

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

**KATE ABNEY**

ABNKAT001

**Whoever said a little ‘dirt’ doesn’t hurt?  
Exploring Tuberculosis (TB)-related stigma in  
Khayelitsha, Cape Town**

Faculty of Humanities

Department of Social Anthropology

University of Cape Town

2011

MA dissertation supervised by Dr. Helen Macdonald submitted in partial fulfillment of the requirements for the award of the degree of MSocSc in the Department of Social Anthropology

## Plagiarism Declaration

1. I know that plagiarism is wrong. Plagiarism is to use another's work and pretend it is one's own.
2. Each significant contribution to, and quotation in this dissertation that I have taken from the works of other people has been attributed, and has been cited and referenced.
3. This dissertation is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

Signed: ..... Date: .....

University of Cape Town

## Acknowledgements

I wish to thank the Centre for Infectious Disease Epidemiology and Research (CIDER) at the University of Cape Town Department of Public Health for funding this research. The deepest respect and gratitude goes to those who participated in this project: thank you for sharing your time, thoughts and sometimes deep personal pain with me. I am very grateful for the ongoing guidance, support, (and unwavering patience through the writing process) from my advisor, Dr. Helen Macdonald, who has carefully and thoughtfully cultivated this research interest. She never failed to show me new entry points and intellectual tools which enriched my work immensely. Thandi, sisi wam: Enkosi and Ndiyabulela kakhulu for your work ethic and budding interest in anthropology. I hope you enjoyed our time in the field. To all in Thandi's family: thank you for your *relentless* hospitality, a 'home base', and endless cups of tea, Ndiyabulela. To Patrick Madden: my editor, thank you for your patience, sense of humour and critical feedback. My writing will never be the same and I found you just in time! To the Abney clan: thank you for patience and space when I had to write during the holidays, and thanks for the continued support from across the puddle. To Laura Winterton: thank you for the comic relief, open ears and sensitive insight. Lastly to Pet'a Mach: Thanks for the big things, the small things, and everything in between.

## **Abstract**

This paper considers the significance of Tuberculosis (TB)-related stigma and stigmatising acts in areas of Khayelitsha Township in Cape Town, South Africa. Data is drawn from three months of in-depth participant observation, interviews and support group sessions. Stigma is a moral process which emerges within social webs of meaning making. By focusing on patient narratives and local illness transmission models (ITMs) both ‘enacted’ and ‘felt’ stigma are explored. Three themes emerged during fieldwork: the singularity of dirt as a mode of TB transmission, the paradoxical visibility of the face hidden by the clinical mask, and the ordering/disordering intentions of those who gossip. Utilising Das’ (1990) idea of ‘organising images’ to understand these themes, it is evident they are each imbued with power and meaning within local worlds and thus extend our understanding of stigma and stigmatisation. I argue for the theoretical expansion of stigma through employing alternative literatures, such as the anthropology of violence, witchcraft and narrative studies. In addition, new methods need to be explored which mirror the adversity faced by those living with TB. In this work I suggest ‘provoking’ stigma is the most effective manner to understand its effects.

# Table of Contents

<b>Table of Figures</b> .....	7
<b>Chapter 1: Introduction</b> .....	8
Local, Moral Worlds .....	9
The Landscape of TB.....	11
The need for ethnographic engagement.....	13
Stigma, Stigmatisation .....	14
TB in Metaphor.....	17
The Imagined and the Imaginary .....	18
Notions of Contagion and Ethnographic Engagement.....	19
Imaginings of Khayelitsha: Ethics and the Politics of Location.....	22
Improvisation .....	25
Methodologies.....	26
In Conclusion .....	29
<b>Chapter 2: Dirty Things and Dirty Habits</b> .....	31
Dirty Places .....	32
Slum Health .....	34
‘The place is not healthy’ .....	35
Managing ‘Dirt’ .....	39
Dirty things .....	43
Drawings and explanations .....	45
Dirty Habits make for Dirty People .....	49
Concluding thoughts .....	51
<b>Chapter 3: ‘Losing Face’</b> .....	53
Mask ‘etiquette’ .....	56
Protection and prevention for whom?.....	56
Masks .....	59

In the clinic .....	61
‘This mask is different’ .....	62
Big Diseases, Big Masks.....	63
Closed Faces and ‘Losing Face’ .....	64
Provoking Stigma.....	66
The Taxi Experiments.....	68
Negotiating spaces and proximity.....	70
Concluding comments .....	70
<b>Chapter 4: Infectious Language: Gossip and Envy .....</b>	<b>72</b>
The Gossip Reel.....	72
The Rumour Mill .....	74
Gossip as Narrative Event and Social Drama .....	74
Nosabata and the Gossips .....	75
Visible signifiers of the body, presence and mobility.....	77
Disclosure and the Temporality of Gossip.....	78
‘Social Diagnosis’, Betty and Disclosure .....	79
Jealousy and Envy.....	81
Indirect Violence and Gossip.....	82
Conclusion .....	83
<b>Chapter 5: Conclusion: A time of need: Identifying ‘what is at stake’.....</b>	<b>85</b>
<b>Appendices.....</b>	<b>88</b>
<b>Bibliography .....</b>	<b>94</b>

## Table of Figures

<b>Figure 1: Storm drain in Blue Falls.....</b>	<b>33</b>
<b>Figure 2: Residential Dumping site in Cloverdale .....</b>	<b>34</b>
<b>Figure 3: Water Tap and surrounding area, Blue Falls.....</b>	<b>37</b>
<b>Figure 4: Foot path between shacks, Blue Falls .....</b>	<b>38</b>
<b>Figure 5: Dumping in between shacks in Cloverdale .....</b>	<b>38</b>
<b>Figure 6: Rubbish strewn behind public toilets, Cloverdale .....</b>	<b>39</b>
<b>Figure 7: 'Clean' and 'Dirty', illustration, little girl, 7 years old.....</b>	<b>39</b>
<b>Figure 8: Front view, author wearing N95 mask .....</b>	<b>55</b>
<b>Figure 9: Side view, author wearing N95 Mask .....</b>	<b>55</b>
<b>Figure 10: Closed shebeen (tavern) window, Cloverdale .....</b>	<b>66</b>

University of Cape Town

## Introduction

‘TB is there... way back. It’s an old disease.’<sup>1</sup>

At the end of March, 2010, I spoke to a nurse who works in the Tuberculosis (TB) treatment area of a government clinic in metropolitan Cape Town. She related stories of ‘outside’ patients who visited her clinic seeking TB diagnosis and treatment. She waved her hand, emphatically pushing away the air as if to emphasize how far away ‘these people’ really were. Her hands ‘swept’ *them* beyond the city centre out to the periphery, far, far away. Later she clarified ‘outsiders’ as ‘those people’ originating from the township of Khayelitsha, a twenty-minute car ride from the city centre.

Initially, this conversation does not appear unusual. People who are ill pursue health services in varying locations in order to receive a diagnosis and treatment. For TB patients, the situation is more complicated. Patients who test positive for ‘active’ TB must enrol in a nation-wide TB register as stipulated by the South African Department of Health (SA DoH). One function of this process locates patients within a particular geographic locale and identifies the closest clinic where they can receive TB treatment. Importantly, as long as a TB patient registers at their ‘local’ clinic, they may receive treatment anywhere in the metropolitan Cape Town area, free of charge<sup>2</sup>.

The Directly Observed Therapy strategy (DOTs) is a centralised treatment strategy favoured by the SA DoH. As the name implies, medicine is administered to patients and they are directly observed ingesting their treatment. In severe cases, patients are hospitalised in long-term TB care facilities. TB treatment is a time-intensive engagement, generally involving six months of daily medication for ‘normal’ TB, and up to two years or more for the multiple-drug-resistant (MDR-TB) and extensive-drug-resistant (XDR-TB) strains. Although these periods may differ between individuals, the onus for treatment success rests largely on the patient. The nurse explained that when a patient ‘defaults’ (a term commonly used to describe non-adherence to TB treatment specifically)<sup>3</sup> there is a follow-up residential visit from a health-care worker (HCW). Often, upon arrival at the registered address, HCWs find

---

<sup>1</sup> Personal correspondence July 2010

<sup>2</sup> Cape Town Municipality area.

<sup>3</sup> Adherence and non adherence are also common terminology describing patient’s medicine taking habits and commitment to treatment for TB. Non adherence means to stop taking treatment.

that the provided address is false. The ‘real’ resident is generally irritated by this unwanted visit. The HCW leaves and the ‘outsider’ becomes virtually impossible to trace.

This dialogue piqued my interest for a number of reasons. Firstly, the nurse was expressing varying degrees of frustration, especially about the very high incidence of a century-old, curable disease. She seemed exasperated with the mobility of patients whom she largely regarded as ‘outsiders’, to the extent that her conversation took on discriminatory tones. Lastly, her language and hand gestures emphasized distance and a vastness of space, reinforcing the idea of their being ‘outsiders’. I was of the impression that she was making a distinct characterisation of certain people and where they live. This moment was a pivotal entry point into the larger conversation about stigma.

