emerged was demolished by the then city council as accusations were made that the land was being occupied illegally. A plaintiff intervened bringing a halt to the evictions that were taking place and following this, Wallacedene was formed. Subsequently there has been a continual influx of people coming from the Eastern Cape and neighbouring areas in search of employment in Cape Town and its surrounds. At the time of the BBS fieldwork, regular relocations and developments within the community seemed drawn out. The community was described as having the potential to sprawl into neighbouring communities as it expanded.

Today, Wallacedene is highly marginalized and was described by fieldworkers as an area “deserted by the government and non-governmental organizations as far as community development is concerned.” Locals themselves feel marginalized with few opportunities to engage in forms of capacity building although some Community Based Organisations (CBOs) and Non Governmental Organisations (NGOs) do exist. They described Wallacedene as the home of TB, using phrases such as “*yenziwa apha iTB*” (TB is made here). Residents consistently defined Wallacedene as a sordid place filled with filth, prostitution, disease and violence. They also explained how TB patients hide their illness fearing isolation and humiliation. Wallacedene was characterized as having more police raids than other research communities, and, as having particularly high levels of rape, murder, child abuse, gang violence, alcoholism and armed robbery. Fieldworkers described how, at peak times, taxi drivers use sticks to clear people standing along a road that forms a hub of the community in order to make their way through. Public space was bustling day and night with locals and outsiders. Traders selling goods in Wallacedene tended to come from surrounding areas and were seldom locals. Large taverns reportedly cater mostly for professionals attracted to the high levels of drinking and prostitution. Low levels of trust amongst community members are evident and fieldworkers spoke of being regarded with suspicion in the field. Begging for food and clothing is common, and Wallacedene was described as the most overcrowded and under serviced community by fieldworkers. There was no burial ground at the time fieldwork took place, the deceased often buried in neighbouring communities or taken to the Eastern Cape. Many residents

⁹ Part of the Eastern Cape Province was a former 'homeland' under Apartheid. The Western Cape Province attracted migrant labour (mostly Xhosa) from the Eastern Cape and mobility between these two provinces is still strong.

had little faith in their local clinic, with traditional healers or private doctors seeming to be the preferred treatment option. Forms of social cohesion, or a sense of community, were evidently difficult for fieldworkers to find.

Using visible indicators of diversity Wallacedene was classified as 'open', but graded towards the closed end of the open-closed 'polar' continuum. Social interaction and mobility were seen to be particularly diverse in this community. When considering factors related to community identity and a sense of cohesion, fieldworkers felt uncomfortable with any interpretation that public health interventions would be absorbed, as the community appeared extremely fragmented with little evidence of social cohesion. Together with its short volatile history and a high degree of mobility, the latter suggested that as a community¹⁰, Wallacedene is incredibly fragile. The likelihood that it is able, in its current form, to successfully receive and sustain biomedical intervention is small.

Delft, Philippi and Harare were also evaluated as being fragmented and marginalized, lacking forms of social cohesion and displaying a very low commitment to a sense of place. The remaining four research sites (Kayamandi, Mbekweni, Site C and Nyanga) were evaluated as being more socially cohesive with an apparent community core. The theoretical interpretation of the circular model is that Nyanga and Site C would potentially have the most successful uptake of any uniform public health intervention. It also implies that the uptake of intervention in Wallacedene and Philippi (to a lesser extent) would be unsuccessful. The polar continuum, on the other hand, suggests that an intervention implemented uniformly across the communities would be successful in all the communities but more so in Kayamandi, Philippi and Nyanga; less so in Communities Mbekweni, Wallacedene and Harare. Wallacedene shifted the most dramatically from being relatively less 'open' than the other communities on the polar continuum, to being so extremely open on the circular model (in terms of community identity and flexibility) that it could possibly be passively 'closed' to public health intervention as a result of social fragmentation.

¹⁰ Community used here to mean a geographical place where a socially cohesive group of interacting people are organized, sharing a sense of belonging and identity.

Discussion

The adaptation of the social systems model was useful in that it allowed us to synthesise qualitative data from high-burden township communities experiencing similar disease and socio-economic profiles. The comparative approach meant that the social complexity of these areas could be condensed into an intelligible and meaningful format. Although the initial set of diversity indicators typed all the communities as 'open' on the Wallman continuum, social diversity did differentiate the targeted communities. The amount as well as the mix of social diversity present varied from community to community. While this may hold implications for interpreting the success of future public health interventions, further research that includes deeper ethnographic accounts and longitudinal assessment of the implementation of interventions are needed to understand the implications of social diversity more comprehensively.

Certain of the social diversity indicators that were defined in the typology exercise, such as mobility and interaction, are potentially very significant for exposure to TB across different infectious pools. For example, a high degree of diverse mobility and interaction within a community (as in the cases of Kayamandi, Site C, Wallacedene, Philippi and Nyanga) may correlate with a diverse mix of TB strains and a high rate of re-infection. Placing information such as the mix of TB strains and prevalence of TB alongside the scored diversity indicators and the open-closed continuum would provide more substantive evidence of any link between social diversity and exposure to TB. It may also direct the weighting of certain diversity indicators as more or less significant for TB control. This is speculative and beyond the scope of this particular exercise, however, which primarily sought to explore defining contextual characteristics that may make one target area more or less receptive to TB control than another. Other types of analyses will be possible after the results from the ZAMSTAR TB prevalence surveys, conducted after the implementation of interventions, become available. Further factors that proved to be potentially relevant for exposure to TB infection were the strong social ties and mobility links across many of the research sites. These provide evidence that TB cases 'float' from target community to target community within the Western Cape. This form of internal migration presents a significant challenge to the 'cohort' approach adopted by TB control policies, used in this area to account and provide for all TB cases within a target community (13).

A major hurdle to the application of the Wallman model to the ZAMSTAR research communities was that most communities comprise multiple cityscapes, suggesting the presence of more than one social system. This made it impossible to type the community as 'open or 'closed' in terms of its social system and as a result, the relative 'open-ness' of each community applies to the community area (as predefined by the ZAMSTAR trial) rather than any type of social system present, providing a caveat to our adaptation of Wallman's model. The practical implication of this is that uniform public health interventions may work differently not only across target communities, but also within a target community. It also made the wider trial more careful of the word 'community' and sometimes 'community' was substituted by 'site' or the name of the clinic by research teams. Interestingly, ZAMSTAR explicitly aimed to select communities that were not "separated by physical or socio-cultural barriers that minimise intermingling of populations"¹¹, which highlights the value of our qualitative community assessment: Despite the trials efforts, fieldwork showed that this was not necessarily the case on the ground when considering a social systems perspective.

A case in point is Delft. Two different areas of Delft, Delft South and Voorbrug present two distinct social systems of their own. Voorbrug is economically better off than Delft South. Residents are mostly Cape Coloured and didn't appear to know much about life in Delft South. Houses were built and rented out by the council before 1994 and title deeds were passed on to tenants after 1994. There is a mix of council houses and 'bank' houses (so named because the houses were extended with finance from the bank). There are many church buildings in the area and it is relatively more stable than Delft South where many people are selling or leasing their houses. Delft South, on the other hand, has more of an ethnic mix between Cape Coloured and Black South Africans who share a different class status to people from Voorbrug. Delft South was developed after the first democratic elections of South Africa that were held in 1994 and is known as one of the first racially integrated communities of South Africa – a rainbow community that symbolised change in South Africa. It comprises predominantly RDP¹² houses and there are more makeshift structures present than in Voorbrug. There are also older council houses and blocks of flats, but RDP one-room 'starter' houses are the most common. These were built with the

¹¹ This was stated in one of the initial protocols of the trial.

¹² These houses were built by the state to meet housing needs, post Apartheid, under the Reconstruction and Development Programme (RDP)

understanding that owners might extend. There are few church buildings in Delft South and most religious gatherings take place in schools, private homes or in the community centre. It is said to be more densely populated than Voorbrug and was blamed for the spread of TB.

The social distinctions between Delft South and Voorbrug illustrate how, based on a limited number of visible indicators – population mix, livelihoods, history and housing – they can be considered as two different social systems although, for the purpose of our exercise (largely because of the broader framework of the ZAMSTAR trial), they were combined into one ‘community’.

Social fragmentation was also identified as a confounder to assessing the relative ‘openness’ of the research communities when using the Wallman model. The extreme degree of community instability and lack of social cohesion highlighted by the case of Wallacedene suggests that susceptible high-burden areas do not necessarily have the capacity to absorb and sustain a public health intervention. A recent ethnography of HIV infected men in a similar high-burden Cape Town township points to assumptions often made, on many levels, that communities are places where people can “generally find care and support from each other” and that community members “would - and should – be prepared to sacrifice their time, energy and expertise for the ‘good of their community’” (14). Indeed, many see a volunteer ethic also crucial to any sustainable response to the TB epidemic; this is particularly evident in the implementation of lay health workers across South Africa to assist TB control programmes (15). The lack of social cohesion and instability found in four out of eight communities undermines the usefulness of appealing to a volunteer ethic in these areas.

The notion of a target ‘community’ is problematic for TB control, mostly because it tends to assume a generally stable and homogeneous entity (14) that displays some form of social cohesion. How community instability can hamper TB control was emphasized during Apartheid (16). The political landscape of South Africa has since democratized, but today, alongside gross inequity and violations of socio-economic rights, our research suggests that community instability still limits the capacity of target endemic areas to sustain a public health intervention. Adjunctive strategies that address social fragmentation are likely to amplify the efficacy of public health interventions in these areas. A possible valuable side-effect may be achieved via the mobility link that many of these communities

have with other high-burden communities that do show signs of social stability and cohesion. The social interconnectedness of the research sites implies that enhancing TB control and treatment success in some communities may have a positive ripple effect in others.

Study results suggest that in an area where social heterogeneity is coupled with social cohesiveness, public health interventions aimed at reducing TB prevalence are likely to be readily received with more success. However, in an area where social heterogeneity is coupled with social fragmentation, it is unlikely that interventions will be successfully sustained. As all the communities researched in this study were typed as being socially diverse, no comment can be made on a scenario with high levels of social homogeneity.

Conclusion

A social system's perspective may prove useful to explain variance in the success of uniform public health interventions aimed at reducing TB prevalence. More than simply the sums of individual TB cases sharing a common diagnostic centre, target populations in and around Cape Town are likely to respond unevenly to intervention, even if these populations share a superficially similar socio-economic profile and burden of HIV. Designing interventions that are sensitive to social fragmentation and the individuality of target communities may enhance the efficacy of curative therapy. A future step would be to compare the forecasted responsiveness with actual intervention evaluations done in each ZAMSTAR community, in order to assess the validity of our findings.

References

1. Gandy M, Zumla A. The resurgence of disease: social and historical perspectives on the 'new' tuberculosis. *Soc Sci & Med* 2002; 55: 385-396.
2. World Health Organisation. WHO Report 2009. Global Tuberculosis Control. Country Profile: South Africa. Geneva, Switzerland: WHO 2009.
3. Statistics South Africa. Mortality and Causes of Death in South Africa: Findings from death notification 2007. STATSSA: 2009. www.statssa.gov.za/publications/statsdownload.asp?ppn=P0309.3&SCH=4507. Accessed November 2009.
4. Bond V, Chileshe M, Sullivan C, Magazi B. The Converging Impact of Tuberculosis, HIV/AIDS, and Food Insecurity in Zambia and South Africa. Final Working Report. Renewal Programme, 2009. <http://programs.ifpri.org/renewal/pdf/ZambiaSAFinalReport.pdf>. Accessed October 2009.
5. Botha E, Den Boon S, Verver S, Dunbar R, Lawrence KA, Bosman M, Enarson DA, Toms I, Beyers N. Initial default from tuberculosis treatment: how often does it happen and what are the reasons? *Int J of Tuberc Lung Dis* 2008; 12: 820-823.
6. Greenhalgh T, Robert G, MacFarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organisations: systematic review and recommendations. *Milbank Quarterly* 2004; 82(4): 581-629.
7. Sismanidis C, Moulton LH, Ayles H, Fielding K, Schaap A, Beyers N, Bond G, Godfrey-Faussett P, Hayes R. Restricted randomization of ZAMSTAR: A 2x2 factorial cluster randomized trial. *Clinical Trials* 2008; 5: 316-327.
8. Wallman S. 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, UK: University College London, 2003. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=464686 Accessed September 2008.
9. Abdool Karim SS, Churchyard GJ, Abdool Karim Q, Lawn SD. HIV infection and tuberculosis in South Africa: an urgent need to escalate the public health response. *Lancet* 2009; 374: 921-33.
10. Robins S, ed. Limits to liberation after Apartheid: Citizenship, governance and culture. Oxford, UK : James Currey Publishers; Athens, OH: Ohio University Press; Cape Town: David Philip, 2005.
11. Norman Rosana, Matzopoulos Richard, Groenewald Pam, Bradshaw Debbie. The high burden of injuries in South Africa. *Bulletin World Health Organisation* Sept 2007; 85(9): 695-702. http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862007. Accessed November 2009.
12. Wallman S. *Kampala women getting by: wellbeing in the time of AIDS*. London, UK: James Currey, 1996.
13. Enarson DA. Migrant Tuberculosis: a moving target. 2006; *Int J Tuberc Lung Dis* 10:945.
14. Colvin CL, Leavens J, Robins S. Seeing like a 'PWA': A study of therapeutic citizens and welfare subjects in Cape Town, South Africa. Chronic Poverty Research Centre; Working Paper 144, 2009. <http://www.chronicpoverty.org/publications/details/seeing-like-a-pwa-a-study-of-therapeutic-citizens-and-welfare-subjects-in-cape-town-south-africa>. Accessed November 2009.
15. Dick J, Murray E, Botha E. The Effectiveness of TB DOTS Supporters in South Africa. *Operations Research Results*. Bethesda, MD: Published for the U.S. Agency for International Development (USAID) by the Quality Assurance Project (QAP), 2005.
16. Yach D. 1988. Tuberculosis in the Western Cape Health Region of South Africa. *Soc Sci & Med*; 27: 683-689.

CHAPTER FOUR

Unraveling the Significance of Popular Perceptions for TB Control

Prevalence surveys provide a population based tool with which to assess the amount of tuberculosis (TB) disease present within a particular community comprehensively and directly. They are difficult and costly to perform and multiple surveys are required to monitor the impact of public health interventions over time. A single survey can, however, provide an indication of the number of patients who remain untreated within a community, despite the availability of diagnostic and treatment services. If the reservoir of untreated TB patients is large, it substantially hampers biomedical control efforts by facilitating ongoing transmission within the community. This has been evidenced by high annual rates of TB infection (ARTI) in such settings. (1, 2) The impact of the ZAMSTAR interventions will ultimately be determined by the results of prevalence surveys conducted within all of the research communities at the end of the study. These are to be compared with baseline epidemiological data gathered from tuberculin skin test (TST) surveys which have been measuring the incidence of TB during the three-year intervention period. ZAMSTAR piloted the prevalence surveys in non-study sites in order to gather a feel for how long the final prevalence surveys would take and what findings may be. Confirming previous findings from a township area similar in profile to the South African townships researched in this study, results from the piloted prevalence surveys show that undetected TB in settings experiencing concomitant HIV and TB epidemics substantially compromises current control programs in southern Africa (3, 4). Findings from the South African township show that despite a well-run DOTS service, 63% of community adult cases with TB remained undetected by TB treatment services and many of these undetected cases were co-infected with HIV (4). Since TB patients remain infectious until they are adequately treated and most transmission takes place between the onset of cough and the initiation of treatment (5), there is urgent need to reduce the number of undetected TB cases in such hyperendemic settings in order to cut levels of transmission through early treatment. (2)

Current TB control policy relies on the voluntary presentation of individuals to local health services (passive case finding) for the diagnosis and treatment of TB, but reluctance to present is a common problem prolonging diagnostic delay in many settings (2). Multiple and sometimes interdependent social factors have been identified as key

contributors to this type of delay and include the use of and preference for alternative treatment options (traditional healers, self-treatment and the use of the private sector), substance abuse, poverty, low educational levels, low awareness of TB, misconceptions about TB, age, gender, history of immigration and stigma (5). Previous social research specifically within the South African context suggests that the social stigma of and local misconceptions about TB are key factors that delay voluntary presentation (6 - 9).

A growing trend in local and international qualitative research is emphasizing how the social impact of HIV on TB is negatively affecting patient treatment seeking behaviour in areas experiencing concomitant TB and HIV epidemics (10-14). Bond and Nyblade demonstrate that HIV has not only shaped the epidemiology of TB, but also the social experiences and perceptions of TB, emphasising the threat posed by the related manifestation of 'HIV-TB' stigma for TB control. They argue that TB stigma can no longer be thought of, or addressed, separately from HIV stigma as HIV and TB have become intertwined diseases – through both biomedical and popular correlation because TB is an opportunistic infection in people infected with HIV. An increasing awareness of the strong association between TB and HIV/AIDS in high burden settings has resulted in local confusion as to whether someone has 'normal' TB (not associated with HIV/AIDS) or 'new' TB (associated with HIV/AIDS) and a conflation of the two diseases in community understanding. (12)

This chapter explores how popular perception and interpretation of TB within the eight South African ZAMSTAR communities, which all carry a large amount of undiagnosed TB, may be meaningful for TB control. In light of the urgent need to increase case detection and the recent call for social science to “promote understanding regarding the complex psycho-social interplay of TB and HIV/AIDS” (15), it flags the prominence of anticipated HIV/AIDS related stigma as a significant finding. The way in which it permeates the participatory approach of the BBS data shows that communities themselves believe this to be a significant factor prolonging treatment delay.