I reflected somewhat uncomfortably on her comments for days. I started to think about the implications of this type of patient behaviour within a high-risk TB environment like South Africa, and specifically Cape Town. My thesis began as a search for these ‘outside patients’: who they are, where they come from, and why they would choose treatment far away (apparently) from their ‘real’ addresses, assuming they had addresses. It seeks to understand the motivations behind this type of treatment-seeking behaviour and mobility. Through this focus, it became clear that researching stigma would be a more practical approach to understanding patient mobility. If stigma could be shown to influence an individual’s mobility, then a patient’s mobility patterns would potentially emerge in conversation with research participants. Also, it became pertinent to recognize both biomedical and non-biomedical TB transmission models. I had to understand how people conceptualised TB transmission in Khayelitsha and how (if at all) their ideas differed from biomedical explanations. I speculated that there might be a link between TB transmission models and TB-related stigma. Lastly, if this type of treatment-seeking behaviour was perpetuated by stigma, I might draw some conclusions linking stigma, TB transmission models and mobility.

## **Local, Moral Worlds**

‘Daily life matters, often deeply.’ (Yang et al 2007:1528).

The data presented is taken from three months of fieldwork in different parts of Khayelitsha Township in Cape Town, South Africa. My research conveys the lived experience of TB-

related stigma and how it affects 'local worlds' (Yang et al 2007:1528). Local worlds are landscapes where 'daily life takes place' (ibid). Most significantly in a local world *something* is at stake, whether it is a job, a relationship, money, integrity, or something else. Stigma is a 'moral experience', a 'register of everyday life and practical engagement that defines what matters most for ordinary men and women' (Kleinman 1997, 1999, 2006 ci Yang et al 2007:1528). Goffman (1963) too recognised stigma as a moral process whereby an individual developed a social identity in accordance with socially constructed categories. This 'moral career' let an individual gauge how society would or would not respond to certain *recognizable* discrediting characteristics (1963:32, emphasis mine). Yang et al refer to this awareness as 'the moral mode' of experience in which it is those *things* which are at stake, those *things* which can be gained or lost (2007: 1528 emphasis mine).

Many anthropological or ethnographic accounts emphasise the social dimensions of illness (Kleinman 1988), stigma and structural violence (Farmer 1992, 1999, 2005) and social suffering (Kleinman, Das, & Lock 1997, Scheper-Hughes 2003). As a result, this paper could have assumed any number of directions. For the scope of this work, I investigated the moral complexities of stigma and how it materialised within a social experience of illness. A *social* experience of illness involves many actors: patients, family, friends, relatives and complete strangers. A social experience of TB-related stigma is embedded in a web of relationships between people and things, it is an agglomeration of *many* local worlds. Here, the focus is how stigma is made visible within these webs of social relationships. As theorists Deacon (2005) and Yang et al (2007) caution, it is not sufficient to assume that stigma produces discrimination. To assume a one-to-one relationship between the former and the latter would deny the historical, cultural, political and social conditions which shape different prejudicial behaviours. Therefore, it is important to investigate the unique circumstances of stigma as a seemingly cross-cultural phenomenon (Link et al 2004).

Stigma remains a complex concept and one on which theorists continue to disagree. . However, it is important to understand the different elements which constitute the initiation and circulation of stigma (Parker & Aggleton et al 2003, Deacon 2005, Yang et al 2007, Gilbert & Walker 2010). I suggest that stigma and stigmatisation<sup>4</sup> are 'ordering' mechanisms, reinforced through compliance with normative moral values and codes of conduct. I also argue that stigma surrounding TB in Khayelitsha is motivated by perceptions of the ways TB

---

<sup>4</sup> I discuss the differences between the two terms later in the introduction.

is transmitted and contracted . This understanding would regard TB-related stigma as particularly damaging because its transmission routes are difficult if not impossible to trace. The ambiguity of stigma parallels the ambiguity of notions of TB transmission.

Within the context of this research it is necessary to recognise the influence of HIV/AIDS in stigma production. This paper does not suggest that the stigmatising processes and effects for TB and HIV are the same, but given the large co-infection rate in South Africa there are many overlapping ideas about both diseases, together and separately. Although Deacon (2005), and Parker and Aggleton (2003) warn of conflating the ideological constructs of stigma with the acted processes thereof, I argue that in order to understand the ideological framework behind stigma, the visible traces of stigma must be better understood.

Lastly, it is necessary to contextualise the intricacies and dimensions of TB in Cape Town. Issues such as personal freedom and safety, human rights, transmission models, stigmatising components and metaphorical representation are just some of these discourses. Throughout this paper I address both biological and non-biological explanations of disease transmission, demonstrating the complexities and the limitations of both without championing one over the other. To contextualise the research setting, I now provide a brief introduction to the global and local biomedical landscape of TB.

## **The Landscape of TB**

### **Global**

Although TB is a curable disease which was identified over a century ago, its re-emergence signifies new challenges in public health endeavours. It is highly contagious and is spread through the air, making it almost impossible to trace its transmission. Most often, TB manifests in the pulmonary form<sup>5</sup>, although other forms of TB are possible. When someone who has ‘active’ TB coughs, sneezes, spits or talks, TB germs (bacilli) are propelled through the air. Ingesting or inhaling even a small number can lead to TB infection, although not everyone will manifest active TB –the bacilli can lay dormant as ‘latent TB’. It is estimated

---

<sup>5</sup> Of the lungs and chest area.

that every person who has active TB infects 10-15 people every year, on average<sup>6</sup>. The WHO also estimates that one new person is infected with TB every second.<sup>7</sup>

According to the WHO, 30% of the world's population (2 billion people) are infected with TB bacilli<sup>8</sup>. It remains the leading killer of people who are HIV/AIDS-positive. In 2008 there were 9.4 million new TB cases and 1.8 million people died from the disease, 500,000 of whom also had HIV. The WHO calculates that this equates to 4,500 deaths a day on average<sup>9</sup>. Due to the high incidence of HIV/AIDS in the country, South Africa's population is particularly vulnerable in this regard.

### **South Africa**

Statistical medical evidence (Bateman 2006 and 2007, Singh et al 2007, London 2009, Macpherson et al 2009) demonstrates the need for diversified approaches to *Mycobacterium tuberculosis* (TB) treatment in South Africa. According to current reports (WHO 2010, MSF 2008-2009) South Africa is on the verge of a TB epidemic. The situation has been exacerbated by the emergence of MDR-TB and XDR-TB in South Africa in late 2006 (Bateman 2006). South Africa ranks among the top five countries with the largest number of MDR-TB cases, along with India, China, the Russian Federation and Bangladesh. These deadly and chronic repercussions of the disease necessitate a new approach to treatment and vaccination to prevent further spread (Bateman 2007).

The SA DoH favours a centralised approach to TB treatment and voluntary isolation for patients who test positive for drug-resistant strains. The ethical and human rights considerations are of paramount importance in considering isolation and successful containment of further infection, since involuntary patient isolation is an extremely contentious issue (London 2009, Harper 2010). There is a significant need, however, to investigate patient perceptions of TB and to understand the lived mobility of those who are being treated for this disease. One of the major concerns here is the potential infection risk unknowingly posed to others (Falzon & Ar't-Belghiti 2007:1266, Macpherson et al 2009). Stated simply, if an individual does not understand how TB is transmitted, is unable to

---

<sup>6</sup> Fact sheet N°104 November 2010

<sup>7</sup> ibid

<sup>8</sup> WHO 2009 Stop TB Update

<sup>9</sup> ibid

recognize symptoms, and/or is unknowingly carrying the disease, a delay in diagnosis may allow the infection of many more people.

Many explanations are offered for the current TB situation in South Africa (Bateman 2006, 2007). Firstly, South Africa has a highly politicized and publicized history of a contemporaneous HIV/AIDS epidemic. Many TB patients (although not all) are also HIV-positive. Large-scale non-adherence to TB drug regimes has also contributed to the spread of MDR-TB and XDR-TB, although the government has also been cited for a poor response (Bateman 2006, Padayatchi & Friedland 2007:1036, Singh et al. 2007, and London 2009). Incompetent medical staff and inappropriate drug regimes administered to patients have greatly complicated the circumstances (Padayatchi & Friedland 2007, Macpherson et al 2009). Many health-care workers have migrated from public to private sectors, exponentially increasing the demand on existing structures. Government clinics and hospitals are generally under-resourced and underfunded, a case of enormous needs coinciding with limited supply (Bateman 2006, 2007). Lastly, given the history of Apartheid, there exist huge social inequalities and class differences in South Africa. For previously advantaged populations, social, economic, political and historical inequalities aggravate the already great obstacles to accessing health care (Farmer 1996, 2005).