Method

BBS data collected from the eight South African township communities previously described were assessed through a comparative and inductive analysis of emergent themes. After becoming familiar with the textual data whilst coding a part of them under relevant nodes in QSR N6 as part of the ZAMSTAR team¹³, I did an independent manual analysis of the activity reports against the computer-based coding for the purposes of this project; identifying popular perceptions and interpretations of TB. For the initial coding of the data, the ZAMSTAR team developed a substantial 'tree' of parent and child nodes under which the activity reports from both the Zambian and South African BBS were coded (see appendix II). Each report was coded by two different coders and codes were then finalized and entered into QSR N6.

A total of 119 South African activity reports were coded in QSR N6. There were approximately fifteen activity reports from each site that covered the following:

- Initial impressions of the community (n=2);
- The free-listing and mapping activity conducted with the ZAMSTAR CABs (n=1);
- Transect walks (n=2);
- Structured observations and discussions at a transport hub (usually a taxi rank), hair salon, place where typically men socialize (usually a drinking place), place where typically women socialise and at the local clinic (n=5);
- Daily-time chart activities and discussion with groups of young women, young men, adult women and adult men that were held where these groups typically congregate (n=4);
- And an evening observation with discussion (n=1)

Delft had 17 instead of 15 activity reports as a result of extra reports written on the second day of transect walks by each of the two research assistants. Harare and Site C had 13 and 14 respectively because of a joint CAB meeting, the dropping of the evening observation for safety reasons (Site C), the failure to identify a transport hub (Harare) and the merging of the salon observation with the daily time chart with women (Harare).

¹³ I supervised the double coding of the activity reports by the ZAMSTAR social science team. I also finalized and inputted the activity reports from two research sites for ZAMSTAR, but then left the coding process. The remaining six sites were finalized and inputted by another member of the ZAMSTAR team.

The length of each activity report ranged from approximately 3 to 5 typed pages and captured the response of the multiple individuals spoken to during the activity. In some cases this included a small group (4 plus) and in others this was a much larger group (20 plus). Textual content was generally structured by fieldworkers under four topics. These comprised:

- (a) The process of the activity that took place - detailing the CAB meeting, transect walk or structured observation.
- (b) What was learnt about the community – From where are people coming and to where are they going? Are people local? What types of social interactions are taking place?
- (c) Where and how time is spent by people - including livelihood options.
- (d) What was learnt from the community about TB and HIV – why and where is TB thought to be spread? How are people with TB treated?

Analysis was focused on the data gathered under topic (d) although activity reports were assessed in their entirety. The relative strength of a theme was determined in accordance with how iterative it was within and across the research communities.

Findings

Two dominant themes emerged from the data; 1) the association of TB with filthy living conditions and 2) the anticipation of HIV related stigma. Findings are presented in three parts that are linked to these themes. The first part explores community ideas about the causes of TB, uncovering how TB is commonly defined as a 'dirty' disease. Both the second and third parts reflect that TB is perceived to generate community suspicion of HIV/AIDS. While the second part draws attention to factors that are said to give rise to HIV suspicion, the third focuses on how communities navigate this suspicion.

1) Popular definition and understanding of TB

Many ideas about the cause of TB emerged across the eight communities. Amongst the common ones were the sharing of food and utensils with TB patients, exposure to damp or extreme temperatures, kissing, overcrowding and malnutrition. Ideas about TB being genetic were evident in Philippi, and, in Harare men claimed that women were more vulnerable to TB and HIV as a result of weak blood. Data also showed that there are bewitchment beliefs linked to TB in all communities and that these are likely to be more prominent amongst the elderly. These include belief in being kicked in the chest by *impundulu* (the lightning bird of Xhosa folklore) or *idliso* (poisoning through witchcraft)¹⁴. In Nyanga and Delft, coughing, spitting and talking closely were often mentioned as spreading disease and in Delft and Kayamandi a strong understanding that TB can be cured was evident. Most dominant in all communities, however, was the popular association made between TB and pollution.

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. The people of Wallacedene breathe these germs [including TB] everyday.”

- Adult woman from Wallacedene, 28/10/05.

TB was primarily and consistently understood as a 'dirty' disease across all eight of the research communities. Heavily associated with filth, blocked drains, poor sanitation and inadequate housing, many blamed the poorest and unserved 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 because of a lack of municipal services. As one respondent from Kayamandi put it, "there is too much TB because people step on faeces". Research assistants felt that in some communities levels of uncollected waste were worse than in others, but all communities faced problems with

¹⁴ For further explanations of *impundulu* and *idliso* please see Hammond-Tooke WD. Rituals and medicines: Indigenous Healing in South Africa 1989: Ad. Donker.

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 prepared unhygienically – was also often mentioned as a cause of TB. In one community, where racial tensions were apparent, Cape Coloureds suggested that there was more TB amongst Black Africans because they thought that they prepared food unhygienically. As in this case, often a certain sector or particular individuals within a community were blamed for the spread of TB because they or their living conditions were viewed as dirty. For example, a salon owner in Mbekweni 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 the salon?" In Kayamandi, locals living in more derelict conditions were blamed, but blame was also placed on other communities, including Wallacedene, as residents knew of many visitors coming to Kayamandi from outside areas and believed these outsiders to bring disease from their home communities which were viewed as more dirt ridden and therefore more diseased.

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, further ideas of individual bodily pollution as a result of working or drug abuse also emerged. Exposure to dust, 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 the following were all mentioned as causing TB: paint during painting work, 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. Smoking, drinking (in particular cheap wine and local commercial '*ijuba*' beer - seen to have more chemicals than traditionally brewed beer) and breathing steam from asbestos (evaporating from houses under the 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 were evident similar to those described by Mavhu *et al.* and Bond and Nyblade (11, 12). Respondents distinguished between 'old/fat' TB

and 'new/thin' TB (or 'TB-plus'), the latter understood as incurable and strongly associated with HIV/AIDS and/or weight loss, the former often understood as curable and associated with weight gain. Talk that TB is a precursor of HIV/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/AIDS, and others thought that AIDS results if TB medication fails. Some assumed that if one contracts TB a second time one has HIV/AIDS, and a few thought that TB necessarily leads to HIV/AIDS or that they are one and the same disease. Themes emerging from BBS data highlight that TB and HIV are linked most prominently, however, when communities speak of HIV suspicion. Communities consistently argue that TB patients face a detrimental risk of being judged as an HIV patient by their community, showing that perceived levels of HIV-TB stigma are very high. As one woman from Mbekweni who was speaking about HIV and TB put it: "It's all the same, because people treat you the same". And from another respondent:

"It is 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 at Kayamandi clinic, 19/07/05.

2) Factors fueling HIV suspicion

Similar clinical presentation

Most communities displayed very good knowledge of TB symptoms, with Harare and Site C the exception. Persistent coughing, back pains, low appetite, fatigue, weight loss, sweating and vomiting blood were frequently mentioned by respondents as signs of TB. Importantly, weight loss was also heavily associated with HIV/AIDS and respondents consistently reported that if a person loses and then does not regain their weight, they are suspected of having HIV/AIDS. The case of David illustrates how loudly weight loss speaks to individuals and their communities alike. David had been recently diagnosed with TB at his local clinic in Delft. 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.

The way thinness is read as a sign of HIV/AIDS is shown in other studies conducted by Magazi (in Mbekweni) and by Matoti-Mvalo (in Site B of Kahyelitsha, a township with a very similar profile to those studied in this study). (10,16) Matoti-Mvalo highlights that respondents were conscious about a thin body as signaling the presence of HIV/AIDS to the point that those who understood obesity was a risk factor for non-communicable diseases, would rather be overweight and obese than lose weight to improve their health because their communities may suspect that they have HIV/AIDS (16). Magazi's anthropological study of TB patients shows that her informants began to move more freely around their community after two months of treatment, because they gradually put on weight. The benefits of putting on weight were twofold. First, it indicated recovery to good health, and second, it dispelled any suspicions of HIV/AIDS illness within the wider community. Like these studies, our data confirms that in all eight communities levels of perceived HIV stigma are extremely high and that weight loss arouses deep suspicion of HIV. It also hints at how complexly it affects TB treatment seeking behaviour. For example, the case of re-treatment patient Nora who had previously been cured from an episode of TB, shows how the urgency of seeking treatment from the clinic was lost because she didn't lose any weight. Nora told research assistants that she worried her TB had returned because she was coughing heavily and always felt cold. She explained that she went to the clinic and had to bring her sputum sample back the following day, but failed to do so because she did not want to return to the clinic 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 unsocial, and if they do display these 'symptoms', HIV/AIDS is often assumed. For example, the youth in Nyanga claimed 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/AIDS are

seen to evoke different emotional performances suggests that TB is understood as a more demonstrative disease than HIV/AIDS. 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]”
- Adult woman living in Delft, 27/06/05.*

Indeed, a strong negative correlation exists between positive community ideas about disease disclosure and the social stigma of disease across the research sites. Communities judge those who conceal a diagnosis of TB, explaining that if individuals ‘hide’ a disease¹⁵ and do not disclose their ‘status’ this is likely to make them suffer more than they need. In Nyanga, for example, youth thought that it was important for individuals to disclose disease ‘status’ because it would help them to heal. Those who ‘hide’ their disease were thought to die sooner because of the stress and pain of experiencing their illness in isolation. Similar positive views about disclosure were expressed in Mbekweni, Phillippi, Kayamandi and Harare. Respondents pointed out that if people did not reveal that they were sick with TB, they faced the added burden of community suspicion of HIV/AIDS because communities can easily identify the sick. For example, young men in Kayamandi suggested that people with TB invite stigma upon themselves because they develop symptoms that can easily be confused with HIV/AIDS – such as weight loss and coughing - and consequently tend to isolate themselves with others then judging them as HIV/AIDS patients. This type of judgment was confirmed by other respondents, such as an adult man from Mbekweni who said: “People who hide their illness are those who are suffering from *le TB enkulu* [the big TB i.e. HIV/AIDS].” This notion of disease disclosure as a positive step to take for TB patients is juxtaposed against TB and HIV stigma, suggesting that TB patients face a ‘catch 22’ situation in which both disclosing and not disclosing their disease ‘status’ 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/TB patients and some respondents blamed individuals for their disease:

¹⁵ Talk of disclosure mostly referred to HIV/AIDS, and to a lesser extent TB.

“People with AIDS deserve it because they are whores”

- Adult woman living in Delft, 21/06/05.

“TB is a person’s own fault because they live in dirt, don’t dress properly and drink too much”. Salon Owner in Kayamandi, 22/07/05.

Residents of Wallacedene were hesitant to talk to research assistants about TB and HIV/AIDS at all. HIV/AIDS was largely seen as a taboo subject associated with promiscuity and abandonment and respondents were reluctant to talk about TB, fearing that others might humiliate and isolate them assuming that they are sick with HIV/AIDS. Those who did speak, said that people with TB hide their disease in fear of being stigmatized. Respondents explained that the sick are not cared for even when they cannot wash themselves as potential carers fear contracting disease.

An HIV positive daughter in Delft explained how after disclosing her status to her mother, the latter accused the former of bringing the name of the family down. She was also ostracized by her community. Parents did not want her to play with their children. A similar theme emerged in Mbekweni where an elderly woman suggested that stigma surrounding HIV/AIDS is perpetuated by parents who do not want friends, relatives or other neighbours to see their children when they are sick. Another woman in Mbekweni explained how her friends abandoned her when they found out she had TB and many said that TB patients faced isolation, a loss of popularity and/or ridicule. In many sites there was evidence of name-calling TB and HIV patients. In Delft, particularly derogatory terms such as ‘vuil teef’ (dirty bitch) were being used to name TB patients.

Expressions of stigma appeared to be linked to disease knowledge in some instances. In Harare, for example, the youth showed a good understanding of the etiology of TB and 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. This type of reasoning was also evident amongst the youth of Delft who

distanced themselves from friends with TB because they feared they may contract it. In many instances the sharing of utensils, cigarettes and drinks were understood as a common way to contract TB and consequently TB patients were made to use separate utensils, smoke a shared cigarette last and drink a shared drink last. In Wallacedene respondents suggested that nobody shares at all with a TB patient.

3) The navigation of HIV suspicion

Avoiding Clinics

A noteworthy number of respondents thought that they probably had TB but did not want to attend their local clinic. Many explained that they only seek care when they are “really sick” as others may insult them or blame them for spreading disease and this makes one suffer more. Across all of the research communities, locals explained how reluctance to test for TB at local clinics resulted from a fear of broken confidentiality. Attending the local clinic was simply viewed as too risky because the community could easily identify a patient and judge him/her as an HIV/AIDS patient. Similarly, respondents also feared attending a community-based DOT supporter (lay health workers used to supervise TB treatment). Confidentiality of patients at clinics was said to be compromised by long waiting times, separated waiting areas, doors that are left open in consultation rooms and a colour coded card system used by clinics. Communities identified TB patients as those with a green card, HIV positive patients as those with a red/pink card. In Site C many didn't want to go to the clinic because it was too near a busy taxi rank and the chance of being identified while attending the clinic was too big. Patients waiting at the clinic avoided certain benches that they said indicated an HIV positive status to others. In Mbekweni, locals complained of a single door that is used for both HIV/AIDS and TB patients, commenting that if you go to the clinic for TB treatment, others might easily conclude that you have HIV/AIDS.

Turning to alternative treatment providers

Fear of being indentified by their community and dissatisfaction with local clinic services not only made people delay seeking treatment from their local clinics, but were also common factors driving people experiencing TB symptoms to turn to alternative treatment providers. Some said that they attended clinics in other communities to

escape the gaze of their local community, but that a general lack of sympathy (from nurses), patient neglect and long waiting times of up to six hours did not help motivate them to return back to the clinic. Some respondents also had a lack of faith in sputum diagnosis, saying that it wasn't reliable and therefore not worthwhile. They thought chest x-rays are more conclusive. Most locals claimed that they would turn to a private doctor first if they could afford it as this was more likely to maintain patient confidentiality. Others preferred to turn to traditional healers, faith healing¹⁶ or herbalists as a way of either avoiding HIV suspicion or supplementing allopathic treatment.

Data suggest that 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*, thereby offering an alternative diagnosis to HIV or TB. Although research assistants learned of traditional healers operating across all of the research communities, many respondents felt that traditional healers were not used that widely for treating TB, with the youth in particular often rejecting bewitchment theories as a 'pack of lies'. Respondents who did use traditional healers often seem to do so pluralistically, ending up having their TB treated by the local clinic. Discussions with traditional healers along transect walks show that they themselves explained how patients are mostly referred directly to local clinics if they are displaying symptoms of TB.

Faith healing has previously been identified as a treatment option in Mbekweni (10) and data showed evidence of this in most communities. Some respondents thought that faith healing was only used as a last resort for the sick in their community. Patients who had been diagnosed with HIV and/or TB are said to take their treatment cards to their church where they would then undergo a process of healing in conjunction with allopathic treatment. In Site C a man who was undergoing faith healing said that people like him were put off the local clinic by the uncaring attitude of staff and the emphasis placed on HIV and TB. He felt that clinics failed to treat their patients holistically: "If they found you are TB negative they say you are fine though you still suffer from pains" 2/09/05. He was happier receiving health care from his church, which he believed was able to address a range of problems somebody might be suffering from such as stiff joints, sterility and stomach pains.

¹⁶ This often involves a process of praying, purging and cleansing with holy water at a church.

Discussion

Associations of TB with filth and the resultant stigmatization of TB as a 'dirty' disease within other endemic parts of South Africa has been previously well evidenced (6, 7 & 17). How this affects TB control is less clear, although some advocate that correcting misconceptions through educational interventions may help reduce the stigmatisation of TB and therefore improve the chances of voluntary presentation at local health services. In this study, however, the association of TB with pollution does not fit comfortably with the idea that there is simply a gap in disease knowledge that needs filling in order to reduce stigma and encourage voluntary presentation across the research sites. I argue that in light of relatively good understandings of the symptoms of TB and its social determinants, it is more relevant to understand the strong association of TB with pollution as an expression of marginalization.

Respondents correctly connected overcrowding, poverty and malnutrition to TB. Most also understood that TB is an airborne disease as well as the concept of increased host susceptibility to disease – 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. Moreover, communities consistently described how TB, like the waste that is symptomatic of their marginalization, is 'all around'. As one respondent from Wallacedene put it, "TB is made here". The association of TB with pollution therefore seems most relevant in terms of how it echoes the everydayness of TB, rather than a lack of understanding about the disease. How TB, like the polluted environment of the high burden communities, is viewed as commonplace and out of an individual's control as a result of communal vulnerability. This is not to say that individual patients are not blamed for TB and stigmatised as 'dirty', but implies that the urgency of seeking health care or a TB diagnosis may be more diluted by the popular understanding that TB is part and parcel of everyday living within the poverty-stricken townships, than by a lack of medical knowledge. A similar observation is put forward by a recent qualitative study of patient adherence to TB treatment 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 study describes 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. The authors argue that when external factors that are out of individual's control are ascribed to causing illness, an individual is less likely to be self-motivated to treat their illness. (18) Moreover, it has been shown that the perception of TB as a common disease can be directly associated with treatment delay (19).

The inconsistency between policy reliance on the self-motivation of individuals to present at health facilities and community perception that TB is as commonplace as dirt and out of individual control, highlights how urgently the vulnerability and susceptibility of communities to disease needs to be addressed. Beyond reflecting how overwhelmed the communities are by TB, it also emphasises the need for community-based interventions that can locally awaken a sense of self-determination and urgency to access TB treatment early. This could be done directly: Through emphasis on how early treatment improves outcome and curbs ongoing transmission within the community. It could also be done more indirectly: Through broader interventions which may help communities to feel less marginalised, thereby encouraging them to be more actively involved in tackling TB - not simply accepting TB as part of their 'lot'. These broader interventions could involve measures such as community organised waste collection and improving levels of service delivery for example.

While the interpretation of TB as a 'dirty' disease may be implicitly contributing to treatment delay, data suggests that 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 by this study, findings show that perceived levels of HIV-TB stigma are very high across all eight of the research sites and that community perceptions are very influential. This means that although our findings strongly suggest that individuals may be trying to escape HIV suspicion by delaying diagnosis or seeking alternative treatment options, further research is needed to validate this as the effect of anticipated stigma on TB treatment delay in the context of HIV/AIDS is not well understood (20).

As highlighted earlier, qualitative studies argue that HIV-TB stigma contributes to treatment delay and that this is significant for TB control, but other studies have doubted

this (20, 21). A good illustration is provided by research from Thailand, where a quantitative study that tried to measure stigma has conflicted with the assertion made by a qualitative study that HIV stigma is contributing to TB treatment delay (14, 20). I argue that there are, however, a number of major and relevant limitations to the quantitative study. Unlike in my analysis, stigma was assessed only after patients presented at the TB clinic. As the authors point out, the levels of stigma recorded may not accurately capture the level of stigma near the time of symptom onset if stigma changes over time. The study also divided disease stigma dualistically into TB and HIV stigma when questioning respondents. This study confirms that TB and HIV stigma have become intertwined within popular discourse, showing that this needs to be accommodated by any kind of questionnaire in settings where the TB and HIV epidemic is concomitant. In light of the amount of qualitative work suggesting HIV-TB stigma is a driver of treatment delay, further ethnographic work is needed to establish conclusively the links made in this study between HIV-TB stigma and actual patient health seeking behaviour.

Data from my analysis does conclusively show, however, that all eight communities doubt their own social support of TB patients because of the association between TB and HIV. Therefore, as advocated by Bond and Nyblade (12), any community-based interventions aimed at enhancing current control efforts need to address TB's social as well as biological entanglement with HIV/AIDS. I also argue that in light of our study's participatory approach and calls for more bottom-up research, my observation that communities themselves describe how anticipated stigma contributes to diagnostic delay suggests that anticipated stigma needs urgent attention, regardless of the fact that actual individual treatment seeking behaviour has not been studied. According to what communities had to say, reducing levels of perceived HIV-related stigma may have a significant ripple effect on encouraging voluntary presentation and this should be heard by policy makers. Like Skordis, Hanson and Mills, this study also recommends that interventions aimed at improving perceptions of both service quality and levels of privacy at clinics are likely to reduce diagnostic delay (22).

It should be noted that while other studies have highlighted provider delay as a significant contributor to diagnostic delay (22, 23), this has not been the focus of this study. The BBS methodology has consequently brought the delay of voluntary

presentation to the fore. Factors contributing to diagnostic delay are potentially numerous and likely to vary considerably in relative importance between different populations and their settings (24). While results cannot be widely generalized, striking similarities in popular perception were evident across the eight research sites, which could help to guide planning of specific public health interventions.

Conclusion

TB control initiatives need to be sensitive to the stigmatisation of TB at the community level. TB is stigmatized as both a dirty and a HIV-related disease, which appears highly relevant in light of reliance on voluntary TB suspect presentation. The fear of HIV-related stigma is particularly worrying, since it is likely to prolong diagnostic delay and facilitate ongoing transmission in these hyperendemic settings. The association of TB with dirt is also worrying because it seems to suggest that communities implicitly understand the control of TB to be outside of the individual's remit, which may have a disempowering effect that negates the urgency of disease prevention and cure.

References

1. Marais BJ, Raviglione MC, Donald PR *et al.* Scale-up of services and research priorities for diagnosis, management and control of tuberculosis – Call to action. *Lancet* 2010; 375: 2179-91.
2. Lonnroth K, Castro KG, Chakaya JM *et al.* Tuberculosis control and elimination 2010-50: cure, care and social development. *Lancet* 2010; 375: 1814-1829.
3. Ayles H, Schaap A, Nota A, Sismanidis C, Tembwe R, De Haas P, Muyoyeta M, Beyers N, Godfrey-Faussett P for the ZAMSTAR Study Team. Prevalence of Tuberculosis, HIV and Respiratory Symptoms in Two Zambian Communities: Implications for Tuberculosis Control in the Era of HIV. *PLoS One* 2009, 4: e5602. doi:10.1371/journal.pone.0005602.
4. Wood R, Middelkoop K, Myer L, Grant AD, Whitelaw A, Lawn SD, Kaplan G, Huebner R, McIntyre J, Bekker L-G. Undiagnosed Tuberculosis in a Community with High HIV Prevalence: Implications for Tuberculosis Control. *Am J Respir Crit Care Med* 2007, 175: 87-93.
5. Storla DG, Yimer S, Bjune GA. A systematic review of delay in the diagnosis and treatment of tuberculosis. *BMC Public Health* 2008; 8: doi 10.1186/1471-2458-8-15.
6. Westaway MS, Womarans L. Cognitive and affective reactions of black urban South Africans towards tuberculosis. *Tubercle Lung Dis* 1994; 75: 447-453.
7. Edginton ME, Sekatane CS, Goldstein SJ. Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. *Int J Tuberc Lung Dis* 2002; 6:1075-82.

8. Promtussananon S, Peltzer K. Perceptions of Tuberculosis: Attributions of Cause, Suggested Means of Risk Reduction, and Preferred Treatment in the Limpopo Province, South Africa. *J Health Popul Nutr* 2005 Mar; 23(1):74-81.
9. Metcalf CA, Bradshaw D, Stindt WW. Knowledge and beliefs about tuberculosis among non-working women in Ravensmead, Cape Town. *S Afr Med J* 1990; 77: 408-11.
10. Magazi B. 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, 2008.
11. Mavhu W, Dauya E, Bandason T, Munyati S, Cowan FM, Hart G, Corbett EL, Chikovore J. Chronic cough and its association with TB-HIV co-infection: factors affecting help-seeking behaviour in Harare, Zimbabwe. *Trop Med Int Health* 2010; 15: 574-79.
12. Bond V, Nyblade L. The Importance of Addressing the Unfolding TB-HIV Stigma in High HIV Prevalence Settings. *J Comm & App Soc Psych* 2006; 16: 452-461.
13. Sengupta S, Pungrassami P, Balthip Q, Strauss R, Kasetjaroen Y, Chongsuvivatwong V, Van Rie A. Social Impact of tuberculosis in southern Thailand: Views from patients, care providers and the community. *Int J Tuberc Lung Dis* 2006; 10: 1008-1012.
14. Ngamvithayapong J, Winkvist A, Diwan V. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS* 2000; 14: 1413-9.
15. Ngamvithayapong– Yanai J, Ishikawa N. The role of social science research in reducing the burden of tuberculosis in high HIV-prevalence settings. *Trop Med Int Health* 2006; 34: 7-13.
16. Matoti-Mvalo T. 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, 2006.
17. Westaway MS. Knowledge, beliefs and feelings about tuberculosis. *Health Educ Research* 1989; 4:205-
18. Naidoo P, Dick J, Cooper D. Exploring Tuberculosis Patients' Adherence to Treatment Regimens and Prevention Programs at a Public Health Site. *Qual Health Research* 2009; 19: 55-70.
19. Ford CM, Bayer AM, Gilman RH, Onifade D, Acosta C, Cabrera L, Vidal C, Evans CA. Factors associated with delayed tuberculosis test-seeking behaviour in the Peruvian Amazon. *Am J Trop Med Hyg* 2009; 81:1097-102.
20. Pungrassami P, Kipp AM, Stewart PW, Chongsuvivatwong, Strauss RP, Van Rie A. Tuberculosis and AIDS stigma among patients who delay seeking care for TB symptoms. *Int J Tuberc Lung Dis* 2010; 14: 181-7
21. Godfrey-Faussett P, Kuanda H, Kamanga J, van Beers S, van Cleeff M, Kumwenda-Phiri R, Tihont V. Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *Int J Tuberc Lung Dis* 2002; 6:796-805.
22. Skordis Worrall J, Hanson K, Mills A. Confusion, caring and tuberculosis diagnostic delay in Cape Town, South Africa. *Int J Tuberc Lung Dis* 2010; 14: 171-80.
23. Meintjies G, Schoeman H, Morroni C, Wilson D, Maartens G. Patient and provider delay in tuberculosis suspects from communities with a high HIV prevalence in South Africa: a cross-sectional study. *BMC Infect Dis* 2008; 8:72. doi:10.1186/1471-2334-8-72.
24. Pronyk PM, Makhubele MB, Hargreaves JR, Tollman SM, Hausler HP. Assessing health seeking behaviour among tuberculosis patients in rural South Africa. *Int J Tuberc Lung Dis* 2001; 5: 619-27.

CHAPTER FIVE

A Multidisciplinary Method to Map Potential TB Transmission ‘hot spots’ in High Burden Communities

South Africa has one of the highest tuberculosis (TB) incidence rates in the world despite formally adopting the directly observed therapy short course (DOTS) strategy in 1996 (1). In the poverty stricken townships of Cape Town, high rates of drug resistance among children with TB suggest that the problem is deepening (2, 3). A key factor sustaining the TB epidemic in such settings is our inability to break an ongoing transmission cycle; high infection pressure is reflected by high annual rates of infection (calculated at 3.8% in one township community of Cape Town¹⁷) and high rates of re-infection disease among adults (4-6).

Molecular strain typing methods show that a significant part of the disease burden in TB endemic areas results from re-infection events (4-6). Importantly, these methods highlight that infection/re-infection frequently occurs outside of the household (7, 8). Verver *et al.* (8) demonstrated that the majority of transmission among adults occurs as a result of extensive social mixing, cautioning that active case finding among household members is likely to have limited effect in high burden communities. Researchers have also documented the impact of community environmental factors on TB transmission; in particular how poverty, crowding and poor ventilation encourage transmission (9, 10). Further, multidisciplinary initiatives have been successful in emphasising the significance of local surroundings. For example, a study conducted in Texas combined biology, epidemiology and network analysis to demonstrate that public places rather than individual people are key to understanding TB transmission (11); and combinations of spatial and molecular analyses have identified TB transmission patterns which show a geographical clustering of TB cases that stretches beyond individual households (12, 13).

Although social mixing and local environment have been identified as significant factors fuelling the TB epidemic, traditional TB control efforts focus almost exclusively on the individual patient. This paper introduces a novel multidisciplinary method that integrates

¹⁷ Personal communication with Professor Nulda Beyers, Director of the Desmond Tutu TB Centre of Stellenbosch University.

qualitative participatory techniques, basic TB transmission principles and geographic information systems (GIS) technology to identify, grade and map potential TB transmission 'hot spots' across a community. Within the social sciences, qualitative participatory techniques have been developed to capture information about social systems in rapid and effective ways (14). GIS technology is able to crystallise locally specific information in a visual format, accommodating the communication of spatial information about disease (15, 16). A combination of the two - rapid qualitative appraisal techniques and GIS technology – provides an efficient multidisciplinary method to improve our understanding of potential TB transmission across high burden communities in a locally sensitive way, moving beyond the boundaries of individual cases to include public spaces. Developed further, the simplification of this method may enhance TB control efforts.

Methods

Study setting

In 2005 and 2006, qualitative data were collected from 24 sub-Saharan African sites as part of a baseline study for a cluster randomised trial. The trial aims to evaluate the efficacy of different public health interventions to reduce TB prevalence and the baseline data collected was fed into the randomization process of the trial (17). The data compares social characteristics of the research sites and in many of the sites the use of public gathering places was emphasised. We draw on the qualitative data and map gathering places in one of the sites: a township community located in Cape Town, South Africa. This specific community was selected because of the availability of GIS data and the particularly high burden of ongoing TB transmission (TB incidence >600/100 000 population/annum). Fieldwork preceded the trial's interventions, ensuring that potential interference with the data collected was excluded.

Study design

The collection of qualitative data commenced with a meeting of a local Community Advisory Board (CAB). Community representatives were asked to list places where people gather in groups and then to direct research assistants on a walk transecting the community in a way that would provide as much of a representation of the community as

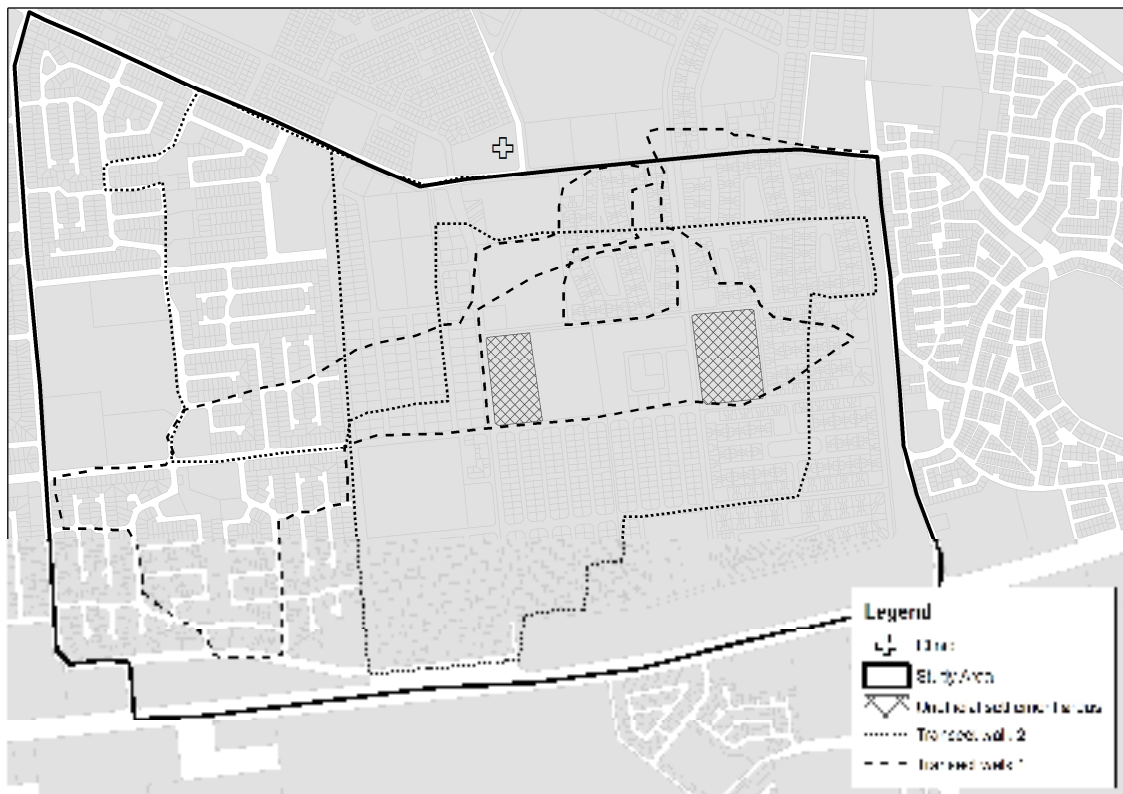
possible. The transect walks¹⁸ (see Figure 1) were conducted over a two day period, after the meeting, to produce a rough qualitative description of the community and its gathering places. During the walks, an observation checklist (see Table 5.1) was filled in at each gathering place identified along the transect walks. The latter briefly described the structure of the building and qualitatively assessed the level of crowding, the type of activities taking place and the profile of the people there. Numbers of people, gender and age were not ‘measured’ in absolute terms, rather they were visually assessed partly on a comparative basis – for example: one place was ‘more’ or ‘less’ crowded than another; ‘busier’ or ‘quieter’ than another; was ‘mostly’ full of men. These data were supplemented with photographs and informal open-ended conversations held with locals along the transect walks. Conversations and observational data were recorded using activity reports, which were constructed from field notes (18).

TABLE 5.1:
Observation checklist.