### **The need for ethnographic engagement**

Although a critical, medical anthropological approach is well situated to examine the lived reality of TB infection, there is a dearth of TB-related ethnographic material available. Harper's work (2006, 2010) in Nepal illustrates the ability of ethnographic research to uncover crucial details often overlooked by health professionals. Investigating DOTs procedures, he was able to identify moral and gender-based stigmatisation amongst TB patients and their immediate kin. Harper writes, 'For many this was a disease linked to notions of impurity, and locally widely associated with dirt and poor habits like drinking and smoking' (2006:62). His findings align with a moral discourse of hygiene, resulting in the marginality of patients and sometimes their social networks too. Draus's work (2004) critically examines the stigmas associated with TB and his experiences as a public health worker in New York and Chicago during the re-emergence of the disease during the late 1980s and early 1990s. Farmer's works (1992, 1996, 1999, 2005) examine the relationship between stigma, structural violence and the outbreak of HIV and MDR-TB in Haiti. His work

echoes the need for more personal ethnographic engagement and an intense anthropological assessment of contagious disease ‘risk’ factors. Steinberg’s *Three Letter Plague* addresses stigma associated with HIV/AIDS and TB in the Eastern Cape, socially ‘acceptable’ behaviour and the use of anti-retrovirals (ARVs) (2008). His work is among few which recognise the moral and social complexities of stigma in South Africa and the often dire social consequences for someone who is stigmatised. Recognising that there are many different theoretical foundations to draw from in relation to stigma, for the scope of this paper I focus on anthropological and sociological perspectives on stigma.

## **Stigma, Stigmatisation**

‘Stigma... is creaking under the burden of explaining a series of disparate, complex and unrelated processes to such an extent that use of the term is in danger of obscuring as much as it enlightens.’ (Prior et al 2003 ci Deacon 2005:2)

Higgins (2007) advocates a ‘critical literacy’ approach in interrogating keywords which are used frequently as buzzwords, yet are ultimately ‘slippery’ when a singular definition is required. I take up his approach in this piece, not to suggest that stigma or stigmatisation necessarily possess one singular definition but to argue that analysing keywords provides clarity for advancing theoretical considerations. Keywords are a useful intellectual tool with which to frame stigma discourses. This is theme runs throughout the paper, but I begin with stigma itself. ‘Stigma’ is used often and has ‘immediate appeal’, yet there remains an ‘underlying uneasiness regarding its precise referent and related conceptual coherence’ (Higgins 2007:99).

## **Stigma**

- Noun: (plural stigmas or especially in sense 2 stigmata)  
a mark of disgrace associated with a particular circumstance, quality, or person.
- (stigmata) (in Christian tradition) marks corresponding to those left on Christ's body by the Crucifixion, said to have been impressed by divine favour on the bodies of St Francis of Assisi and
- Medicine: a visible sign or characteristic of a disease. a mark or spot on the skin.<sup>10</sup>
- Noun: Shame, disgrace, dishonour, ignominy, opprobrium, humiliation.<sup>11</sup>

---

<sup>10</sup> Concise Oxford Dictionary 2011

The following section establishes a tenable definition of stigma employed throughout the rest of the work. Again, I emphasise the moral ordering/othering function of stigma and its influence on social contexts. According to Aggleton, stigma is an ancient concept (2002:8 cited in Mawadza 2005:3 np). The origins of the word derive from the Classical Greek era and language, where pariahs were branded with a special mark labelling them socially inferior to others (ibid). Much of established sociological theory invokes Goffman's original definition (1963) which identified stigma as 'an attribute which is severely discrediting', thus devaluing an *individual's* status according to society (cited in Brown, Trujillo, & MacIntyre 2001, Link & Phelan 2001, emphasis mine). Goffman (1963) also differentiated between stigma that are 'discredited' and those that are 'discreditable'. The former refers to visible stigmas and the latter to invisible ones<sup>12</sup>. I suggest that invisibility and visibility are instrumental to stigmatisation processes in local worlds.

## **stigmatisation**

- Noun: act of characterising something as disgraceful; act of marking with a stigma; branding, act of stigmatising (also stigmatization).<sup>13</sup>

Stigmatisation is the act of discrimination, accusation or condemnation of another person or group. Consequently, stigmatisation actively produces social marginality and alienation due to negative connotations associated with the specific stigma attribute. Link and Phelan state that stigma is present when: '... elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them' (2001: 377 cited in Heijnders and Van Der Meij 2006:1). Deacon adds, 'Stigmatisation is regarded as a complex social process tied into existing social mechanisms of exclusion which include stereotyping and scapegoating' (2005:3). Parker and Aggleton maintain that 'stigma must be regarded as a social process in which people out of fear of the disease want to maintain social control by contrasting those who are normal with those who are different' (2003 cited in Heijnders and Van Der Meij 2006:1). Parker and Aggleton's definition of stigma differs from the others

---

<sup>11</sup> Concise Oxford Thesaurus 2011

<sup>12</sup> This ties into a larger theme of visibility and invisibility in this work.

<sup>13</sup> Concise Oxford Dictionary 2011

provided because it directly addresses disease and stigma. In their definition the disease is the discrediting attribute, but it is the *individual* who becomes the carrier of the stigma and a target for stigmatisation thereafter.

Stigma can also be deployed in myriad ways. Mawadza argues that ‘language is central to how stigma is perpetuated and constructed’ (2005 np). Stigma is multi-faceted and unfolds in various forms, from media representation and biomedical discourse to popular culture. Ogden and Nyblade identified different types of AIDS-related stigmas in their study covering Ethiopia, Tanzania, Vietnam, and Zambia (2005). In their research they identified various forms of stigma under the following categories: linguistic/verbal, social, institutional and physical (2005:26). These categories were mutually distinct due to different modes and scales of stigmatising practices, but all featured social interaction between individuals and groups. Thus, stigma exists because of its diverse reproductions (knowingly and unknowingly) within a discursive, social space. It is crucial to add here that TB and HIV/AIDS stigma and stigmatising practices often overlap due to the high co-infection rate. As one of my interlocutors articulated, ‘Sometimes they think because you have TB, you also are HIV-positive’.

‘For the stigmatized, stigma compounds suffering. For the stigmatizer, stigma seems to be an effective and natural response, emergent not only as an act of self-preservation or psychological defence, but also in the existential and moral experience that one is being threatened.’ (Yang et al 2007:1528)

Lastly, the circulation of stigma and the act of stigmatisation produce both visible and invisible boundaries separating the ‘normal’ and ‘abnormal’, ‘us’ and ‘them’, the ‘outsiders’ and the ‘insiders’, the ‘self’ and the ‘other’ (Link Phelan 2001, Ogden Nyblade 2005). These ideas link to Douglas’s thoughts on the marginality of the borders of the body, primarily the ‘marginal stuff of the most obvious kind...spittle, blood, milk, urine...by simply issuing forth have traversed the boundary of the body’ (1966:150). She argues, ‘...all margins are dangerous’ and warns, ‘The mistake is to treat bodily margins in isolation from all other margins’ (ibid). In relation to TB, an airborne and highly contagious disease, it is this very ‘marginal stuff’ which emerged repeatedly in conversations throughout research. I suggest that because it is almost impossible to trace transmission, margins are rendered invisible as the microscopic bacterium is ingested. Thus, the margins of the body are permeable and vulnerable to things considered impure or unhygienic.

In a study of Filipino immigrants in the United States, Yamada (et al 1999) concluded that explanatory models of TB were directly linked with social stigmatisation. Notions of TB patients as ‘dirty’, ‘highly contagious’ and ‘infected’ were accompanied by severe social marginality and isolation by their perpetrators (1999:478). In a comparative study of infectious disease stigmas in Hong Kong, popular TB stigmas were widely attributed as non-morally deplorable. Rather, public opinion dictated that poor hygiene and patients’ bacterial exposure were the root causes of infection (Mac et al 2006). In my research I found similar stigmatising language, engineered through a set of moral imperatives. This moralised language was presented as an ongoing hygiene discourse which placed the ill patient within a dirty/clean dichotomy.

Much of the literature on stigma focuses on those who are perceived as stigmatisers and is presented on an ‘individual level’ (Parker & Aggleton 2003, Deacon 2005, Yang et al 2007, Gilbert & Walker 2010). Other literature has focused on public opinion polls and surveys about HIV/AIDS stigma and those perceived to be ‘at risk’ (Blendon & Donelan, 1988; Stipp & Kerr, 1989, Herek & Glunt, 1991, Blendon et al 1992, Herek, 1999, Herek et al 2002, Price & Hsu, 1992). As many theorists have observed, stigma may be ‘enacted’, ‘felt’, or both (Weiss and Ramakrishna 2001, Parker and Aggleton 2003, Scambler 2004, Gilbert and Walker 2010). The previous section focused on ‘enacted’ forms of stigma: stigma which is visible through physical and spoken processes. Enacted stigma arises in the form of an event or set of events – it can be witnessed. In contrast, ‘A ‘felt’ negative evaluation refers to the shame associated with having a condition and to the fear of being discriminated against on the grounds of imputed inferiority or social unacceptability’ (Chapple, Ziebland & McPherson 2004:328). Gray points out that, ‘...the experience of stigma is often based on a perceived combination of the two [enacted and felt stigma] and may have the effect of overestimating the frequency of enacted stigma’ (2002:740).