Date:	Description of Gathering Place:
Time:	
GPS co-ordinate:	<ul style="list-style-type: none"> • Structure New/Old Permanent/ Temporary Large / small (estimate in metres) Well ventilated/ not well ventilated / open air
Name of gathering place:	
Type of gathering Place: e.g. <ul style="list-style-type: none"> • Health facility • Recreational space – library, sports venue, disco, community hall, video club etc. • Place of worship • Liquor outlet – liquor store, nightclub, shebeen, tavern, bar, hotel etc. • Commercial premise – market area, hair salon etc. • Station/stops - bus, minibus, taxi etc. • Non Governmental Organisation • School • Crèche • Residential housing • Boundary landmark • Police station • Other 	<ul style="list-style-type: none"> • Building materials Brick, concrete, grass, mud, plastic, makeshift, other <ul style="list-style-type: none"> • Crowding Busy/Quiet Cramped/ Spacious <ul style="list-style-type: none"> • People Activities taking place (drinking, football, card playing, singing etc.) Estimate number of men / women / children Estimate average age of children / youth/ adults/ elderly present <p>Include any other significant features</p>

¹⁸ Transect walks are a participatory method which allows research assistants to speak to locals and observe the community. See Chambers R & Mayoux L. Reversing the Paradigm: Quantification and Participatory Methods. Submitted to the EDIAIS conference on New Directions in Impact Assessment for Development: Methods and Practice. University of Manchester, UK: November 2003. Access to paper (online): <http://www.iapad.org/publications/ppgis/Chambers-Mayoux.pdf> (20 January 2009)

Figure 5.1:
Map of transect walks.



Following the transect walks, research assistants observed key gathering places during different times of the day for two to three hour periods. During these observations, daily time charts were completed with differing groups of women, men and youth. This qualitative component of fieldwork provided coarse ethnographic descriptions of who gathered where, for what reason and for how long. All fieldwork was conducted prior to the initiation of trial interventions.

To guide an objective ranking of the TB transmission risk posed by different social gathering places, we created a scorecard using well-established TB transmission principles (Table 5.2). The scorecard was designed around three significant factors related to transmission; 1) the likelihood of an infectious TB patient (source case) being present, 2) the risk of airborne transmission (intensity and duration of exposure) taking place and 3) the number of people exposed. We used age as a surrogate of the likelihood that an infectious source case may be present. Owing to the fact that in this

community the age category 25-54 years is most severely affected by highly infectious cavitary TB, a multiplier of 2 was applied to gathering places where people from this age-group were likely to congregate. Children <8 years of age tend to have paucibacillary TB and rarely transmit the organism (19), which explains why 0 was used as the multiplier in settings where young children tend to congregate. The presence of an infectious adult, such as an adult teacher with smear positive TB, poses a serious transmission risk in these settings because young children are particularly susceptible to TB infection. To account for the vulnerability of young children we increased the multiplier in places where young children and adults congregate.

The risk of airborne transmission is mainly determined by the following variables: effective aerolisation of the organism i.e. from coughing and/or singing; the size of the airspace and/or proximity to the source case; the frequency of air exchange (ventilation); exposure to UV light and the length of time spent in the environment. The observation checklists were used in conjunction with ethnographic descriptions to assign a relative transmission risk score to each public gathering place identified, ranging from 0 (negligible) to 11 (high). The score was then adjusted according to the age of persons likely to gather in that type of gathering place, providing a final score that ranged between 0 (negligible) and 22 (high). Gathering places were then plotted on a GIS map and results from the scoring process were attributed to the gathering places on the map. This demonstrates the geographic distribution of gathering places and the transmission risk assigned to each.

Table 5.2:
Scorecard used to grade TB transmission risk

VARIABLES	SCORE
A) SIZE of AIRSPACE	
> 4x4x2m	0
< 4x4x2m	1
B) VENTILATION	
Completely Open	0
Open windows/doors	1
Closed windows/doors	2
C) UV LIGHT	
Open air/daytime	0
Night time/shielded from light	1
D) SINGING	
No	0
Yes	1
E) DURATION of EXPOSURE	
< 2hrs/ week	0
2 hrs/ week	1
4-10hrs/ week	2
> 10 hrs/week	3
F) NUMBER/DENSITY of PEOPLE	
Few people (<10)	0
Moderate number of people (10-30)	1
Many people (>30) / loosely packed	2
Many people (>30)/ tightly packed	3
G) AGE of PEOPLE (multiplier)	
<8yrs	0
8-19yrs	1
20-49yrs	2
>50yrs	1

Fieldnotes from the transect walks explained how unofficial settlement¹⁹ areas, that have no municipal services, form pockets within the larger community. These are particularly poor and over-crowded areas, within which boundaries between public and private spaces are extremely blurred; people live and socialise in cramped makeshift structures that are very poorly ventilated. Owing to the high concentration of people, confined spaces, and amount of ongoing social mixing found, an increased transmission risk for these areas (relative to the wider community area) is implied.

Feedback from this fieldwork has already been delivered to research communities via local advisory committees in the form of a flyer with written text and graphics. Confidentiality of participants has been ensured and actual site and place names have

¹⁹ Referred to by locals as 'informal' settlements.

been avoided. This study was approved by the Ethics Review Board of Stellenbosch University.

Results

The following were identified as public gathering places in the community: Unlicensed drinking places (locally known as *shebeens*), pre-schools (crèches), clinics, churches²⁰, community halls, schools, waterpoints, markets, container shops, welfare grant payout points, libraries, game shops/jukeboxes (places where youth gather to listen to music and play video-games), *braais* (areas where meat is barbequed), supermarkets, sports grounds, cash stores, hair salons, taxi ranks, public libraries, Non Governmental Organisations (NGOs), old age homes, industrial work areas and hostels (previously compounds used to house miners, now derelict buildings providing over crowded shelter and business space).

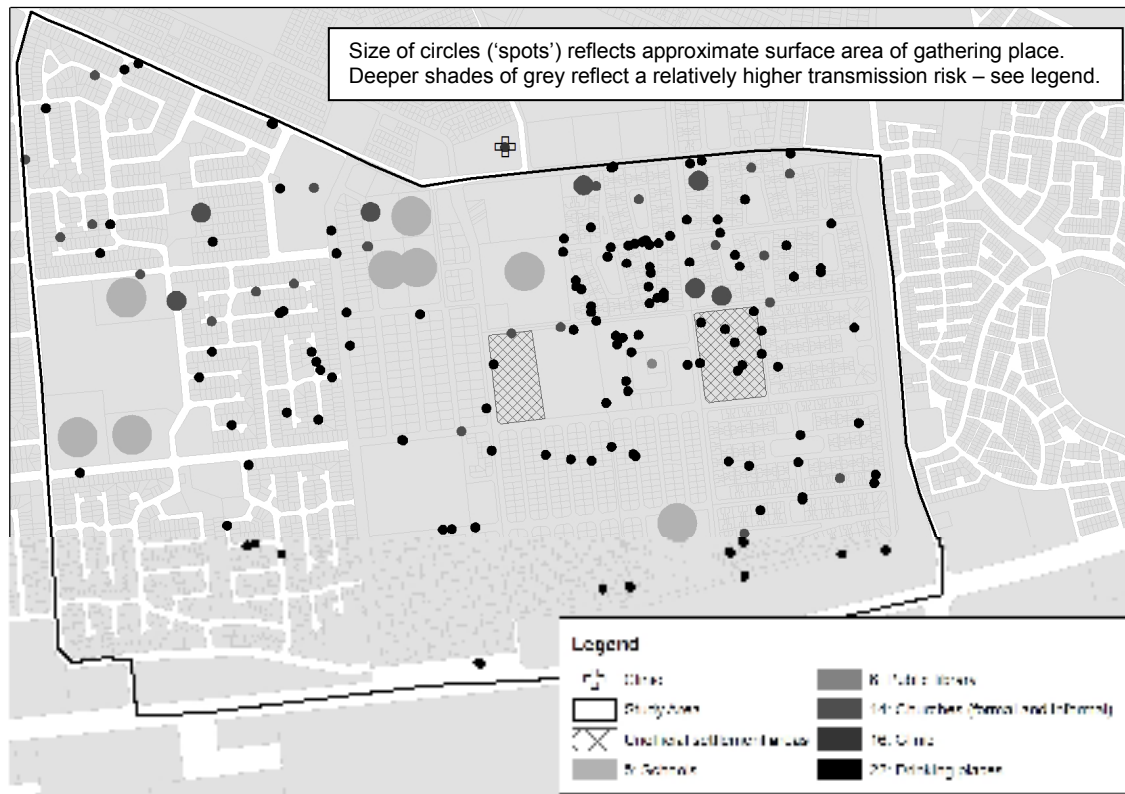
TB 'transmission risk' scores calculated for the different types of gathering places, guided by the scorecard shown in Table 5.2, are reflected in Table 5.3 (see below). The scores assigned to gathering places before reaching the cumulative 'transmission risk' score reflect a relative value (rather than an absolute value) for the average gathering place of this description i.e. we can conclude that, in general, *shebeens* have less ventilation than hair salons. For gathering places with insufficient data to assign scores, TB transmission risk was not calculated. *Shebeens*, with a score of 22, emerged as places that potentially pose the highest transmission risk. Clinics and churches were also identified as gathering places that potentially pose a high TB transmission risk. Figure 5.2 visually presents the geographic distribution of gathering places and their relative 'transmission risk'. Unofficial settlement areas need to be noted as 'high risk' areas, but cannot be compared to the public gathering places identified due to the blur between public and private space found there - they are not public gathering places as such. Instead of assigning a transmission score to these areas, we have demarcated them on the map and acknowledge that they potentially compound the transmission risk associated with *shebeens* and other 'high risk' places of social mixing that overlap or are in close proximity to the unofficial settlement area.

²⁰ Refers to Churches which gather in private homes and in public structures.

Table 5.3:
Transmission risk score for congregate setting

Public gathering places identified	A	B	C	D	E	F	Total score (A+B+C+D+E)	x G	Calculated transmission risk
Drinking Places (incl. <i>shebeens</i>)	1	2	1	1	3	3	11	2	22
Clinics	0	2	1	0	2	3	8	2	16
'Home' Churches (held in private homes)	1	1	1	1	2	1	7	2	14
Churches	0	1	1	1	1	3	7	2	14
Community Halls	0	1	1	1	1	2	6	2	12
Container Shops [†]	1	1	1	0	1	2	6	2	12
Supermarkets [†]	0	2	1	0	1	2	6	2	12
Cash Stores [†]	0	1	1	0	2	2	6	2	12
Hair Salons [†]	1	1	1	0	0	2	5	2	10
Braai Areas [†]	0	0	0	0	2	2	4	2	8
Taxi Ranks [#]	0	0	0	0	1	3	4	2	8
Public Libraries	0	1	1	0	1	0	3	2	6
Schools	0	1	0	0	2	2	5	1	5
Pre-schools (chreches) [†]	0	2	0	1	3	0	6	2	12
NGOs*									
Sports Grounds*									
Old Age Homes*									
Industrial Work Areas*									
Game Shops*									
Grant Payout Points*									
Hostels*									

Figure 5.2:
Map showing the potential transmission risk posed by different congregate settings.



Discussion

It is well recognized that the TB epidemic persists in geographically distinct poverty-stricken pockets of society (13, 20) and the importance of public health strategies that respond to both physical and social environments has been emphasised (21). Yet, it remains difficult to tackle TB in an effective and locally sensitive way; multidisciplinary approaches are often said to be hampered by poor cross-discipline communication or appear overwhelming in complexity (22, 23). The method we present demonstrates the potential value and efficiency of a multidisciplinary approach to TB transmission. Combining rapid social appraisal techniques with basic infectious disease principles and GIS technology can not only provide an avenue to improve our understanding of TB transmission, but also an environmentally and socially informed platform to guide public health intervention.

The significance of public gathering places in facilitating the transmission of TB has been documented in other studies (11) and our findings are consistent with evidence from molecular epidemiology studies conducted in Cape Town's township areas. Drinking places have previously been shown to pose a high TB transmission risk (24, 25) and Classen *et al.* (26) used DNA fingerprinting techniques in conjunction with in-depth interviews to document the high transmission risk posed by *shebeens*. Our findings allow accurate spatial mapping of multiple gathering places as potential transmission "hot spots" within the community; they also allow for comparison between various public gathering places, suggesting that *shebeens*, clinics and churches pose a higher transmission risk than public libraries, schools, *braais* and taxi ranks in this research area. It is acknowledged that the current application of potential transmission 'hotspots' remains theoretical, reflecting the possible risk of infection instead of measuring actual infection. However, it utilizes universally accepted transmission principles which, in the absence of tools to accurately measure infection (both primary and re-infection) in TB endemic areas, represent a surrogate. Superimposing transmission data that displays strain types on the current GIS map would show whether those frequenting the same gathering places share the same strains of TB. This might be highly informative if the data become available. Application of a similar refined mapping methodology may help other high burden areas identify high risk transmission 'hot spots'.

To refine our mapping method, certain components of the data collection tool would need to be more appropriately designed. The observation checklist would have been more effective if completed after the TB transmission scorecard variables had been determined. This would have narrowed the focus of the qualitative data collected on the transect walks and ensured that all the relevant data were collected. GIS data for certain types of gathering places were also lacking, preventing them from being mapped accurately.

Although studies in other settings have documented the high transmission risk posed by work environments (27), previous research in the Cape Town area suggests that recreational contact within the community is probably the most important contributor to ongoing transmission (26). Gross unemployment, a large unregulated economy and the volatility of short-term contract work (often situated outside the research site) make it

difficult to unravel how places of employment may contribute to TB transmission. This emphasises that while fieldwork conducted in a “snap shot” fashion may be the most efficient method for gathering large amounts of relevant data about the social fabric of a community in a short period of time, it does not provide deep ethnographic accounts, which may be needed in order to comprehensively understand certain social factors (such as unemployment or employment) linked to gathering places (28). Moreover, other important risk factors for TB exposure and infection linked to social interaction, such as internal mobility, may be significant for TB control (29).

In practice, TB control strategies have primarily focused on case-finding i.e. on the individual patient. Our research responds to many arguments that multidisciplinary efforts are needed to evaluate and curb disease contributing factors operating beyond the control of the individual patient (20, 30, 31, 32, 33). The scoring of transmission ‘hotspots’ suggests that substituting ‘case-finding’ with ‘place-finding’ - previously proposed by Klovdahl *et al.* (11) - deserves urgent consideration in high burden endemic areas where social mixing plays a significant role in the transmission of TB. As an adjunctive strategy, ‘place-finding’ would enhance applied research; it need not neglect the importance of diagnosing and treating individual ‘cases’ while assessing a disease prone environment. Moreover, the locally nuanced ‘snapshot’ of public gathering places that the transect walks and scoring provides, can rapidly inform both research and interventions.

Conclusion

At a time when the HIV epidemic is rampant and primary transmission of extensively drug-resistant (XDR) TB is increasing, innovative responses to the tuberculosis epidemic are a matter of urgency (34, 35). This study shows how a combination of qualitative techniques and GIS technology can deliver a valuable assessment of potential TB transmission dynamics within a community. These techniques, if further refined and validated, may also offer powerful tools to direct targeted public health interventions.