## **TB in Metaphor**

‘TB is a disease of time; it speeds up life, highlights it, spiritualizes it.’ (Sontag 1978:14)

Susan Sontag wrote about the metaphors attendant to illness and the manner in which metaphor moulds experience and perception, thus producing and exacerbating value judgements towards those whom are ill (1978). Sontag’s main argument is that victims of

disease are often blamed for their own suffering by people around them; she implores society to strip disease of metaphor and depend solely on biomedical descriptions. She also argues that some metaphors reach epidemic proportions (in frequency or incidence) when the cause of illness or treatment is unknown and the illness thus achieves a complex metaphorical representation. This has historically been the case with TB, cancer and currently with HIV/AIDS.

Sontag's work chronicles TB and the metaphors that have surrounded the disease over time, especially the romanticised visions of the TB sufferer. In the 19<sup>th</sup> century, TB was regarded as a disease of passion and 'inward burning'. A TB patient was deemed to be of more acute sensibilities, emotionally, creatively and intellectually (and sometimes these qualities were seen as a precursor to contracting the illness). According to Sontag, the romantic images of the TB patient were the first widespread examples of a 'distinctively modern activity, promoting the self as an image' (1978: 29). Sontag failed to address the second part of her argument, however: biomedicine is equally laden with (and responsible for) metaphors related to disease. Metaphors are inherent in language as symbolic meaning-making devices, so language cannot be stripped of metaphor. Metaphors are utilitarian: they exist for a purpose beyond demoralising those who suffer from the diseases they come to represent. Metaphoric thinking and image making are creative processes which engage imagination and this may underlie the efficacy and persistence of illness metaphors. In response to Sontag's influential book, DiGiacomo (1992) calls for a more critical medical anthropology which does not take for granted the suffering of the individual, nor render them invisible through a biomedical gaze and/or statistical analysis (1992:133).

## **The Imagined and the Imaginary**

Yet how do illness metaphors relate to stigma? I suggest that metaphors animate the moral dimensions of stigma, they help to order a disorderly social world. TB is an extremely ambiguous disease, confounding attempts to trace its transmission. Metaphors often mimic the negative qualities of stigma and equally the use of metaphors implies a 'distancing': the image of a TB patient in metaphor is more easily grasped than the 'real thing'. Lastly, metaphors are a linking mechanism: they assist in creating a larger narrative that is constantly being negotiated, re-authored and re-scripted. Local worlds and chronic illness are often

portrayed through metaphorical language. Metaphor is an inescapable aspect of language and probably impossible to discard totally. In conversation about social identity and ethnicity, Jenkins helps to illustrate this point, one which I employ throughout this work. He relates:

‘If ethnicity is imagined, however, it is anything but imaginary. It is ‘real’, in that people orient their lives and actions in terms of it, and it has very definite consequences. What is more, ethnicity may be emotionally authentic, or tactically and strategically manipulable, or, indeed, both simultaneously; for these are not necessarily contradictory. Everything depends on constraints and opportunities, contexts and situations, cultures and histories.’ (2008:114)

TB metaphors may be imagined, but this does not mean they are imaginary. On the contrary, they are real in effect. I extend this argument to stigma and TB transmission models. For example, if someone conceives of TB transmitted solely through dust inhalation (an imagined concept) they act upon their belief by removing dust from their house. As researchers we can study the *effect* of these imaginings because they manifest themselves within a local world. Someone may imagine themselves being stigmatised, or they may have fear of stigma associated with TB. Their fears are framed around their local context. They are intrinsically positioned within a web of meaning-making and orient their lives accordingly. Often, this is a truly dangerous existence and perceived threats are real and imminent. Yang et al sum up my point:

‘Responses are not only determined by cultural imperatives, meanings, or values, but refer to a real world of practical engagements and interpersonal dangers. Both the stigmatisers and the stigmatised are engaged in a similar process of gripping and being gripped by life, holding onto something, preserving what matters, and warding off danger.’ (2007:1528)

I now shift focus to notions of contagion and how these may influence stigma.

## **Notions of Contagion and Ethnographic Engagement**

‘...recognition that concepts of diseases are constructed differently in different cultures points out the manner in which all disease concepts, including biomedical ones, are related to social and cultural factors...’ (Yamada et al 1999:480)

Many anthropological texts have acknowledged the importance of understanding the causes of illnesses according to those who suffer from them. Technically speaking, ‘Ethnoetiology is the branch of ethnomedicine concerned with theories of illness causation’ (Green 1998:127).

With the exception of a few scholars, ‘African’ contagion theories are grounded in supernatural, exogenous, and witchcraft paradigms (Green 1998). This line of thinking situates Africans as irrational, superstitious, or steeped in the supernatural. It is not my objective to duplicate these misconceptions, although I am aware that I may inadvertently and unintentionally do so. I refer to Jenkins’s thoughts on imaginary vs. imagined (2008) which run throughout this piece: while the former and the latter cannot be conflated, ‘Africans’ have historically been aligned with the supernatural, and thus the imaginary.

Historically, many writers (including anthropologists) have contributed to this misconception:

‘The first thing to grasp is the fundamental difference in ideas of causation between Western man and the African. Among all Bantu-speakers all misfortune and all illness and death, except that from extreme old age, is sent by supernatural beings. There are two possibilities and only two. The misfortune can be caused by ancestral shades or by a witch/sorcerer.’ (David Hammond-Tooke 1975 ci Boonzaier 1988:77)

‘If evil eye or witchcraft or soul loss is a major component of a culture’s explanatory model of illness, it is less likely that a person from that culture will believe that one can control disease through pragmatic, preventative measure.’ (McElroy and Townsend 1996, ci Green 1999:218)

In discussing ‘First world’ and ‘Third world’ patients, Boonzaier argues that overgeneralisations such as these are dangerous. He writes:

‘Statements such as these appear to deny that Africans or members of the “third world” have the capacity to think rationally or to understand natural causes of disease and ignore the reality of change associated with a long history of contact with Western medicine.’ (1988:77)

However, there are also a few works which rebuke these reified notions (Douglas 1966, Murdock 1980, Green 1998, 1999). In her seminal piece on pollution and contamination Mary Douglas writes:

‘Pollution ideas work in the life of society at two levels, one largely instrumental, one expressive. At the first level, the more obvious one, we find people trying to influence one another’s behaviour. Beliefs reinforce social pressures...’ (1966:3)

She also adds that pollution beliefs help structure a disorderly social world, thus reinforcing particular ideas about status, perceived danger, and immoral acts (1966). Are ideas about pollution and contagion similar and in what ways are they different? Edward Green, arguably the foremost scholar and founder of African 'Indigenous Contagion Theory' (ICT), asserts that contagion and pollution are interlinked (1999). Green asks, '*what about variation?*' (1999: 35) and provides ample ethnographic examples to highlight this observation (1999:42 - 47).

Green bases ICT on Murdock's analysis of African contagion models and explanations (1980). About infectious, contagious diseases like TB and HIV/AIDS, he argues that in contrast to popular belief ICT generally does not link causation to supernatural or personalistic causes but stems instead from naturalistic or impersonal causes (1998, 1999).

He states:

'ICT comprises at least three types of etiologic belief: (1) 'naturalistic infection' (or indigenous germ theory); (2) 'mystical contagion' or pollution; (3) environmental dangers (the belief that elements in the environment including the air one breathes can cause or spread illness).' (1998:128)

Green supports integrating local belief systems and biomedical practice, citing their similarities (1988). Boonzaier, too, emphasises the significance of many treatment avenues used by South African patients (1985). He argues that 'patients can and do exercise significant choice in movement *between* different medical systems' (1985:237 emphasis in original). Fiona Ross's ethnography based in 'The Park' speaks to the socially constructed dichotomous relationship between biomedicine and 'local' interpretation (2010). Ross argues that the local and the biomedical conflate and resemble an agglomerate of local understandings of disease (2010:125-126). MacDonald et al's study on indigenous Canadian groups concludes that although local knowledge lacks biomedical underpinnings, a formidable knowledge base is present in local conceptions of TB (2010). She also advocates integrating this knowledge into biomedical assessments when treating these communities (2010:580). Mengoni's work in Chiapas, Mexico (1996) found that TB patients interpreted TB causation using a shared, communal knowledge framework and developed positive or negative feelings about the physical attributes of sputum. Stigma then would develop based on the negative attributes. This culturally sensitive approach mimics Waisboard's call for 'social rationality' when it comes to treating different populations and when dealing with varying conceptions of contagion, transmission and stigma (2007).

Stigma is made visible in myriad ways and is not distinct from Illness Transmission Models (ITMs). Rather, I argue they are mutually interdependent. I choose the terminology ITM because I have reservations about the term ‘Indigenous Contagion Theory’ (Green 1998, 1999). ‘Indigenous’ reifies the concept, removing local ‘African’ perspectives from a long historical engagement with biomedicine. ‘Theory’ reduces their perspectives to an idea. This terminology inadvertently produces a dichotomy between the ‘traditional’ and the ‘modern’, creating a strict fissure between the biomedical and non-biomedical. As Spiegel has warned (1994), reproducing binaries of this sort can be dangerous as it implies the pre-modern and an inability to conform or adjust to modern ways of thinking. He observes:

‘The epithet ‘traditional’ has long been used as an alternative to such labels as ‘uncivilized’, ‘primitive’, ‘pre-literate’, ‘tribal’ or ‘non-western’ – a namely to identify the ‘other’. Indeed, much social science has contrasted ‘tradition’ on the one hand with ‘reason’, ‘rationality’ and ‘science’ on the other (Shils 1981), and it has implied that the lives of ‘traditional’ people are ‘bound by the cultural horizons set by [their] tradition’ whereas ‘modern’ people are conceived as culturally dynamic, oriented to change and innovation’ (Eisenstadt 1973:1). (Spiegel 1994:186)

I now discuss Khayelitsha and the ways in which the ‘field’ as research site is embedded with multiple meanings and imaginings. Khayelitsha too is imagined along distinct discourses which may appropriate the space along specific political and social lines.