References

1. World Health Organisation. Global Tuberculosis Control: WHO Report 2007. Published online: http://www.who.int/GlobalAtlas/predefinedReports/TB/PDF_Files/zaf.pdf. Accessed July 2007.
2. Schaaf HS, Marais BJ, Hesselning AC, Gie RP, Beyers N, Donald PR. Childhood drug-resistant tuberculosis in the Western Cape Province of South Africa. *Acta Paeds* 2006; 95: 523-8.
3. Marais BJ, Victor T, Hesselning AC *et al.* Beijing and Haarlem genotype families are over-represented among children with drug resistant tuberculosis in the Western Cape, South Africa. *J Clin Microbio* 2006; 44: 3539-43.
4. Van Rie A, Warren R, Richardson M *et al.* Exogenous reinfection as a cause of recurrent tuberculosis after curative treatment. *N Engl J Med* 1999; 341: 1174-9.
5. Verver S, Warren RM, Beyers N *et al.* Rate of reinfection tuberculosis after successful treatment is higher than rate of new tuberculosis. *Am J Respir Crit Care Med* 2005; 171:1430–5.
6. Den Boon S, van Lill SWP, Borgdorff MW *et al.* High prevalence of tuberculosis in previously treated patients, Cape Town, South Africa. *Emerg Infect Dis* 2007; 13: 1189-94.
7. Schaaf HS, Michaelis IA, Richardson M *et al.* Adult-to-child transmission of tuberculosis: household or community contact? *Int J of Tuberc Lung Dis* 2003; 7: 426-31.
8. Verver S, Warren R, Munch Z *et al.* 2004. Proportion of tuberculosis transmission that takes place in households in a high-incidence area. *Lancet* 2004; 363: 212-214 S.
9. Wanyeki I, Olson S, Brassard P *et al.* Dwellings, crowding, and tuberculosis in Montreal. *Soc Sci & Med* 2006; 63: 501-11.
10. Marais BJ, Obihara CC, Warren RM, Schaaf HS, Gie RP, Donald PR. The Burden of Childhood Tuberculosis: A public Health Perspective. *Int J Tuberc Lung Dis* 2005; 9: 1-9.
11. Klovdahl AS, Graviss EA, Yaganehdooost A *et al.* Networks and tuberculosis: an undetected community outbreak involving public places. *Soc Sci & Med* 2001; 52: 681-94.
12. Haase I, Olson S, Behr MA *et al.* Use of geographic and genotyping tools to characterise tuberculosis transmission in Montreal. *Int J Tuberc Lung Dis* 2007; 11: 632-8.
13. Moonan PK, Bayona M, Quitugua TN *et al.* Using GIS Technology to Identify areas of tuberculosis transmission and incidence. *Int J Health Geographics* 2004; 3:23.
14. Wallman S. *Kampala Women Getting By: Wellbeing in the time of AIDS*. London, UK: James Currey, 1996.
15. Maguire DJ, Goodchild MF and Rhind D eds. *Geographical Information Systems: Principles and Application*. New York: John Wiley & Sons, 1995.
16. Beyers N, Gie RP, Zietsman HL *et al.* The use of a geographical information system (GIS) to evaluate the distribution of tuberculosis in a high-incidence community. *S Afr Med J* 1996; 86: 40-1.
17. Sismanidis C, Moulton LH, Ayles H *et al.* Restricted Randomization of ZAMSTAR: a 2 x 2 factorial cluster randomized trial, *Clinical Trials* 2008; 5: 316-327.
18. Denzin NK and Lincoln YS eds. *Collecting and Interpreting Qualitative Mateials*. Thousand Oaks, CA, USA: University of Chicago Press, 1998.
19. Gie RP, Schaaf HS, Hesselning AC *et al.* The natural history of childhood intra-thoracic tuberculosis – A critical review of the pre-chemotherapy literature. *Int J Tuberc Lung Dis*. 2004; 8: 392-402.
20. Farmer P. Social Scientists and the New Tuberculosis. *Soc Sci & Med* 1997; 44: 347-358.

21. Porter JDH, Ogden J, Pronyk PM. The way forward: an integrated approach to tuberculosis control. In: Grange J, Porter JDH eds. *Tuberculosis: An Interdisciplinary Perspective*. London, UK: Imperial College Press, 1999: pp 359-378.
22. Farmer P. *Infections and Inequalities*. Berkley, Los Angeles & London, UK: University California Press, 1999.
23. Mann JM, Gruskin S, Grodkin MA, Annas GJ eds. *Health and Human Rights: A Reader*. New York: Routledge, 1999.
24. Kline SE, Hedemark LL, Davies SF. Outbreak of tuberculosis among regular patrons of a neighbourhood bar. *N Engl J Med* 1995; 333: 222-7.
25. Munch Z, Van Lill SWP, Booyesen CN, Zietsman HL, Enarson DA, Beyers N. Tuberculosis transmission patterns in a high-incidence area: a spatial analysis. *Int J Tuberc Lung Dis* 2003; 7: 271-7.
26. Classen CN, Warren R, Richardson M *et al*. Impact of social interactions in the community on the transmission of tuberculosis in a high incidence area. *Thorax* 1999; 54: 136-140.
27. Siegrist J, Marmot M. Health Inequalities and the psychosocial environment – two scientific challenges. *Soc Sci & Med* 2004; 58: 1463-1473.
28. Wallman, S. The Diversity of Diversity: Implications of the Form and Process of Localised 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. Access to paper (online): <http://www.feem.it/web/activ/wp.html> or http://papers.ssrn.com/abstract_id=XXXXXX. Accessed September 2008.
29. Enarson DA. Migrant tuberculosis: a moving target. *Int J Tuberc Lung Dis* 2006; 10: 945.
30. Ming-Jung Ho M.-J. Sociocultural aspects of tuberculosis: a literature review and a case study of immigrant tuberculosis. *Soc Sci & Med* 2004; 59: 753-762.
31. Hurtig AK, Porter JDH, Ogden JA. Tuberculosis control and directly observed therapy from a public health/human rights perspective. *Int J Tuberc Lung Dis* 1999; 3: 553-560.
32. Porter JDH, Ogden JA. Commentary on 'the resurgence of disease: social and historical perspectives on the 'new' tuberculosis. *Soc Sci & Med* 2002; 55: 397-8.
33. Leinhardt C, Ogden JA. Tuberculosis control in resource-poor countries: have we reached the limits of the universal paradigm. *Trop Med Int Health* 2004; 9: 833-841.
34. Gandhi NR, Moll A, Sturm AW *et al*. Extensively drug-resistant tuberculosis as a cause of death in patients co-infected with tuberculosis and HIV in a rural area of South Africa. *Lancet* 2006; 368: 1575-1580.
35. Van Rie A, Enarson D. XDR tuberculosis: an indicator of public-health negligence. *Lancet* 2006; 368: 1554-1556.

CHAPTER SIX

Concluding Comments and Recommendations

Proponents of complexity theory argue that what appears chaotic and unpredictable at one (usually lower) level may be relatively simple and stable at another (usually higher) level(1). This study has explored the community level, as opposed to the individual level, in order to elevate social factors from the contextual chaos of TB in South Africa that are particularly pertinent to improving the control of endemic tuberculosis in Cape Town. I will now turn to an epidemiological study of an urban township community similar in terms of disease burden, geography and socio-economic standing to those I have assessed - conducted by Bekker and Wood (2) – to demonstrate that the findings produced by my study seem highly relevant, are locally responsive and provide valuable pragmatic direction for future research and public health response.

Bekker and Wood emphasise that the driver of the TB and HIV co-epidemic is a high annual risk of *M. tuberculosis* infection in their study community, showing how a significant proportion of TB disease is attributable to recent infections. Their findings strongly link the high risk of infection to high levels of undetected disease coupled with intense social interaction. In conclusion, two recommendations are emphasised: (1) the need for active community-based case finding to combat treatment delay, thereby decreasing the TB infectious pool; and (2) the need to increase our understanding of how the intensity of social interactions within the community has exacerbated the TB epidemic. From an alternative qualitative perspective, chapters four and five of this study echo a very similar sentiment - that treatment delay and social interaction are potentially key factors sustaining the TB epidemic in Cape Town.

In chapter four, the two dominant themes to emerge involved the stigmatization of TB as a 'dirty' disease and the anticipation of HIV-related stigma. Both are assessed as relevant to enhancing current TB control efforts precisely because of their potential contribution to diagnostic delay. This is highly significant in light of the emphasis Bekker and Wood place on the need to combat diagnostic delay and limit ongoing transmission. Moreover, my analysis presents a nuanced range of potential interventions that could curb treatment delay and suggests that the impact of case-finding – irrespective of whether it is community or clinic based – will be undermined unless the high levels of

perceived TB-HIV stigma are addressed. A combination of strategies that reduce the marginalization of endemic communities, increase their sense of control over TB and address HIV related stigma may positively impact on diagnostic delay. In contrast to the community-based case-finding and contact tracing that the Bekker and Wood study recommends, this recommendation breaks away from the traditional focus on finding individual cases and their contacts, to a more inclusive approach that also addresses the sociological features of TB endemic populations as a whole.

In chapter five my results once again emphasise a need for control policies to shift away from finding individual cases - to finding places. Like the Bekker and Wood study, it identifies the intensity of social interaction within the research sites as an important factor sustaining the TB epidemic. It identifies the likely role of public gathering places in facilitating the transmission of TB, developing a novel methodology that begins to answer the question, as posed by Bekker and Wood, of how social interaction exacerbates the epidemic. The biological plausibility and relevance of these findings to epidemic control are apparent, and further validation with actual transmission data will strengthen evidence. The epidemiological insight generated by this novel GIS-based approach demonstrates the potential value of complementing traditional 'case-finding' with targeted 'place-finding'. Public health intervention may include measures to reduce the transmission risk posed by specific gathering places (through environmental measures, such as increased ventilation or the provision of sterilizing ultraviolet light, as well as encouraging TB suspects to present early for diagnostic evaluation).

Providing a caveat to the interventions recommended by chapter four and five, chapter three shows that the study communities, while displaying many common socio-economic features and a common discourse that stigmatizes TB as both a dirty and HIV related disease, have unique sociological characters, in which levels of social fragmentation play a defining part. The impact of interventions are likely to be enhanced if they are implanted with sensitivity to this - capitalizing on social cohesion, finding ways to reduce social fragmentation and being considerate to the social 'life' of target populations. Results from chapter four suggest that further unraveling of the relationship between social cohesion/fragmentation and variability in responses to TB may be highly relevant for TB control. In chapter four data presented exceptionally powerful indications of disease stigma in Wallacedene which was also classified as one of the most socially

fragmented sites in chapter three. Respondents were reluctant to talk about TB to research assistants at all, fearing that others might humiliate and isolate them. This is in contrast to other research sites where respondents spoke comfortably about TB and/or HIV/AIDS, suggestive of a correlation between disease stigma and social fragmentation.

ZAMSTAR pre-selected the study communities as a unit of randomization. In this “cluster randomized trial” the unit of randomization was defined as a community, suffering concomitant HIV and TB epidemics, served by a single diagnostic centre. BBS results from chapter three encourage researchers and public health officials to reconsider the assumption that an individual research site/community will respond uniformly to a particular health intervention, since most ‘communities’ comprise sociologically distinct areas on both micro and macro levels. In light of this, the study recommends a more sociologically sensitive understanding of community that acknowledges and integrates these complexities, as often there is the implicit assumption that target ‘communities’ are homogenous entities as a result of their common socio-economic vulnerability to disease.

The analyses performed in this study reduce the complexity of the social terrain of endemic TB into a pragmatic format that leans on a limited number of variables potentially relevant to TB control. I emphasise that their current application requires further validation. The ‘open and closed’ typologies present a predicted response, rather than a measured one; likewise the discourse analysis in chapter four generates the hypotheses that the stigmatization of TB as both a dirty disease and a HIV related disease is negatively impacting on health seeking behaviour, and the identification of potential transmission ‘hotspots’ reflects the possible risk of infection rather than measuring actual transmission. However, there are clear steps that can be taken towards validating the hypotheses that this study has generated.

In chapter three, this would entail placing findings from the ZAMSTAR trial against our predictions. The effectiveness of the ZAMSTAR interventions is to be measured by comparing prevalence surveys at the end of the study with baseline epidemiological data derived from TST surveys. Placing prevalence data and other factors such as the uptake of HIV testing alongside the predictions made by the ‘open and ‘closed’ typologies of these research sites will enable us to indentify any meaningful correlations. This may be

highly informative and provide an opportunity to weight the comparable social characteristics that were identified (across target communities) in terms of their relevance to TB control. In chapter four, further ethnographic research that can assess the social impact of marginalisation and HIV/AIDS on actual TB treatment seeking behaviour amongst the broader community is needed. This could validate the link made between the stigmatization of TB as a dirty, HIV-related disease and treatment delay. In chapter five, there is the possibility of superimposing actual transmission data using detailed strain typing on the current GIS map. This would be possible if this type of data were to become available. This 'next step' could provide conclusive evidence that these areas are in fact high-risk, rather than potentially high-risk, for the transmission of TB.

Methods used in both papers produce findings that are specific to the communities of Cape Town that were under study, but I argue that they hold direct public health relevance because they offer such contextually informed and specific results(1). Applying a social systems perspective to other endemic areas may allow for the classification of sociological characteristics that are specific to the uptake of public health interventions in these areas to emerge. The use of a similar populations based discourse analysis may provide insight in other high burden areas as to how TB control efforts need to be adjusted in accordance with popular perceptions of disease. The application of a similar GIS mapping method to that which is used in chapter 5 should assist similar hyperendemic areas to evaluate potential transmission 'hot spots' at the community level, which may spatially guide suitable public health interventions.

Most importantly this study has demonstrated that there are innovative and highly informative approaches which allow us to appreciate the significance of social terrain for TB control. It has been shaped by my involvement within a large multidisciplinary study, rather than any particular academic discipline and shows that by exploring the social terrain of endemic TB further, through approaches that cross disciplinary boundaries, we can open new paradigms for its control. While TB continues to ravage the poor and vulnerable, constraining and degrading lives further, the need for such innovation is desperate. My hope is that this study will contribute to more frequent and constructive transdisciplinary dialogue; honest and critical assessment of current control strategies; and novel approaches that link the individual patient to the social terrain of endemic TB, which ultimately sustains the epidemic at a population level.

Main recommendations

Whalen argues that novel public health strategies acting as companions to DOTS should primarily aim to interrupt the spread of TB (3) and, in sum, this study concurs with this statement. It suggests that TB control policies are likely to be enhanced through a combination of the following which may have a direct and/or indirect impact on reducing TB transmission:

- Improving service delivery and reducing the marginalization of hyperendemic communities to increase patient agency for seeking TB treatment
- Addressing the stigmatisation of TB as an HIV-related disease and improving perceptions of levels of patient privacy at local clinics
- Raising awareness about the urgency of seeking TB treatment early in order to limit ongoing transmission
- Designing socially sensitive interventions that are considerate of local levels of social cohesion and fragmentation.
- Identifying transmission “hot spots” and reducing the transmission risk posed by public gathering places through innovative interventions.

References

1. Pearce N, Merletti F. Complexity, simplicity, and epidemiology. *Int J Epidemiology* 2006; 35: 515-19.
2. Bekker L-G, Wood R. The Changing Natural History of Tuberculosis and HIV Coinfection in an Urban Area of Hyperendemicity. *Clin Infect Dis* 2010; 50: S208-14.
3. Whalen CC. Failure of Directly Observed Treatment for Tuberculosis in Africa: A Call for New Approaches. *Clin Infect Dis* 2006; 42:1048-50.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BBS	Broad Brush Survey
BCG	Bacillus Calmette-Guerin
CAB	Community Advisory Board
CBO	Community-Based Organisation
CREATE	Consortium to Respond Effectively to the AIDS TB Epidemic
DOT	Directly Observed Therapy
DOTS	Directly Observed Treatment Short-course
DTTC	Desmond Tutu TB Centre
GIS	Geographic Information Systems
HIV	Human Immunodeficiency Virus
LSHTM	London School of Hygiene and Tropical Medicine
MDR	Multi- Drug-Resistant
MTB	Mycobacterium tuberculosis
NGO	Non-Governmental Organization
PAR	Participatory Action Research
SOP	Standard Operating Procedure
TB	Tuberculosis

TST	Tuberculin Skin Test
WHO	World Health Organisation
ZAMBART	Zambia AIDS Related Tuberculosis Project
ZAMSTAR	Zambia and South Africa Tuberculosis and AIDS Reduction study

APPENDIX i

STANDARD OPERATING PROCEDURE (SOP) for BBS FIELDWORK ZAMSTAR Social Science Year One

As part of the baseline profiling of 24 communities (16 Zambia, 8 South Africa) Broad Brush Surveys (BBS) will be conducted. To provide an outline of the fieldwork involved and to ensure maximum standardisation across research sites, the following SOP is provided. It begins with an overall outline of the BBS (1) which comprises a community advisory board (CAB) meeting (1.1), transect walks (1.2) and structured times observations (1.3).

1	BROAD BRUSH SURVEY (BBS)
Aim	<p>The key objective of the BBS in ZAMSTAR is to give us shallow and wide understanding of domains of TB in the local community through observing and recording the following</p> <ul style="list-style-type: none"> ➤ Who bumps into whom? Capture population movement within the community and in and out of the community. Gather indications of networks of communication and population density. ➤ Who hangs out where and for how long? Use of space and time according to age, gender and occupation. ➤ Where do people congregate? Do locals think that TB is transmitted in any of these places? The places where people congregate considered as relevant by locals to TB transmission (TB “hot spots”). ➤ Where do people in this community get treated for TB? The range of TB treatment options and opinions about these different options. ➤ What are local beliefs about the origins, transmission and causes of TB? ➤ How do others treat people who are suspected or known to have TB in this community? Level and type of TB related stigma. ➤ How do people make a living in this community? Local options for livelihood. ➤ What is the housing like in this community? The range of local housing. ➤ What are the factors that influence people’s use of the local health centre (TB diagnostic centre)? Snapshot of use of the local health centre. ➤ What kind of urban system is this? Class, ethnic, unique, leadership, local economy characteristics, and range of social interactions. ➤ What is the difference that makes a difference between communities? Preliminary indications of features of difference in the local context that could shape the uptake of TB services and interventions.
Tools	<p>The BBS consists of:</p> <ul style="list-style-type: none"> ➤ A brief discussion with the Neighbourhood Health Committee (NHC) or Community Advisory Board (CAB)

	<ul style="list-style-type: none"> ➤ Transect Walks through the community ➤ Structured Timed Observations at key places
Time Span	<p>The BBS team will spend one week (four and a half days) in each site. The BBS will always be conducted before any more intensive social science fieldwork, allowing us to build our focus group discussions, key-informant interviews and timelines on the shallow and wide knowledge obtained through the BBS.</p>
Schedule	<p>Day 1: NHC / CAB meeting. Begin Transect Walks (through hub of community) Day 2: Continue Transect Walks Day 3: Structured Timed Observations (e.g. transport depot, hair salon, water point) Day 4: Structured Timed Observations (e.g. health centre, video club, game shop, bar) Day 5: Mopping up, writing field notes, pursuing new leads</p> <p>In Zambia, these five days will be from Monday to Friday. In South Africa, a total of ten days is allocated to allow for transport between the office and the sites, possibly slower processes involving the CAB and stricter working hours. Each scheduled day may thus span two calendar days.</p>
Personnel requirements	<ul style="list-style-type: none"> ➤ Two full-time Research Assistants (RAs), one male and one female, to work throughout all sites for 7 months, conducting fieldwork and assisting with data entry. ➤ Two Local Fieldworkers (LFWs), one male and one female, per site for minimum of one week to act as guides to the Research Assistants. In Zambia, these are identified through the health centre and the NHC. In South Africa they are recruited through an advertising process guided by the CAB. ➤ The core Social Science team to train, supervise, support and debrief the fieldwork team and analyse the data collected. ➤ A male driver, to provide transport at the beginning and end of each day. It is important that the BBS team work alone and walk around and are not shadowed by a vehicle. However, the driver will accompany the male RA and male LFW during the evening observation on day 3. As a safety precaution, he will remain in the vicinity of the female RA and LFW during structured observations as well as any other situation that calls for his support.
General Material Requirements	<ul style="list-style-type: none"> ➤ Two ergonomic field bags for RAs ➤ Zamstar Introductory Letter for each RA and LFW ➤ Zamstar informative leaflets for enquiring community members ➤ Maps of area - 2 large copies (preferably A1) and 6 smaller (e.g. A4) copies ➤ One ream of flipchart paper per site ➤ Marker pens of assorted colours ➤ Poster Roll to store flipchart paper ➤ Drinks and snacks ➤ Two hand-held GPS receivers (entry level model with Waypoint, Track Log and Time functions) and spare batteries (or recharger for rechargeable batteries) ➤ Cameras ➤ Plenty A4 blank paper (for daily activity charts and sketching transect walks) ➤ Lap-top computer for data entry for Zambian team (SA team use faculty office) ➤ Notebooks for field notes ➤ Clipboards ➤ TRANSECT WALK OBSERVATION CHECKLIST ➤ Pens ➤ Data capture sheets and storage envelopes ➤ Petty cash, wallet, receipt book <p>Note: Items over-budgeted to allow for contingency and for possibility of buying</p>

	<p>soft drinks for other locals as a gesture of goodwill in the field. One RA to hold petty cash and to account for it on return with receipts.</p> <ul style="list-style-type: none"> ❖ Zambia: LFW daily wages - K50,000 x 4 days x 2 = K400,000 (South African LFW paid through University for longer period) ❖ Drinks and snacks for NHC / CAB meeting – K50,000 / R50 ❖ Refreshments for Daily time chart participants – K50,000 / R50 x 3 groups ❖ Hairdo at hair salon – K20,000 / R20 ❖ Soft drinks for bar observations – K25,000 / R25 x 2 visits ❖ Communication in field – photocopying K50,000 / R50, phone K50,000 / R50 ❖ TOTAL: K770,000 / R370 <p>➤ Trunk with padlock for transport and storage of all items</p>
Data & Software Requirements	<ul style="list-style-type: none"> ➤ ArcGIS software ➤ Microsoft Word ➤ NUD*IST QSR N6 ➤ In Zambia, the RAs enter the data onto a laptop when they are in the field at the end of each day and feedback their data to the core team on returning to Lusaka. ➤ In South Africa, the RAs will return to the office each afternoon to enter the data onto a computer accessible to the core team.
Preliminary arrangements	<ul style="list-style-type: none"> ➤ Complete process of gaining community consent and establishing links with NHC / CAB. ➤ Recruit two local fieldworkers per site through NHC / CAB ➤ Set up a meeting of 1-2 hours with NHC / CAB
Sites	<p>Zambia: 17 sites – 1 pilot site and 16 selected sites South Africa: 9 sites – 1 training site and 8 selected sites</p>
Logistical requirements	<ul style="list-style-type: none"> ➤ In Zambia, the BBS team will be transported to the sites and have a driver at their disposal during fieldwork. ➤ In South Africa, the driver and the RAs are to leave from the office in the morning with materials needed, meet the LFWs in the field, and return in the afternoon to do data entry.

1.1	BBS Meeting with CAB / NHC
Aim	The BBS begins with an informal meeting with the Community Advisory Board or Neighbourhood Health Committee, as appropriate, to obtain an overview of the community through free listing and mapping places of relevance to TB transmission and treatment and patterns of movement and communication.
Process	<p>One RA facilitates the meeting while the other RA makes notes of the conversation. LFWs are present to help to clarify references made to places and local particularities, but do not give input of their local knowledge nor assist in facilitation.</p> <p>Introduction:</p> <ul style="list-style-type: none"> ➤ The RA welcomes and thanks everyone for attending. ➤ Explain the purpose of the meeting, saying that the discussion will give us an introduction to the community before we begin walking around and spending time there during the week that follows. ➤ Clarify that attendance at the meeting is voluntary. Drinks and snacks will be provided. Their assistance is not required after the meeting, as there are local fieldworkers to guide the team and teach the RAs more about what is observed.

	<ul style="list-style-type: none"> ➤ The meeting should last between one and two hours depending on the discussion. ➤ Send around an attendance list to be filled in. <p>Free listing and discussion – in any order:</p> <ul style="list-style-type: none"> ➤ The RA asks the Committee to list or name the places in the community where people gather in groups and writes these down on flipchart paper. ➤ Ask them to indicate in which of these places they believe that TB is commonly spread. Mark these with an asterisk. ➤ Which places outside the community do they believe TB is coming from? ➤ Ask them to list or name places or people that can be consulted for treatment of TB or its symptoms. Write this on a separate flipchart page. ➤ Ask which are the most common or popular. Note next to each option. ➤ Do people normally come in to work, to buy, to sell, to visit? What age and sex? ➤ Do people regularly go out to work, to buy, to sell, to visit? What age and sex? ➤ Do many people pass through here on their way somewhere else? When? <p>Mapping:</p> <ul style="list-style-type: none"> ➤ Either ask the committee to make a sketch map of the area on flipchart paper, providing a number of marker pens and encouraging all to participate. Make clear that the map does not have to be perfect. If necessary, suggest that they begin with the main roads and boundaries. Encourage them to use whatever symbols and words they choose. Or, if a formal map exists, this can be taken along and the map sketched onto it once all have recognised and comprehended the existing map. It may be necessary to make corrections. ➤ Ask the committee to indicate any significant socio-economic sub-divisions and boundaries within the community. ➤ Situate on the map the important places named during the free listing and discussion. ➤ Situate any other informal gathering places – communal water points, people playing games, etc. ➤ Indicate on the map the main entry/exit points in and out of the community. ➤ Using the map and the free listing of TB 'hot spots' and treatment options, ask the group to help plan the transect walks through the community. Explain that there is a day and a half available to walk through the community, seeing the 'hot spots' and treatment options listed and getting a feel for what the community is like. Ask the group to draw the recommended routes on the map. <p>Thank the committee for their time and contributions. Complete Activity Report Form</p>
DATA recording, entry and storage	<ul style="list-style-type: none"> ➤ Field notes kept by RA transferred to an ACTIVITY REPORT FORM. ➤ 3 Sheets of flipchart paper – list of places, list of treatment options, sketch map. ➤ Data collected to be entered into MS word and later transferred to QSR N6 ➤ Maps and free-lists are to be coded and stored in a secure place.
Outcome	<ul style="list-style-type: none"> ➤ An overview of the community and its domains of TB as projected by the NHC/CAB. ➤ Using the sketch map and the advice of the NHC, the BBS team is able to plan the routes of the transect walks to pass through different areas and TB domains within the community. ➤ The discussion provides an initial indication of movement and communication patterns and local perceptions of TB. This provides direction for possible issues to be explored further during the remainder of the BBS.
Logistical requirements	<ul style="list-style-type: none"> ➤ Arrange meeting time and venue. Members of the NHC / CAB may only be able to meet in the evenings after work. The schedule is then to be adapted and

	<p>transport arrangements made.</p> <ul style="list-style-type: none"> ➤ Purchase snacks and drinks beforehand.
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1.2	BBS Transect Walk
Aim	<ul style="list-style-type: none"> ➤ To become familiar with the spatial organisation and physical structures of the area ➤ To physically map cross-sections (transects) of the community by plotting with GPS technology places of relevance to TB – where people congregate, TB hotspots and TB treatment options. ➤ To survey the patterns of activities and movement and options for livelihood. ➤ To gain a wide and shallow understanding of how people believe TB is spread and how people with TB are treated. ➤ To identify sites for structured timed observations on days 3 & 4.
Process	<ul style="list-style-type: none"> ➤ Routes are chosen with the assistance of the NHC that cut across the main hub and different sub-areas in the community from boundary to boundary, capturing the TB transmission ‘hot-spots’, the TB treatment options and the range of housing. ➤ A RA and a LFW pair up in two teams to do each of the two routes, each team consisting of a man and a woman. Or the group remains in one team, taking different roles at each place of significance (e.g. one RA takes GPS co-ordinates whilst the other writes a description of the place and chats to people). ➤ The LFWs acts as a guide on the walks while the RAs takes GPS readings and records observations, checking these with the LFWs. ➤ The GPS receiver is to be switched on and left on during the entire walk so as to be able to view the route walked on the device’s display screen. This is a “breadcrumb trail” called a Track Log. <p>During the walk:</p> <ul style="list-style-type: none"> ➤ The RAs observe the places passed, noting conditions in different sub-areas and housing clusters, activities and movements of people and livelihood options. ➤ The RAs ask the LFWs and others who they pass probing questions about the different housing clusters and important places in the area with regard to the transmission and treatment of TB. Make rough notes in the notebook. ➤ The RAs and LFWs look out for the types of places suggested by the Transect Walk List of Places i.e. health facilities, commercial premises, places of worship, recreational spaces, boundary landmarks, schools, etc (see TRANSECT WALK OBSERVATION CHECKLIST). They stop at each such place. ➤ Take photographs of different household types, the diagnostic centre, and other significant TB “hotspots”. Note that in South Africa, should pictures of an identifiable place be taken, permission from the owner/manager/person in charge is to be requested and the photograph consent form is to be completed before a picture is taken. In Zambia, the consent form will only be used for photos of individuals. <p>For each place (called a waypoint in GPS terms):</p> <ul style="list-style-type: none"> ➤ The RA takes GPS readings in an unobstructed position. The waypoint number and coordinates are recorded on the GPS DATA CAPTURE SHEET. In Zambia, three readings will be taken; in South Africa, just one reading will be taken. ➤ The type of place (selected from the TRANSECT WALK OBSERVATION CHECKLIST) and the name of this particular place (if applicable) are indicated for the waypoint. ➤ A description is given of: time (use time of GPS waypoint reading); the structure, including its size and the degree of crowding and ventilation; the number, age

	<p>and gender of the people present; and the activities taking place.</p> <ul style="list-style-type: none"> ➤ The RAs and LFWs assess whether the place is a possible observation point to return to on the following days. ➤ If people ask, explain that the team are getting to know the places in the community for the purposes of a TB research project. Engage in brief informal conversation if it ensues and make field notes afterwards. Where feasible, discuss issues that were raised during the NHC / CAB meeting. <p>Afterwards:</p> <ul style="list-style-type: none"> ➤ Each RA and LFW pair make a rough sketch of the transect walk on blank A4 paper, indicating all the places plotted and observed during the walk. At this point the Track Log function of the GPS receiver will be of assistance as it will display the entire route walked as well as all the waypoints plotted en route. ➤ Each RA completes the ACTIVITY REPORT FORM, describing the process and the findings (from notes made in the note book) as they relate to activities and mobility of people, livelihood options and perceptions of TB. ➤ On day one, each RA reflects on and completes the FIRST IMPRESSIONS OF THE COMMUNITY REPORT FORM.
Schedule	The transect walks are to begin following the NHC / CAB meeting on day one and are to be completed on day two. Time is given at the end of each day to write up notes and complete recording forms.
DATA recording, entry and storage	<ul style="list-style-type: none"> ➤ GPS DATA CAPTURE SHEET will be entered by data entry clerks into ARC GIS ➤ ACTIVITY REPORT FORM will be entered into MSword by RAs and then transferred to QSR N6 ➤ A rough sketch of the transect walk on A4 paper. This will be scanned in. ➤ FIRST IMPRESSIONS OF THE COMMUNITY REPORT FORM will be entered into MSword by RAs and then transferred to QSR N6
Outcome	<ul style="list-style-type: none"> ➤ GPS data collected is downloaded to ArcGIS to create enriched maps of relevance to Zamstar for research and intervention purposes. ➤ Indication of the type of urban system and first impressions of population movement, networks of communication, local patterns of TB and popular knowledge on TB.
Logistical requirements	<ul style="list-style-type: none"> ➤ Once the Transect Walk routes are decided on at the beginning of the day, fieldwork teams must liaise with the driver to arrange collection points.

1.3	BBS Structured Timed Observations
Aim	While the Transect Walk explores the spatial dimension of the movement of people and their use of space in a community, the Structured Timed Observations add a temporal dimension to understanding spaces within the community.
Tools	<p>Tools used during the Structured Timed Observations:</p> <p>Transport Depot Data Capture Sheet</p> <p>Observations are made at a transport depot in the morning and the evening to get an indication of the movement of people – women, men and children – in and out of the community.</p> <p><i>Process:</i></p> <ul style="list-style-type: none"> ➤ The male RA and male LFW situate themselves in a place in the transport depot area from which they are able to view people boarding and alighting from

vehicles as best as possible. If possible, conversations can be held with local people about population movement and TB but this should not interfere with counting process.

- The TRANSPORT DEPOT DATA CAPTURE SHEETS consist of four forms to record each of: people coming in the morning, people going in the morning, people coming in the evening, people going in the evening. The RA notes on the relevant form: the name of the intervention site and of the entry/exit point, the time, the date and day of the week, and the names of the RA and the LFW.
- For the duration of the observation period, The RA counts and records the number of people coming per age and gender category (i.e. Men and Women, Under 20, between 20 and 35, over 35, babies and small children) while the LFW counts and records those going (or vice versa).
- Numbers are recorded according to the convention of making four vertical strokes crossed by one horizontal stroke for every five people.
- At the end of the observation period, the strokes are counted and the total number indicated.

Diagnostic Centre Questionnaire

The Diagnostic Centre Questionnaire is administered at the health centre selected for the Zamstar study. It is intended for collection of data regarding patients' visits to the clinic and asks eight simple questions about the distance, means and time spent reaching the clinic, time spent at the clinic, and the cost of the visit. The purpose is to give a snapshot of factors that influence local access to the health centre.

Process:

- It is very important that the RA does not interfere with the running of the clinic and displays sensitivity to patients' conditions.
- After having spent some time in the health centre making one's presence comfortable, the RA will ask individual patients waiting for consultation if they are willing to answer a few questions to assist with research, taking less than five minutes.
- On the DIAGNOSTIC CENTRE DATA CAPTURE SHEET, the RA ticks the responses to each question.
- The questionnaire can be administered to as many willing patients as time allows.

The Daily Time Chart

In each community, at least one group of men and women will be asked to run through their typical daily activities and to plot on to a map where they went in the community the day before. The aim is to capture women's and men's use of space and mobility within the community. Places that are clearly gendered space will be used for this activity, for example for women this could be a hairdressing salon or a water point, and, for men, where draughts (board game played by men) are played.

What is a daily time chart?

- It is a participatory time-related data-gathering tool that explores daily patterns of work, movement and other activities.
- It will allow us to examine daily activities of a selected sector of the community and to compare the daily activities of the group.
- This method is a good ice-breaker and helps in starting a discussion. Questions can be asked on the basis of the analysis carried out by the group.