### **Imaginings of Khayelitsha: Ethics and the Politics of Location**

Initially, this project failed to receive departmental ethical clearance due to the way potential safety and security issues were presented. I was concerned that townships are often labelled as both ‘safe places for white people’<sup>14</sup> as well as dangerous spaces rife with crime. It is useful to consider the different ways that Khayelitsha is imagined and the weight afforded to these notions. As a researcher, this diversity of notions becomes an important component to navigate. These imaginings are unique to their settings. In the following section, I look at Khayelitsha through an ethical and political lens, highlighting the real effects of the imagined and the ways they coincide with stigma.

---

<sup>14</sup> As articulated by a professor during the ethical review session

This was my first research experience in an urban environment and it necessitated a constant reflection on presence, unintended consequence and potential harm. Imagining can create real forms of ‘othering’, originating in the Academia and extending to the day-to-day practicalities of conducting fieldwork in an unknown environment.

The residual effects of the apartheid<sup>15</sup> system are among the greatest challenges facing a democratic South Africa . These effects are deeply embedded within the geography of Cape Town, a city which remains visibly racially segregated through multiple material indicators. Spatial allocation and housing conditions are just two of these long-term effects. Built upon sand dunes and low-lying *veld* forests; the name Khayelitsha mirrors the government-imposed relocation of black African people to the larger Cape Flats area. Translated from isiXhosa, Khayelitsha means ‘new home’. It is estimated that 800,000 inhabitants reside here, 35 kilometres from the Cape Town city centre<sup>16</sup>. It is also the second-largest township in South Africa<sup>17</sup>. The Group Areas Act of 1950 redefined housing areas according to race and, as a result, black and coloured<sup>18</sup> people were forced to the margins of the city (Oelefse & Dodson 1997). This racist policy simultaneously created a highly mobile population, township residents commuting to and from the city for employment.

Housing conditions and the spatial layout of Khayelitsha render it both an orderly and disorderly landscape. Grossly inadequate access to basic services like potable water, sanitation, electricity and sewage exacerbate already bleak circumstances. Infrastructure (in the form of water, sanitation, urban design, electricity) is severely lacking and the taxi ranks, community clinics and the few services which are available fall short of ‘satisfactory’. Rubbish litters the streets and dusty footpaths emerge in a labyrinthine maze between shacks. Thomas estimates that more than 40% of Khayelitsha’s population lives in informal housing, shacks which are constructed from found materials, plastic or scrap metal (2009:8). He speculates that more than 30% of the population is unemployed (ibid). Apartheid-era policies inscribed themselves pathologically onto people’s bodies, too, in the form of disease. Khayelitsha has the highest rates of MDR-TB and XDR-TB in the country. In 2008, antenatal HIV prevalence was measured at 31.1%, the TB case-notification rate reached nearly 1,600

---

<sup>15</sup> Literally ‘apartness’ in Afrikaans

<sup>16</sup> Thomas 2009:8

<sup>17</sup> ibid

<sup>18</sup> A racial category invented by apartheid policies; a person of mixed race, a ‘Cape Coloured’.

per 100,000 in 2008, and TB/HIV co-infection is close to 70%<sup>19</sup>. Tragically, almost seventeen years after the apartheid system was dismantled, conditions have not significantly improved for people living in this area or other townships in the larger Cape Flats area. The material deprivation of the majority, stemming from the policies of the previous government, is still a blatant reality. Thus, this situation presents a complex layering of challenges for the government, health care and urban planning initiatives alike<sup>20</sup>.

I return to the nurse working with ‘outsider’ TB patients from Khayelitsha. Her comments, paired with research conducted within a specific area like Khayelitsha, reduces the scope of the illness to a geographically bounded location. The presence of multiple health-oriented non-profit agencies in Khayelitsha speaks to a frequency of disease unparalleled in the rest of the Western Cape. In the departmental ethical clearance meeting, I was asked whether wearing a mask would further stigmatise project participants. In many ways, I came to embody the conventions and moral codes of others, reproducing different types of stigma in unexpected ways<sup>21</sup>. I was also advised to live with those who were ill in order to realise the full ethnographic potential of the project. Both of these concerns directly confront issues surrounding TB transmission, my personal health and the practicalities of working with chronically ill individuals.

It is broadly acknowledged that there is a high incidence of crime in South Africa as a whole. I was warned of conducting ‘9am to 5pm’ ethnography because Thandi, my research assistant, had advised against fieldwork during night-time hours. This temporal dynamic replicated itself in the field. Collaborators were legitimately concerned for *their* personal safety *during* and *after* daylight hours and my presence increased their concern for *my* personal safety as well as their own. In addition, I had listed my personal vehicle as ‘insured and licensed’ in the original project proposal. The ethical clearance team assumed that I was worried the car would be stolen, leaving me unable to research. Ironically, one of my most productive research days in Khayelitsha was the day someone tried to steal my car.

My aim here is to illustrate the intricacies of the discourses whilst demonstrating how they influence the field site and the fieldwork conducted there, specifically within a township

---

<sup>19</sup>MSF Khayelitsha Report 2008-2009:6

<sup>20</sup> For a longer discussion of apartheid policy, urban poverty and housing provision see: Western (1997), Rogerson (1999) and Tshitereke (2009).

<sup>21</sup> I elaborate on this in Chapter Three.

environment. The attempt *not* to essentialise a geographic space or those who reside there, can affect that exact process of essentialisation. If academic assumptions remain unquestioned, many more are perpetuated. As anthropologists, we would like to think we do not contribute to processes of othering, but it is naive to think that we are somehow immune to it. Practical research concerns were obfuscated by personal and ideological insecurities. Instead of producing a critical *and constructive* dialogue, essentialised narratives of what constituted ‘the field’ and attendant concerns were presented as foundational truth. This was the starting point for my research.

## **Improvisation**

Every fieldwork endeavour is paired with a visible set of ethical concerns as well as with those which emerge only during the fieldwork experience. Lisa Malkki has argued that fieldwork is an ‘improvisation’ (2007). Her insight is particularly useful, not only in an ethical sense, but methodologically (a point I return to later). As an anthropologist in the field, one must contend simultaneously with the intended and the unforeseen, sometimes unknowingly acting as a vector for visibility and invisibility. As Malkki states, ‘In your field sites, you cannot be transparent, nor a fly’. You take up social space as a person...’ (2007:177). Intuition paired with the aptitude to grapple with the unforeseen act as an ever-shifting ethical and methodological compass.

In any human-based research, the privacy and safety of one’s collaborators is of utmost importance. With illnesses that carry a social stigma such as TB and HIV (Sontag 2002, London 2009) it was essential to protect the identities of those involved in the research process. Consent to participation in this context could not be reduced to a signed piece of paper. Rather, ‘consent’ was continually reinforced through communication with participants. Every participant reserved the right to withdraw from the research project at any time. My research with children required the consent of the child and their legal guardian. In addition, the names of all research collaborators (including my research assistant/translator) have been replaced with pseudonyms for the sake of confidentiality.

My primary concern was the potential harm (and increased attention from the community) I might incur on project participants and their families due to the subject of the research. My mere presence could have revealed someone’s illness unintentionally. I discuss these and

other ethical challenges later in this work. I catered my purpose and presence to the desires and concerns voiced by collaborators. Interviews were largely conducted in private homes or those of relatives. Clinics and support groups in particular warranted a huge degree of trust and discretion and I was very cognisant of the acclimation process of becoming a ‘group listener’ as opposed to an active participant. Peer educators also acted as conduits to these support groups and facilitated ‘getting to know’ support-group members on an individual basis.

Lastly, I echo Patti Henderson’s ethical concerns about working with chronically ill people in qualitative research. She states that it is necessary to ‘work alongside’ those who are very ill, and argues:

‘When meeting a person about whom one is to write, one does not begin from a position of understanding. Rather, understanding unfolds through time and with the way in which one’s interlocutors, and oneself, rise up to challenge or surprise. Of equal importance here, is not only how to elicit free forms of speech but how to learn how to listen to silence and the halting nature of speech and how to witness corporeal presence in all its agony in ways that do justice to the sufferer.’ (2005:82-83)

There were many moments of silence, and equally, conviviality. Many times in support groups the audio recordings were not decipherable because members would argue or speak over each other. Most of the support group sessions were held outside to allow for ventilation, so the sound of wind became an obstacle during the translation/transcription process. I recorded with the full permission of all present. If a new support group member was introduced I always explained my research interests and asked for permission to record.