	<p><i>Process:</i></p> <ul style="list-style-type: none"> ➤ Since the analysis is about how people spend a typical day, the first thing to ask the participants is how they would like to divide the day. Some may divide it by the hour and some may simply divide it by morning, afternoon, evening and night. ➤ The participants are asked to analyze how their time is spent during a typical day. ➤ On a flipchart sheet, different activities are placed along the time line, and are either represented by words, symbols, blocks of time, or graphs. ➤ As each participant is likely to use his or her time differently, it may be useful to construct a matrix of activities, with columns for the time blocks and activities of different participants. ➤ The daily activity analysis does not give us complete information, but provides an opportunity to ask a number of questions. Once the group has prepared an analysis, they can be asked several questions like: <ul style="list-style-type: none"> ❖ Do you think this analysis will apply for all the men/women/boys/girls in this compound or would it be different for some? ❖ Will the daily analysis for the opposite sex look the same? ❖ Would this look different for weekdays and weekends, and for different seasons of the year? ➤ Transfer the completed daily time chart from the flipchart paper to the DAILY TIME CHART ACTIVITY REPORT FORM. 	
<p>Process & Schedule</p>	<p>Each RA works on separate tasks, accompanied by a LFW of the same gender.</p> <p>It is important to dedicate time after each activity to make field notes, as it is preferable not to make notes during observations so as to minimise the conspicuousness of the observation.</p> <p>AN ACTIVITY REPORT FORM will be completed at the end of every activity or observation. The Daily Time Chart and the AR must be written up and inputted as one document.</p> <p>Conversation that emerges around TB should be directed to uncovering beliefs about origin, transmission and causes as well as gauging how people suspected or known to have TB are treated.</p>	
<p style="text-align: center;">Female RA plus female LFW (in SA, shadowed nearby by driver for safety)</p>	<p style="text-align: center;">Male RA plus male LFW</p>	
<p>Day Three</p>		
<p><i>Morning (total 5 hours):</i></p> <p>a. In Zambia: Early morning observation (6h00 to 8h00) at a communal water point In South Africa: Morning observation in a communal space, preferably used by women and/or children (8h00-10h00). Observe and discuss: Who comes and goes? How long do they spend there? Are clients local or not? What is happening there? Is this a popular meeting and gossiping place for women? What is the ventilation like? What are their stories about TB?</p> <p>b. Spend time in a hair salon. One of the pair</p>	<p><i>Morning (5 hours)</i></p> <p>a. 6h00 to 8h00 at the bus station, taxi rank or equivalent entry/exit point, observe and count the numbers of men and women coming and going. Record on the TRANSPORT DEPOT DATA CAPTURE SHEETS. Observe and discuss movement of people.</p> <p>b. 10h00 to 11h00. Brief observation at a video club or other male youth's communal space. Informal conversation with attendant and clients, as appropriate: are people there local or not? How much time do they spend there? Gather a group of boys/men for a</p>	

<p>could have her hair done. Observe and discuss: Who comes and goes? How long do they spend there? Are clients local or not? What is happening there? Is this a popular meeting and gossiping place for women? What is the ventilation like? What are their stories about TB? Gather a group of women for a daily time chart.</p> <p>Write up notes.</p>	<p>daily time chart. Write up notes.</p>
<p><i>Afternoon (maximum 1 hour):</i> Third observation in women's space, observing and having informal discussions about movement of people and doing another daily time chart. This could be an informal trading stall, or another women's space indicated through the NHC discussion or transect walk e.g. a Growth Monitoring Point. This could also be carried out in afternoon of Day Four.</p>	<p>Accompanied by the driver. <i>Evening (total 1 hour):</i> 17h00 to 18h00. Observe and count at the exit/entry point as above and record.</p>
<p>Write up notes. Complete Daily Activity Report Form</p>	<p>Write up notes. Complete Daily Activity Report Form</p>
<p>Day Four</p>	
<p><i>Morning (max 3 hours):</i></p> <ol style="list-style-type: none"> Attend the health centre (the diagnostic centre selected for the Zamstar study). What is happening? How many people? Chat to one staff member: How long do people wait? Where do they come from? Get a general picture. Observe as a communication centre. Note the interaction between patients waiting. Complete checklist – DIAGNOSTIC CENTRE DATA CAPTURE SHEET – with as many waiting patients as are willing to participate in the allocated time. 	<p><i>Morning (max 3 hours):</i></p> <ol style="list-style-type: none"> Observation and conversation at a men's communal space, such as a drafts club venue in Zambia. Who is there? Ages? Local or not? Regulars? How long do they spend there? What is the ventilation like? Draw a group together for a daily time chart.
<p><i>Afternoon (max 1 hour):</i> Third observation at a women's communal space if not already carried out in Day Three</p>	<p><i>Afternoon (max 1 hour):</i> Brief revisits to the video club and bar to observe at a different time of day. OR Brief observation and conversation at another place where men gather, as advised by LFW or noted during transect walk.</p>
	<p><i>Evening (1-2 hours):</i> 19h00 to 20h00: Night walk/observation. Brief observation of the site at night, walking around the centre of the community, noting the difference to the daytime and how the place feels at night e.g. who is around (locals/not locals, men/women, children)? Activities? Busy/not busy? This should include a brief observation at a bar. Who is there (age, gender)? Is it crowded? If possible speak to</p>

	the bar attendant, otherwise check with the LFW: Are the customers mostly local? Are they regulars to that bar? When is it busy? Does it get very crowded?
Write up notes. Complete DAILY ACTIVITY REPORT FORM	
Day 5	
Flexible time for mopping up, writing notes, pursuing interesting new leads.	
DATA recording, entry and storage	<ul style="list-style-type: none"> ➤ DIAGNOSTIC CENTRE DATA CAPTURE SHEET will be entered into Microsoft Excel by social science team. The observation is also written up as an AR, capturing and summarising the DCSs and the process. ➤ Four TRANSPORT DEPOT DATA CAPTURE SHEETS – Coming In Morning & Evening, Going Out Morning & Evening will be entered into Microsoft Excel by social science team. The observation is also written up as an AR, capturing and summarising the DCSs and the process. ➤ Completed DAILY TIME CHART ACTIVITY REPORTS will be entered by RAs into MSWord and then transferred to QSR N6 ➤ ACTIVITY REPORT FORMS – one per RA are entered into MSWORD and then transferred to QSR N6
Outcome	<ul style="list-style-type: none"> ➤ Indication of local economy ➤ Indication of mobility in and out of community and within community. ➤ Indication of how time is spent, where and for how long. ➤ Indication of range and type of social interactions. ➤ Indication of gendered space and activities. ➤ Local perceptions of TB transmission. ➤ Local knowledge and opinion of TB treatment options. ➤ Level and nature of TB related stigma. ➤ Insight into patients' experiences of the use of the health centre. ➤ Shallow typology of the type of urban system and what differences in the system could make a difference to the shape and uptake of TB services and interventions.
Logistical requirements	The driver is to meet up with the RAs and LFWs after every activity. Although not present during the observations, they should remain in the vicinity should they be required.

APPENDIX ii

QSR N6 'TREE NODE' REPORT ZAMSTAR Social Science Year One

Textual data from the Zambian and South African BBS was coded within the following 'tree' of 17 parent nodes (in bold and uppercase) and their relevant child nodes. The tree was used for all qualitative data collected in the first year of the trial of which BBS was a part. This means that some of the nodes are not applicable to BBS data. These and others that are only applicable to Zambian data are highlighted with an asterisk.

Node Reference:	Node Description:
(1)	BASE DATA
(1 1)	Base Data/Age
(1 1 1)	Base Data/Age/Children
(1 1 2)	Base Data/Age/Youth
(1 1 3)	Base Data/Age/Adults
(1 1 4)	Base Data/Age/Elders
(1 1 5)	Base Data/Age/Mixed
(1 2)	Base Data/Gender
(1 2 1)	Base Data/Gender/Female
(1 2 2)	Base Data/Gender/Male
(1 2 3)	Base Data/Gender/Mixed
(1 3)	Base Data/Residence
(1 3 1)	Base Data/Residence/Southern Province*
(1 3 2)	Base Data/Residence/Lusaka Province*
(1 3 3)	Base Data/Residence/Central Province*
(1 3 4)	Base Data/Residence/Copperbelt*
(1 3 5)	Base Data/Residence/Luapula Province*
(1 3 6)	Base Data/Residence/Western Cape Province
(1 3 6 1)	Base Data/Residence/Western Cape Province/Cape Town Metropole
(1 3 6 1 1)	Base Data/Residence/Western Cape Province/Cape Town Metropole/Site C
(1 3 6 1 2)	Base Data/Residence/Western Cape Province/Cape Town Metropole/Harare
(1 3 6 1 3)	Base Data/Residence/Western Cape Province/Cape Town Metropole/Nyanga
(1 3 6 1 4)	Base Data/Residence/Western Cape Province/Cape Town Metropole/ Mzamomhle
(1 3 6 1 5)	Base Data/Residence/Western Cape Province/Cape Town Metropole/Delft
(1 3 6 1 6)	Base Data/Residence/Western Cape Province/Cape Town Metropole/Wallacedene
(1 3 6 2)	Base Data/Residence/Western Cape Province/West Coast Winelands
(1 3 6 2 1)	Base Data/Residence/Western Cape Province/West Coast Winelands/Kayamandi
(1 3 6 2 2)	Base Data/Residence/Western Cape Province/West Coast Winelands/Mbekweni
(1 4)	Base Data/Occupation
(1 5)	Base Data/Ethnicity
(1 5 1)	Base Data/Ethnicity/Cape Coloured
(1 5 2)	Base Data/Ethnicity/amaXhosa
(1 5 3)	Base Data/Ethnicity/Other African SA
(1 5 4)	Base Data/Ethnicity/Other African - non SA
(1 5 5)	Base Data/Ethnicity/Mixed
(1 6)	Base Data/Language
(1 6 1)	Base Data/Language/isiXhosa
(1 6 2)	Base Data/Language/Afrikaans
(1 6 3)	Base Data/Language/English
(1 6 4)	Base Data/Language/Mixed
(1 7)	Base Data/Method
(1 7 1)	Base Data/Method/FGD*
(1 7 2)	Base Data/Method/TB Patient II*

(1 7 3) Base Data/Method/Case Study*
 (1 7 4) Base Data/Method/Timeline*
 (1 7 5) Base Data/Method/NHC/CAB Meeting
 (1 7 6) Base Data/Method/Transect Walk
 (1 7 7) Base Data/Method/Observation
 (1 7 7 1) Base Data/Method/Observation/Hair Salon
 (1 7 7 2) Base Data/Method/Observation/Transport Depot
 (1 7 7 3) Base Data/Method/Observation/Video Club*
 (1 7 7 4) Base Data/Method/Observation/Board Games
 (1 7 7 5) Base Data/Method/Observation/Water Point
 (1 7 7 6) Base Data/Method/Observation/GMP*
 (1 7 7 7) Base Data/Method/Observation/Flower Farm*
 (1 7 7 8) Base Data/Method/Observation/Clinic
 (1 7 7 9) Base Data/Method/Observation/Drinking Place
 (1 7 7 10) Base Data/Method/Observation/Market
 (1 7 7 11) Base Data/Method/Observation/Grinding Mill*
 (1 7 7 12) Base Data/Method/Observation/Bicylce Repair Store*
 (1 7 7 13) Base Data/Method/Observation/Blacksmith*
 (1 7 7 14) Base Data/Method/Observation/Other
 (1 7 7 15) Base Data/Method/Observation/Business area
 (1 7 7 16) Base Data/Method/Observation/Stall/Spaza shop
 (1 7 8) Base Data/Method/Daily Activity Charts
 (1 7 9) Base Data/Method/First Impressions
 (1 8) Base Data/Daily Activity Charts
 (1 9) Base Data/First Impressions

(2)

GENERAL COMMUNITY PROFILE

(2 1) General Community Profile/Population
 (2 2) General Community Profile/Places where people congregate
 (2 2 1) General Community Profile/Places where people congregate/Clinic
 (2 2 2) General Community Profile/Places where people congregate/Video Clubs*
 (2 2 3) General Community Profile/Places where people congregate/Drinking Places
 (2 2 4) General Community Profile/Places where people congregate/Police Station or cells
 (2 2 5) General Community Profile/Places where people congregate/GMP posts*
 (2 2 6) General Community Profile/Places where people congregate/Schools
 (2 2 7) General Community Profile/Places where people congregate/Waterpoints
 (2 2 8) General Community Profile/Places where people congregate/Households
 (2 2 9) General Community Profile/Places where people congregate/Churches
 (2 2 10) General Community Profile/Places where people congregate/Markets
 (2 2 11) General Community Profile/Places where people congregate/Funeral homes
 (2 2 12) General Community Profile/Places where people congregate/Transport Depot
 (2 2 13) General Community Profile/Places where people congregate/Compounds
 (2 2 14) General Community Profile/Places where people congregate/Hammer mill*
 (2 2 15) General Community Profile/Places where people congregate/Hair salon
 (2 2 16) General Community Profile/Places where people congregate/Other
 (2 2 20) General Community Profile/Places where people congregate/Grant pay out points
 (2 2 21) General Community Profile/Places where people congregate/NGOs
 (2 2 22) General Community Profile/Places where people congregate/Library
 (2 2 23) General Community Profile/Places where people congregate/Community Hall
 (2 2 24) General Community Profile/Places where people congregate/Creche
 (2 2 25) General Community Profile/Places where people congregate/Game shops or Juke Box
 (2 2 26) General Community Profile/Places where people congregate/Braai Place
 (2 2 27) General Community Profile/Places where people congregate/Shops
 (2 2 28) General Community Profile/Places where people congregate/Sports ground
 (2 2 29) General Community Profile/Places where people congregate/Stall/spaza shop
 (2 3) General Community Profile/Mobility
 (2 3 1) General Community Profile/Mobility/men
 (2 3 2) General Community Profile/Mobility/women
 (2 3 3) General Community Profile/Mobility/children
 (2 3 4) General Community Profile/Mobility/youth
 (2 3 5) General Community Profile/Mobility/mixed
 (2 4) General Community Profile/Local economy

(2 4 1) General Community Profile/Local economy/formal
 (2 4 2) General Community Profile/Local economy/informal
 (2 4 2 1) General Community Profile/Local economy/informal/ntemba or spaza shop
 (2 4 2 2) General Community Profile/Local economy/informal/sex work
 (2 4 2 3) General Community Profile/Local economy/informal/fishing*
 (2 4 2 4) General Community Profile/Local economy/informal/artisans
 (2 4 2 5) General Community Profile/Local economy/informal/street vending
 (2 4 2 6) General Community Profile/Local economy/informal/marketeers
 (2 4 2 7) General Community Profile/Local economy/informal/servicing
 (2 4 2 8) General Community Profile/Local economy/informal/domestic work
 (2 4 2 9) General Community Profile/Local economy/informal/callboys/conductors*
 (2 4 2 10) General Community Profile/Local economy/informal/drivers
 (2 4 2 11) General Community Profile/Local economy/informal/farming
 (2 4 2 12) General Community Profile/Local economy/informal/livestock rearing
 (2 4 2 13) General Community Profile/Local economy/informal/traders
 (2 4 2 14) General Community Profile/Local economy/informal/other
 (2 4 2 20) General Community Profile/Local economy/informal/taxi owner
 (2 4 2 21) General Community Profile/Local economy/informal/child minding
 (2 4 2 22) General Community Profile/Local economy/informal/leasing
 (2 4 2 23) General Community Profile/Local economy/informal/clandestine
 (2 4 2 24) General Community Profile/Local economy/informal/drinking places
 (2 4 3) General Community Profile/Local economy/unemployment
 (2 5) General Community Profile/Poverty
 (2 6) General Community Profile/Environment
 (2 6 1) General Community Profile/Environment/shelter
 (2 6 1 1) General Community Profile/Environment/shelter/material?
 (2 6 1 1 1) General Community Profile/Environment/shelter/material?/mud*
 (2 6 1 1 2) General Community Profile/Environment/shelter/material?/brick
 (2 6 1 1 3) General Community Profile/Environment/shelter/material?/concrete
 (2 6 1 1 4) General Community Profile/Environment/shelter/material?/makeshift
 (2 6 1 1 8) General Community Profile/Environment/shelter/material?/wood
 (2 6 1 1 9) General Community Profile/Environment/shelter/material?/zinc
 (2 6 1 1 10) General Community Profile/Environment/shelter/material?/asbestos
 (2 6 1 2) General Community Profile/Environment/shelter/size?
 (2 6 1 2 1) General Community Profile/Environment/shelter/size?/very small
 (2 6 1 2 2) General Community Profile/Environment/shelter/size?/small
 (2 6 1 2 3) General Community Profile/Environment/shelter/size?/medium
 (2 6 1 2 4) General Community Profile/Environment/shelter/size?/large
 (2 6 1 3) General Community Profile/Environment/shelter/setting? (Zam]*
 (2 6 1 3 1) General Community Profile/Environment/shelter/setting? (Zam]/Village*
 (2 6 1 3 2) General Community Profile/Environment/shelter/setting? (Zam]/Council*
 (2 6 1 3 3) General Community Profile/Environment/shelter/setting?/Site and Service*
 (2 6 1 4) General Community Profile/Environment/shelter/roofing
 (2 6 1 4 1) General Community Profile/Environment/shelter/roofing/thatched*
 (2 6 1 4 2) General Community Profile/Environment/shelter/roofing/iron or zinc sheets
 (2 6 1 4 3) General Community Profile/Environment/shelter/roofing/asbestos
 (2 6 1 4 8) General Community Profile/Environment/shelter/roofing/tiled
 (2 6 1 4 9) General Community Profile/Environment/shelter/roofing/makeshift
 (2 6 1 4 10) General Community Profile/Environment/shelter/roofing/wood
 (2 6 1 5) General Community Profile/Environment/shelter/type (SA)
 (2 6 1 5 1) General Community Profile/Environment/shelter/type (SA)/Informal settlement
 (2 6 1 5 2) General Community Profile/Environment/shelter/type (SA)/Hostels
 (2 6 1 5 3) General Community Profile/Environment/shelter/type (SA)/Council Houses
 (2 6 1 5 4) General Community Profile/Environment/shelter/type (SA)/Council Flats
 (2 6 1 5 5) General Community Profile/Environment/shelter/type (SA)/RDP Houses
 (2 6 1 5 6) General Community Profile/Environment/shelter/type (SA)/RDP Flats
 (2 6 1 5 7) General Community Profile/Environment/shelter/type (SA)/Federation Houses
 (2 6 1 5 8) General Community Profile/Environment/shelter/type (SA)/Privately Built
 (2 6 1 5 9) General Community Profile/Environment/shelter/type (SA)/Other
 (2 6 2) General Community Profile/Environment/clean?
 (2 6 3) General Community Profile/Environment/dirty?
 (2 6 4) General Community Profile/Environment/water, sanitation & waste disposal