## **Methodologies**

‘That you as an ethnographer work with what you are given – even as you make new things – means that your gender, age, race, nationality, class, temperament, imagination, subjectivity, histories, and your whole social personhood are in some degree constitutive in the fieldwork process.’ (Malkki 2007:177)

When I started thinking through the methodologies I wanted to use during research I felt particularly daunted by the challenge of investigating something which is present most vividly when it is provoked. I had difficulty visualizing circumstances which would elicit stigmatised responses, behaviour and language, and an even harder time comprehending how to negotiate

those potential circumstances ethically. Stigmatisation is something which can be witnessed or observed, but much stigma experience is translated through post-event narratives. This presented a challenge given the length of time allotted for research in the field. I had no way to gauge whether I would be present to witness stigmatising processes. It became apparent within the first week of research that TB as a discourse is visible in many parts of Khayelitsha in the form of elaborate TB treatment murals, 'Stop TB' stickers on Taxis, masks in clinics, and so on, yet few people were interested in discussing their views on TB. To address this relative (or perceived) silence, my research assistant and I conducted a survey and also visited taxi ranks at peak hours to ask people about their perspectives on TB.

As Yang et al (2007) found in China, stigma does not only affect individuals but may extend to entire social networks. Therefore, it was important to work with as many participants as possible without jeopardizing a sentient approach to the subject matter. My primary method was participant observation, accompanying collaborators in their day-to-day routines. Other methods I initially wanted to use did not 'work' in the field. For instance, asking participants to write experiential diaries failed<sup>22</sup>. I had provided diaries to participants and expressed our shared objectives, but they preferred to talk about their experiences. In another instance, none of the adults I worked with wanted to draw their own conceptions of TB<sup>23</sup>; children on the other hand were enthusiastic participants. The adults felt it was a child-like activity. It became apparent that my methodologies would have to mirror a less individualistic focus. I would try to extract a 'felt' sense of discrimination in order to write about it in an articulate and sensitive way.

It also occurred to me that those who stigmatise others would not openly admit that they did so, perhaps out of guilt or fear of social retribution. As Deacon has noted with HIV/AIDS stigma, stigmatising attitudes and ideas are not always translated into active or verbalised stigmatisation (2005:2). Sometimes stigmatising attitudes are not directed toward others, but maintained in private. To address this challenge, I wore an N95 respirator mask in public spaces and taxis throughout Cape Town. I actively rendered myself an instigator and a

---

<sup>22</sup> Zimmerman and Weider (1977) discuss the benefits of diaries as a method of field work notation. In their 'Diary-Interview method', the researcher and the informant simultaneously write in a personal diary, which then acts as a base for further research questions.

<sup>23</sup> Investigating Metaphors of AIDS, Cancer and Heart Disease, Meira Weiss used a 'free association' approach (1997). Participants were asked to answer questions like 'How do you see cancer?' (1997:459). Participants were given the option of drawing their interpretations and describing them in detail to her. Weiss found, more often than not, that all of the participants utilized the drawing option.

conversational piece of scorn, aggression, and in some cases verbal violence. I describe this process as ‘provocation’. As a researcher, and particularly one who attempts to articulate the lived reality of the chronically ill and the stereotypes attendant on them, I wore a mask to provoke the insecurities and anxieties of others.

This methodology was not without ethical reservations<sup>24</sup>, as I was not ill nor was I feigning illness. In one sense, I wore a simple mask, but in another a very serious material object which produces fear and stigmatised behaviour towards the individual wearing it. I wore the mask in different environments to document different types of reactions<sup>25</sup>. I consider the mask-wearing method one of the more important aspects of this research. To comprehend more thoroughly how one changes from being invisible to hyper-visible, it is an imperative to approach the very edges of one’s own insecurities and reservations as a researcher. My purpose was to understand how people perceive and experience the terror of TB and how daily practices at the margins shape stigmatisation – a kind of ‘anthropology in the margins’.<sup>26</sup>

Whereas the mask-wearing informed much of the research on TB-related stigma, other methods were used to gather data. I attended support groups for MDR-TB patients, conducted a survey in two different areas of Khayelitsha and also facilitated focus-group sessions with children to glean a larger understanding of how everyday people conceptualize disease. To expand the understanding of stigma in this environment, it is important to move beyond biomedical etiologies and models of contagion which may be raised in conversation by HCWs, peer educators and patients. Therefore, I drew upon a range of social networks: family members, previous TB patients, those who had never had the disease, the young and old alike. I expand upon these methodologies and challenges later in this work.

Lastly, I employed a research assistant for a portion of the three-month fieldwork period to assist in the translation and transcription of interviews conducted in isiXhosa. A fellow student at University of Cape Town and born in Khayelitsha, Thandi introduced me to potential contacts. She also introduced me to potential research sites. Although she did not accompany me to support groups in order to maintain the privacy of those involved, she was

---

<sup>24</sup> I discuss this in greater detail in Chapter three.

<sup>25</sup> I elaborate in Chapter three.

<sup>26</sup> This is a reference to *Anthropology in the Margins of the State* (Das and Poole 2004) which invites the reader to reconsider margins and state control. The margins here may imply disorder; the inability of the state to exert sovereign control over those areas categorised as ‘marginal’. Another pertinent theme explored is the creativity and energy activated through the experience of local worlds and daily practice (2004:22).

an integral part of the research process. Surveys, exercises and becoming acquainted with Khayelitsha would have been impossible without her knowledge and acute eye and ear for detail.

## **In Conclusion**

In the following chapters I investigate the moral dimensions of stigma, an ordering mechanism which for purposes of clarity has been presented through ‘organising images’ (Das 1990). Organising images are themes which feature in conversation and narrative. They are imbued with power, unique to cultural context, and they help to make sense of an individual’s world (Das 1990). Each chapter centres on organising images and accompanying keywords. I analyse keywords and their definitions to understand stigma as a morally influenced ordering device in social situations. In Chapter Two I discuss ideas surrounding ‘dirt’ and how people conceptualise the ‘dirt of the everyday’, its implications in ITMs, ‘transmission’ and ‘contagion’ and its negative associations in the form of stigma. The manner in which dirt is imagined helps to produce ideas surrounding hygiene.

Chapter Three focuses on mask ‘etiquette’ and the idea of ‘losing face’ when one wears an N95 respirator mask. The mask is not only an active site of stigmatised behaviours but, I argue, it also interrupts the perception of order in a social environment. It calls attention to the heightened visibility of the wearer and the simultaneous concealment of the face.

In Chapter Four I address the way that gossip appropriates others’ disorder to regain order in the stigmatiser’s life. Gossip and stigma are strategic: gossip is circulated with specific intentions and for individual gain but may possess characteristics which have not been investigated thoroughly enough. I suggest that gossip may ironically boost the self-esteem of those being gossiped about. Lastly, although stigma and stigmatisation are associated with negativity, stigmatisers are acting rationally in accordance with what is perceived as dangerous or threatening. This insight could assist future research into how stigma is produced.

Currently, stigma theory is too general, signalling the need for more research in local worlds. Complementary insights may reside within other bodies of knowledge and literature. In the following work I draw on diverse literature spanning the anthropology of violence, witchcraft and narrative studies. There are incredible parallels which aid an understanding how TB-

related stigma functions. 'Organising images' make visible what is at stake for those who are stigmatised. Analysing stigma as a moral process equally emphasises the dangers perceived by those who stigmatise and those stigmatised. This insight can have larger impact on health policy and community initiatives in addressing community and individual concerns. This research also demonstrates that methodology must change according to environmental and theoretical challenges. 'Provoking' stigma is one way to improve an understanding of the real-world concerns and challenges posed to TB patients.

University of Cape Town

## Chapter 2: Dirty Things and Dirty Habits

‘The idea of society is a powerful image. It is potent in its own right to control or to stir men to action. This image has form; it has external boundaries, margins, internal structure. Its outlines contain power to reward conformity and repulse attack. There is energy in its margins and unstructured areas. For symbols of society any human experience of structures, margins or boundaries is ready at hand.’ (Douglas 1966:114)

A twenty-minute drive from metropolitan Cape Town, Khayelitsha sits on the periphery, a rhizomatous mass of settlements interconnected by small arteries of movement: unpaved roads and dusty foot trails. The N2 highway cuts through the settlement, which is contained on either side by cement walls. In some places the walls have given way to foot traffic, allowing pedestrian access at various points. The ‘shacks’, as they are commonly called, come in different shapes, styles and sizes. Some are rudimentary, others in various stages of construction. A billboard on the side of the highway depicts a young black daughter and mother in a loving embrace, smiling in front of their new concrete-block home. It reads ‘From Shack Lands to Dignity’. This tagline commends a governmental housing program, an attempt to replace ‘informal’ shacks with ‘formal’ housing. Below the billboard cluster houses which emulate the advertisement, but their number is dwarfed by the informal settlement surrounding them. Another signpost indicates the turnoff to the ‘public viewing area’. Here, tourists and township tours congregate to ‘experience’ and photograph the sprawl of urban poverty. It is simultaneously a chaotic spectacle and a captured moment, a nucleus of activity at the perimeter, a pulsing energetic organism.