- (2 6 5) General Community Profile/Environment/roads
- (2 6 6) General Community Profile/Environment/physical layout
- (2 6 7) General Community Profile/Environment/congestion
- (2 6 8) General Community Profile/Environment/busy?
- (2 6 9) General Community Profile/Environment/quiet?
- (2 6 10) General Community Profile/Environment/dusty?
- (2 6 11) General Community Profile/Environment/VENTILATION
- (2 6 15) General Community Profile/Environment/disasters
- (2 7) General Community Profile/Daily activities
- (2 7 1) General Community Profile/Daily activities/men
- (2 7 2) General Community Profile/Daily activities/women
- (2 7 3) General Community Profile/Daily activities/mixed
- (2 7 4) General Community Profile/Daily activities/children
- (2 7 5) General Community Profile/Daily activities/youth
- (2 7 6) General Community Profile/Daily activities/elderly
- (2 8) General Community Profile/Social mobilisation
- (2 8 1) General Community Profile/Social mobilisation/leadership
- (2 8 2) General Community Profile/Social mobilisation/community organisations
- (2 8 3) General Community Profile/Social mobilisation/other
- (2 9) General Community Profile/Other
- (2 10) General Community Profile/State Grants
- (2 11) General Community Profile/Ethnicity
- (2 12) General Community Profile/Ilness (not TB&HIV)
- (2 13) General Community Profile/Sexual Conduct
- (2 14) General Community Profile/Violence
- (2 15) General Community Profile/Other major problems
- (2 16) General Community Profile/Housing
- (2 17) General Community Profile/Alcohol/Drug Use

(3) TB PREVALENCE

(4) TB TRANSMISSION

- (4 1) TB Transmission/Where
- (4 1 1) TB Transmission/Where/clinic
- (4 1 2) TB Transmission/Where/drinking places
- (4 1 3) TB Transmission/Where/churches
- (4 1 4) TB Transmission/Where/markets
- (4 1 5) TB Transmission/Where/video clubs*
- (4 1 6) TB Transmission/Where/schools
- (4 1 7) TB Transmission/Where/police station or cells
- (4 1 8) TB Transmission/Where/funeral homes
- (4 1 9) TB Transmission/Where/GMP posts*
- (4 1 10) TB Transmission/Where/water points*
- (4 1 11) TB Transmission/Where/households
- (4 1 12) TB Transmission/Where/transport depot
- (4 1 13) TB Transmission/Where/compounds
- (4 1 14) TB Transmission/Where/place of work
- (4 1 15) TB Transmission/Where/other
- (4 1 20) TB Transmission/Where/community halls
- (4 1 21) TB Transmission/Where/sportsgrounds
- (4 1 22) TB Transmission/Where/informal settlements
- (4 1 23) TB Transmission/Where/hostels
- (4 1 24) TB Transmission/Where/braai places
- (4 1 25) TB Transmission/Where/prisons
- (4 1 26) TB Transmission/Where/library
- (4 1 27) TB Transmission/Where/supermarkets
- (4 1 28) TB Transmission/Where/Stalls/spaza shops
- (4 2) TB Transmission/How
- (4 2 1) TB Transmission/How/inherited
- (4 2 2) TB Transmission/How/airborne
- (4 2 3) TB Transmission/How/sexual
- (4 2 4) TB Transmission/How/smoking

- (4 2 5) TB Transmission/How/heavy work
- (4 2 6) TB Transmission/How/dirty environment
- (4 2 6 1) TB Transmission/How/dirty environment/dust
- (4 2 6 2) TB Transmission/How/dirty environment/air pollutants
- (4 2 6 3) TB Transmission/How/dirty environment/smoke
- (4 2 6 4) TB Transmission/How/dirty environment/exposed waste
- (4 2 6 5) TB Transmission/How/dirty environment/other
- (4 2 7) TB Transmission/How/drinking
- (4 2 8) TB Transmission/How/abortion etc.
- (4 2 9) TB Transmission/How/sharing
- (4 2 9 1) TB Transmission/How/sharing/utensils
- (4 2 9 2) TB Transmission/How/sharing/room
- (4 2 9 3) TB Transmission/How/sharing/food
- (4 2 9 4) TB Transmission/How/sharing/communal substance use
- (4 2 10) TB Transmission/How/ventilation
- (4 2 11) TB Transmission/How/overcrowding
- (4 2 12) TB Transmission/How/food
- (4 2 13) TB Transmission/How/other
- (4 2 20) TB Transmission/How/wetness & cold
- (4 2 21) TB Transmission/How/kissing
- (4 2 22) TB Transmission/How/substance abuse
- (4 2 23) TB Transmission/How/Bewitchment
- (4 3) TB Transmission/Who
- (4 3 1) TB Transmission/Who/sex workers
- (4 3 2) TB Transmission/Who/outside
- (4 3 3) TB Transmission/Who/women
- (4 3 4) TB Transmission/Who/men
- (4 3 5) TB Transmission/Who/other
- (4 3 10) TB Transmission/Who/treatment defaulters
- (4 3 11) TB Transmission/Who/those living in hostels or informal settlements
- (4 4) TB Transmission/Fears

(5) SIGNS & SYMPTOMS

(6) TB DIAGNOSTIC PATHWAY

- (6 1) TB Diagnostic Pathway/Where
- (6 1 1) TB Diagnostic Pathway/Where/government health centre
- (6 1 2) TB Diagnostic Pathway/Where/government hospital
- (6 1 3) TB Diagnostic Pathway/Where/private clinic
- (6 1 4) TB Diagnostic Pathway/Where/private hospital
- (6 1 5) TB Diagnostic Pathway/Where/NGO
- (6 1 6) TB Diagnostic Pathway/Where/traditional healer
- (6 1 7) TB Diagnostic Pathway/Where/other
- (6 1 8) TB Diagnostic Pathway/Where/private doctor
- (6 2) TB Diagnostic Pathway/Within community
- (6 3) TB Diagnostic Pathway/Outside community
- (6 4) TB Diagnostic Pathway/Steps
- (6 5) TB Diagnostic Pathway/Type
- (6 5 1) TB Diagnostic Pathway/Type/x-ray
- (6 5 2) TB Diagnostic Pathway/Type/sputum
- (6 5 3) TB Diagnostic Pathway/Type/blood
- (6 5 4) TB Diagnostic Pathway/Type/other
- (6 6) TB Diagnostic Pathway/Barriers
- (6 7) TB Diagnostic Pathway/Opinion

(7) TREATMENT OPTIONS

- (7 1) Treatment Options/Where
- (7 1 1) Treatment Options/Where/government health centre
- (7 1 1 1) Treatment Options/Where/government health centre/environment
- (7 1 1 2) Treatment Options/Where/government health centre/patients
- (7 1 1 2 1) Treatment Options/Where/government health centre/patients/male
- (7 1 1 2 2) Treatment Options/Where/government health centre/patients/female

(7 1 1 2 3) Treatment Options/Where/government health centre/patients/children
 (7 1 1 2 4) Treatment Options/Where/government health centre/patients/resident
 (7 1 1 2 5) Treatment Options/Where/government health centre/patients/non-resident
 (7 1 1 2 6) Treatment Options/Where/government health centre/patients/mixed
 (7 1 1 3) Treatment Options/Where/government health centre/travel to clinic
 (7 1 1 3 1) Treatment Options/Where/government health centre/travel to clinic/how?
 (7 1 1 3 1 1) Treatment Options/Where/government health centre/travel to clinic/how?/on foot?
 (7 1 1 3 1 2) Treatment Options/Where/government health centre/travel to clinic/how?/bus/taxi/train
 (7 1 1 3 1 3) Treatment Options/Where/government health centre/travel to clinic/how?/bicycle
 (7 1 1 3 1 4) Treatment Options/Where/government health centre/travel to clinic/how?/carried/
 wheelbarrow/ trolley
 (7 1 1 3 1 5) Treatment Options/Where/government health centre/travel to clinic/how?/ambulance
 (7 1 1 3 2) Treatment Options/Where/government health centre/travel to clinic/time?
 (7 1 1 3 2 1) Treatment Options/Where/government health centre/travel to clinic/time?/less than 1 hour
 (7 1 1 3 2 2) Treatment Options/Where/government health centre/travel to clinic/time?/1-3 hours
 (7 1 1 3 2 3) Treatment Options/Where/government health centre/travel to clinic/time?/3+ hours
 (7 1 1 4) Treatment Options/Where/government health centre/Previous visit
 (7 1 1 4 1) Treatment Options/Where/government health centre/Previous visit/when?
 (7 1 1 4 1 1) Treatment Options/Where/government health centre/Previous visit/when?/first visit
 (7 1 1 4 1 2) Treatment Options/Where/government health centre/Previous visit/when?/earlier in week
 (7 1 1 4 1 3) Treatment Options/Where/government health centre/Previous visit/when?/previous week
 (7 1 1 4 1 4) Treatment Options/Where/government health centre/Previous visit/when?/previous month
 (7 1 1 4 1 5) Treatment Options/Where/government health centre/Previous visit/when?/>month ago
 (7 1 1 4 2) Treatment Options/Where/government health centre/Previous visit/length?
 (7 1 1 4 2 1) Treatment Options/Where/government health centre/Previous visit/length?/less than 1 hour
 (7 1 1 4 2 2) Treatment Options/Where/government health centre/Previous visit/length?/1-2 hours
 (7 1 1 4 2 3) Treatment Options/Where/government health centre/Previous visit/length?/2-3 hours
 (7 1 1 4 2 4) Treatment Options/Where/government health centre/Previous visit/length?/3+ hours
 (7 1 1 5) Treatment Options/Where/government health centre/cost of visit
 (7 1 1 5 1) Treatment Options/Where/government health centre/cost of visit/less than k5000*
 (7 1 1 5 2) Treatment Options/Where/government health centre/cost of visit/k5000-10000*
 (7 1 1 5 3) Treatment Options/Where/government health centre/cost of visit/k10000-30000*
 (7 1 1 5 4) Treatment Options/Where/government health centre/cost of visit/k30000+*
 (7 1 1 5 5) Treatment Options/Where/government health centre/cost of visit/nothing
 (7 1 1 5 6) Treatment Options/Where/government health centre/cost of visit/less than ZAR5
 (7 1 1 5 7) Treatment Options/Where/government health centre/cost of visit/ZAR5-10
 (7 1 1 5 8) Treatment Options/Where/government health centre/cost of visit/ZAR10-20
 (7 1 1 5 9) Treatment Options/Where/government health centre/cost of visit/ZAR20+
 (7 1 2) Treatment Options/Where/government hospital
 (7 1 3) Treatment Options/Where/private clinic
 (7 1 4) Treatment Options/Where/private hospital
 (7 1 5) Treatment Options/Where/NGO
 (7 1 6) Treatment Options/Where/traditional healer
 (7 1 7) Treatment Options/Where/drug store (pharmacy)
 (7 1 8) Treatment Options/Where/spiritual healer
 (7 1 9) Treatment Options/Where/other
 (7 1 10) Treatment Options/Where/church
 (7 1 11) Treatment Options/Where/herbalist
 (7 1 12) Treatment Options/Where/private doctor
 (7 2) Treatment Options/Within community
 (7 3) Treatment Options/Outside community
 (7 4) Treatment Options/What
 (7 4 1) Treatment Options/What/TB therapy drugs
 (7 4 1 1) Treatment Options/What/TB therapy drugs/problems
 (7 4 1 1 1) Treatment Options/What/TB therapy drugs/problems/adherence
 (7 4 1 1 2) Treatment Options/What/TB therapy drugs/problems/barriers to access
 (7 4 1 1 3) Treatment Options/What/TB therapy drugs/problems/side effects
 (7 4 2) Treatment Options/What/herbal medicine
 (7 4 3) Treatment Options/What/home treatment or remedy
 (7 4 4) Treatment Options/What/other
 (7 4 5) Treatment Options/What/faith healing
 (7 5) Treatment Options/Opinion

- (8) TB CARE**
 - (8 1) TB Care/Health Centre
 - (8 2) TB Care/Hospital
 - (8 3) TB Care/Household
 - (8 4) TB Care/Community Base Carers
 - (8 5) TB Care/Other
 - (8 6) TB Care/Disability Grant
- (9) TB PREVENTION**
- (10) TB STIGMA**
 - (10 1) TB Stigma/Forms
 - (10 1 1) TB Stigma/Forms/name-calling
 - (10 1 2) TB Stigma/Forms/other
 - (10 2) TB Stigma/Causes
 - (10 3) TB Stigma/No stigma
- (11) IMPACT OF TB**
 - (11 1) Impact of TB/Community
 - (11 2) Impact of TB/Household
 - (11 3) Impact of TB/Individual
 - (11 3 1) Impact of TB/Individual/female
 - (11 3 2) Impact of TB/Individual/male
 - (11 3 3) Impact of TB/Individual/children
 - (11 3 4) Impact of TB/Individual/youth
 - (11 3 5) Impact of TB/Individual/adults
 - (11 3 6) Impact of TB/Individual/elderly
- (12) RELATION TO HIV/AIDS**
- (13) PERSONAL STORIES ABOUT TB**
 - (13 1) Personal Stories about TB/Individual patient
 - (13 2) Personal Stories about TB/Within family
 - (13 3) Personal Stories about TB/Within community
- (14) SOURCES OF INFORMATION**
 - (14 1) Sources of information/Where
 - (14 2) Sources of information/Lack of information
 - (14 3) Sources of information/Information request
- (15) INTERVENTION**
- (16) TB KNOWLEDGE**
- (17) HIV/AIDS**

Appendix iii

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A multidisciplinary method to map potential tuberculosis transmission 'hot spots' in high-burden communities

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SUMMARY

BACKGROUND: Global control of the tuberculosis (TB) epidemic remains poor, especially in high-burden settings where ongoing transmission sustains the epidemic. In such settings, a significant amount of transmission takes place outside the household, and practical approaches to understanding transmission at community level are needed.

OBJECTIVE: To identify and map potential TB transmission 'hot spots' across high-burden communities.

SETTING AND DESIGN: Our method draws on data that qualitatively describe a high-burden community in Cape Town, South Africa. Established transmission principles are applied to grade the potential TB transmission risk posed by congregate settings in the community.

Geographic information systems (GIS) technology then creates a visual map, locating potential transmission 'hot spots' in the community.

RESULTS: Drinking places (*sbeebens*), clinics and churches (often gatherings in confined homes) emerge as gathering places that potentially pose a high transmission risk, particularly if located in overcrowded and impoverished areas of the community.

CONCLUSION: This proof-of-concept study demonstrates that combining qualitative techniques with GIS mapping may improve our understanding of potential TB transmission within a community and guide public health interventions to enhance TB control efforts.

KEY WORDS: tuberculosis; transmission; community

SOUTH AFRICA has one of the highest tuberculosis (TB) incidence rates in the world despite having formally adopted the DOTS strategy in 1996.¹ In the poverty-stricken townships of Cape Town, high rates of drug resistance among children with TB suggest that the problem is worsening.^{2,3} A key factor sustaining the TB epidemic in such settings is our inability to break an ongoing transmission cycle; high infection pressure is reflected by high annual rates of infection (calculated at 3.8% in one township community of Cape Town) (Personal communication, N Beyers) and high rates of reinfection disease among adults.⁴⁻⁶

Molecular strain typing methods show that a significant proportion of the disease burden in TB endemic areas results from reinfection events.⁴⁻⁶ These methods highlight that infection/reinfection frequently occurs outside of the household.^{7,8} Verver et al. demonstrated that the majority of transmission among adults occurs as a result of extensive social mixing, cautioning that active case finding among household members is likely to have limited effect in high-burden

communities.⁸ Researchers have also documented the impact of community environmental factors on TB transmission, and in particular how poverty, crowding and poor ventilation encourage transmission.^{9,10} Furthermore, multidisciplinary initiatives have been successful in emphasising the significance of local surroundings. For example, a study conducted in Texas combined biology, epidemiology and network analysis to demonstrate that public places rather than individual people are key to understanding TB transmission,¹¹ and combinations of spatial and molecular analyses have identified TB transmission patterns that show a geographical clustering of TB cases that stretches beyond individual households.^{12,13}

Although social mixing and local environment have been identified as factors fuelling the TB epidemic, traditional TB control efforts focus almost exclusively on the individual patient. This paper introduces a novel multidisciplinary method that integrates qualitative participatory techniques, basic TB transmission principles and geographic information systems (GIS)

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