Turning off the N2 highway there are *spaza* shops (small convenience shops, hair salons, fruit stalls, butcheries and *braai* (barbecue) stands sprinkled throughout, hawking wares and services. Purples, greens, aqua and pink awaken the eye unexpectedly. There is an inexplicable reverberation, a vibe, a rhythm humming throughout. Alongside one turnoff a black-and-white mural reads: ‘And the Rich Shall Inherit the Country’s Wealth’. There is something ironic, haunting and bittersweet in these words when contrasted with the meagre surroundings, litter, and general day-to-day hustle.

Elsewhere in Khayelitsha, dust is swirling outside Thandi’s home in the Bluefalls area, the street littered with sweet wrappers and empty crisp packets. Thandi and I are surrounded by seven children ranging in age from three to eleven years old. We sit together around the family coffee table, the laminate floor covering immaculately clean, with a trace of wear from

the constant foot traffic of children and visible deposits of sand emerging in the seams. I have asked the children to draw ‘what TB looks like’<sup>27</sup>. Siso (age eight) is explaining why he *cannot* draw TB:

‘Well...I don’t really know how to draw TB. I don’t know what it looks like. Maybe it is green or red or purple or even white. I cannot draw it if I don’t know what it looks like. But it will make you sick!’

I ask, ‘Do you know how people get TB?’

He responds: ‘Well... It can fly around in the air like this (flickers his fingers overhead). Yes, TB can fly around in the air.’

This chapter traces the genealogy of ‘dirt’ in Khayelitsha through local notions of ‘dirt’ and how ‘dirty things’ are employed in illness transmission models (ITMs). It is beyond the scope of this chapter to differentiate between contagion, contamination, infection or pollution and consider the different ways these terms have been configured and considered over time.<sup>28</sup> Rather, transmission is the umbrella term employed here. I argue that ‘dirt’ is an organising image understood to operate as a means of transmission for TB. In unpacking ‘dirt’ as a discourse one can understand the moral dimensions of stigma as a larger ordering process. I also suggest that dirt indicates dirty bodies which need be excluded from society via stigma. ITMs inform stigmatising discourses, actions and language. Thus, ‘dirt’ frames social conventions and expectations about moral and hygienic practices.

## **Dirty Places**

### **Dirt**

- (noun) a substance, such as mud, that is regarded as dirty.
- (Informal) excrement: dog dirt.
- loose soil or earth.
- (informal) scandalous or sordid information.<sup>29</sup>

---

<sup>27</sup> This method was extremely effective and was informed by Weiss’ methods (1997).

<sup>28</sup> Werner (1993) defines ‘infection’ as a sickness caused by germs or bacteria, while a ‘contagious disease’ is a sickness which can be spread easily between various people.

<sup>29</sup> Oxford Concise Dictionary 2011

I found that Khayelitsha was considered a ‘dirty’ place by most of the residents I interviewed, and interestingly it was not considered to be part of Cape Town. Some neighbourhoods were deemed more or less ‘dirty’ than others, thus creating a ‘hierarchy’ of (un)cleanliness. Areas of heavy traffic or congestion were also considered unhygienic, contaminated, and potential vectors for TB transmission, but not necessarily in ways one might expect. I suggest these ideas actuate and circulate a ‘hygiene discourse’, reinforcing notions of dirt, cleanliness and socially mediated expectations of personal hygiene. Likewise, ‘dirty things’ are those organising images which help to frame a clean/dirty binary. This form of stigma is associative; an individual is associated through their interaction with the dirty object.

Many of the clean places indicated by children were located outside of Khayelitsha: Somerset West, ‘Town’ (Cape Town CBD), and Muizenberg beach<sup>30</sup>. Clean places within Khayelitsha were the shopping mall, the Pick N’ Pay and Shop Rite<sup>31</sup>. A three-year-old explained to us, ‘It’s very clean where children are given medicine and where they drink medicine. It is also clean where children are given sweets and nice things and then they eat them.’ Connotations of sweet and clinically clean were far more palatable than the reality of the public spaces in Khayelitsha. It was easy to understand the characterisation of outside places cleaner because the daily navigated landscape was so rife with filth.



**Figure 1 : Storm drain in Blue Falls**

<sup>30</sup> Somerset West is 45 minutes east of Cape Town metropolitan area, Muizenberg is a popular beach.

<sup>31</sup> Two large grocery store chains

**Figure 2: Residential Dumping site in Cloverdale**



## **Slum Health**

‘Life in a house is better than in a shack’.<sup>32</sup>

The connection between inadequate housing and disease prevalence has long been established, but has re-emerged in recent years (Veillers 1911, Stein 1950, Krieger & Higgins 2002, Sclar Garau and Carolini 2005, Strong et al 2005, Riley et al 2007). The type of housing one resides in is a particularly salient topic of discussion especially in relation to disease and its proliferation. As Krieger and Higgins (2002) observe, healthy housing and better civic planning lead to healthier people. They argue:

‘Beyond the condition of the housing unit itself, the site of the home may be a determinant of health. Neighbourhood-level effects on health have been documented; these include elevated rates of intentional injury, poor birth outcomes, cardiovascular disease, HIV, gonorrhoea, tuberculosis, depression, physical inactivity, and all-cause mortality in neighbourhoods of low socioeconomic status, independent of individual level risk factors.’ (2002:759)

---

<sup>32</sup> Personal correspondence

In urban slum areas, where there is there are many chronic, communicable and non-communicable diseases, there is often no clear indication of the *real* magnitude of disease, yet these communities exhibit very specific health conditions (Riley et al 2007). As Sheuya et al suggest, ‘Most communicable diseases are associated with the conditions that characterize slums, and indeed, substandard housing in developed countries’ (Sheuya et al. 2007; 2 ci Petersen 2010:16 np).

As early as 1950 Stein recognised a positive correlation between poor housing conditions and TB. Habib et al (2008) associated household overcrowding and poorly built houses with an increased risk of TB infection. Gustafson et al (2004) found that there was no positive correlation between the absence of a ceiling and overcrowded conditions on the one hand and TB transmission on the other. The factors that did affect overall TB prevalence in Gustafson et al’s research were baseline factors such as mud floors, no indoor toilet facilities, no indoor kitchen, a poor-quality roof and structural quality of walls (Gustafson et al 2004; 165). All of these types of housing conditions are applicable to the ongoing struggle for housing in a post-apartheid-era South Africa, paired with the high prevalence of TB and MDR-TB and XDR-TB strains<sup>33</sup>.

### **‘The place is not healthy’**

The housing discussion emerged consistently throughout research, from conversations with my translator’s family to discussion in support groups and private interviews. The type of dwelling was either a source of pride or shame, directly mirroring the socio-economic situation of the people living there. The individuals and the families I worked with lived in a variety of dwellings, from shacks constructed of scrap and corrugated metal to free-standing homes with terracotta tiled roofs and imported fixtures. Amandla, an MDR-TB- and HIV-positive patient, had just built a brand-new home like this. In one of our first meetings I was given a tour. An obvious source of pride, his home was constructed of concrete, had a ‘proper’<sup>34</sup> tiled roof and contained multiple bathrooms and bedrooms.

---

<sup>33</sup> The debate regarding whether or not poor housing affects TB transmission is beyond the scope of this paper. See Munch et al (2003) and Maziak et al (2009) and Perdue et al (2003) for further reading.

<sup>34</sup> Meaning a formal roof (i.e. not built from found/scrap material)

Amandla explained his stay in Bluefalls in 2007, ‘coming back and forth between there and Manzini. I couldn’t stay there anymore though...that place is just too dirty. The water is just running and everyone is just going [defecating] wherever they want to.’ He described people who ‘lean up against the side of your home and hang out in front of your place.’ If he chased them away, they responded ‘Oh you are better than us, you are a high class person, you don’t want us here. Why do you stay here with us then? Go to the white areas.’ His wife also liked Manzini because it was clean and quiet.

In another conversation, he observed:

‘There’s new places that are cleaner than the old places like Cloverdale...like Manzini where I live, Kuala, Hanzvers<sup>35</sup>. But it is a cycle of building and rebuilding and the government tearing down shacks. It’s bad...the germs cause people to get sick. The place is not healthy.’

Here the home becomes an intersection of material practices and socio-economic plentitude or dearth with ideologies associated with aspirations which may or may not be achievable. Amandla’s home, education and ‘material life’ are abundant compared to others I came to know during research. I contrast Amandla’s thoughts with those of another collaborator, Zandi. She stayed one block away from her family in one of the ‘informal’ areas of Bluefalls. Her house was a modest three-room shack built from scrap with a small front *stoep* (veranda) area. There is a small wooden gate in front of her home, ‘to prevent men and dogs from going (defecating) there’.

She explained to me the disadvantages of living in her area and complained about a specific neighbour who operates a *braai* (barbecue) stand around the corner from her home. The neighbour regularly butchers an entire pig near the water tap area and refuses to clean the area. ‘It is just disgusting...there is blood everywhere, mixing into the sand and the dirt...the children play and track it inside. It’s dirty Kate, it’s unhealthy,’ she told me. She also explained that the drains are always ‘clogged’, creating ‘water everywhere mixed with old food, nappies, and other things floating down the road’.

‘Dirt and disease have gone hand in hand too long... modern medicine is about to come into its own through the banishment of dirt from our communal life. The slum, the mother of disease, is now doomed. Its end is in sight. From ocean to ocean, throughout the land, there is a newly awakened consciousness

---

<sup>35</sup> Other neighbourhoods in Khayelitsha

of our past folly and a slowly dawning perception of our inherent right to decent conditions of living.’ (Veiller 1911:13)

Veiller’s observations from 1911 seemed optimistic for his time and look even more so now in 21<sup>st</sup>-century South Africa, given the reality of sanitation, sewerage and ‘everyday dirt’ spoken of in Khayelitsha<sup>36</sup>. The ‘banishment of dirt’ along with curable diseases like TB is, in fact, *far* from reaching conclusion<sup>37</sup>.

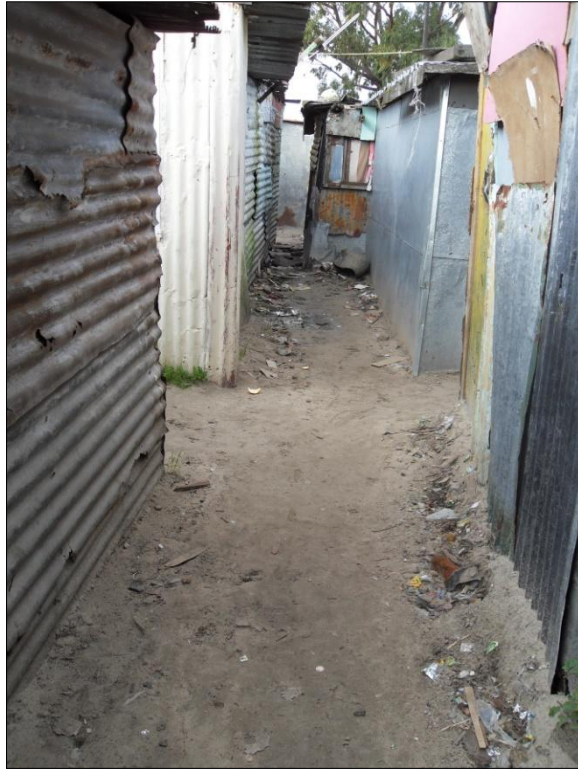


**Figure 3: Water Tap and surrounding area, Blue Falls**

---

<sup>36</sup> Snodgrass (2010 np) found similar circumstances with sanitation, access to water and illness in Mandela Park, another informal area of Cape Town.

<sup>37</sup> Winterton (2010 np) supports my scepticism; although TB is regarded as ‘curable’ given the abject poverty in South Africa and conditions of developing countries, cure rates have not been achieved on a large scale.



**Figure 4: Foot path between shacks, Blue Falls**



**Figure 5: Dumping in between shacks in Cloverdale**

Figure 6: Rubbish strewn behind public toilets, Cloverdale



## Managing 'Dirt'

'Our idea of dirt is compounded of two things, care for hygiene and respect for conventions'  
(Douglas 1966:7).

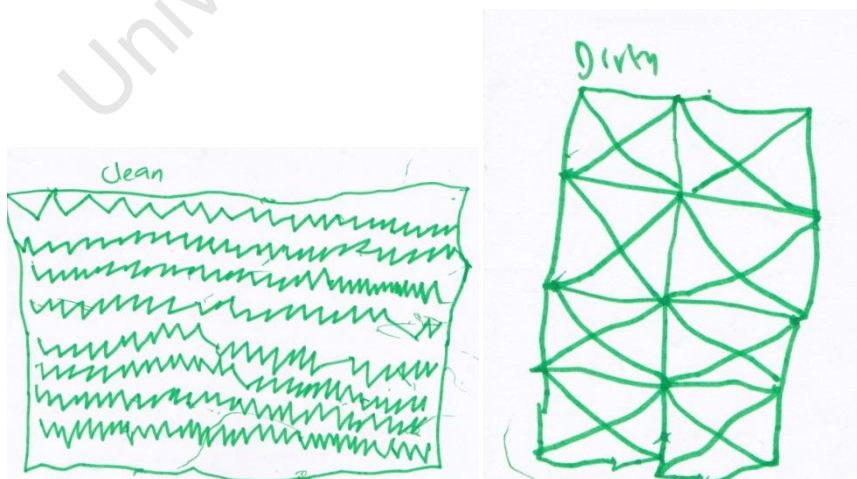


Figure 7: 'Clean' and 'Dirty', illustration, little girl, 7 years old

It became apparent throughout the 12-week research period that notions of dirt and dirty things were common in everyday conversations. Dirt as an organising image first presented itself in the way that children were admonished by adult family members when they crossed the threshold of the front door, or were 'caught' playing with 'dirty things'. The usual 'Don't touch that, it's dirty' or 'Go and wash your dirty hands', were common reprimands directed towards children at play. At other times, children were warned to avoid certain areas that were considered unclean or germ-filled. Adult perceptions were similar to children's perceptions of spaces as being 'clean' or 'dirty'.

In my research, three features were consistently interwoven and prominent in conversation. Firstly, all, whether young or old, past or current TB patients, as well as those who had never had TB, referred to notions of dirt as a means for TB transmission. Secondly, the structured binary of clean and dirty were often used in tandem. And thirdly, references to this binary were frequent.

Taking these ideas into account, it is necessary to understand that dirt can move and transverse boundaries and spaces. Boundaries are both physical things and socially constructed entities (Newman & Paasi 1998). Newman and Paasi suggest that boundaries, 'manifest themselves in numerous social, political and cultural practices' (1998:187-188). Silbey adds, 'in all kinds of political, social and socio-spatial relationships, boundaries then assume considerable significance because they are simultaneously zones of uncertainty and security' (1995:183 *ci in ibid*). Often, managing 'dirt' extended beyond one's personal life into the possibility of managing other people's dirt. Therefore, the boundaries between private and public, body and space are always contracting and expanding. Boundaries work in constant friction against each other.

Douglas observes that:

'The body is a model which can stand for any bounded system. Its boundaries can represent any boundaries which are threatened or precarious. The body is a complex structure. The functions of its different parts and their relation afford a source of symbols for other complex structures. We cannot possibly interpret rituals concerning excreta, breast milk, saliva and the rest unless we are prepared to see in the body a symbol of society, and to see the powers and dangers credited to social structure reproduced in small on the human body.' (1966:115)

The boundaries of both the human body and the geo-spatial landscape which are transversed by daily movements are an appropriate starting point. Because TB is transmitted through the

air, a human body is vulnerable to the disease through the very acts of breathing, sneezing and coughing infected air which contains active TB. It is pertinent to consider the things that cross these permeable divisions, the boundaries and margins of the body. This ‘matter out of place’ as Douglas defined it, is considered dirty once it crosses these boundaries, yet is not dirty in its own right (1966:35).

‘Because of its natural history, the transmission of *M. tuberculosis* is difficult to study; *M. tuberculosis* is spread by airborne droplets of respiratory secretions expelled by an infectious person to a susceptible host, who may or may not be known to the source (Riley, Nyaka 1959 cited in Castro and Jaffee 2002). The bacterium can remain latent as an asymptomatic infection for years, and the source of such infections can be difficult to ascertain. Thus, the *places* and *persons* involved in a chain of transmission may be puzzling to identify or exclude.’ (Castro and Jaffe 2002, emphasis mine).

Betty, a Community Health Care Worker (who is HIV-positive and had TB in the past), illustrates these points with incredible complexity and nuance.

‘Many people don’t want to share food, or utensils, plates...they separate everything and *you are separated through that action*<sup>38</sup>. It’s sometimes the thing where they don’t want you cooking. With people here, if I am cooking they will eat my food and I am fine to cook for them. Sometimes people will say ‘No, I am not hungry’ as an excuse to not eat your food...they don’t want someone with HIV or TB to make their meal. But with me it’s fine I cook, except if I am itching then I wouldn’t cut vegetables or cook things...’

K: ‘If your skin is itching? Why would you not make food?’

B: ‘I don’t want to have them see me itching my skin, then maybe they would think the skin is going into the food and is contaminated.’

K: ‘Oh ok...I understand. Even though you know that you would not be contaminating the food if skin fell into the food?’

B: ‘Yes...even then.’

K: ‘Are skin flakes the same kind of contamination as blood, or saliva? I know it sounds like a strange question.’

B: ‘No, I do understand what you are saying...it’s not strange. I don’t know though. Spit, blood, dry skin flakes? It is a part of your body right? It’s never happened that thing,

---

<sup>38</sup> My emphasis

but people are scared. People don't have enough education...they don't know what transmits the diseases...like AIDS and TB. Personally for me, I won't share a cup if I have a cut on my lip...when I had TB I did not share cups either...it is ignorance on their part and education on my part...I am educated about these things you know?'

Betty's concerns were supported by further anecdotal evidence when asked how one 'gets TB'.

'Sharing utensils with someone who has TB.'

'Sharing food with someone who has TB.'

'Drinking from the same glass.'

Responses like these were common in our survey as well. Thandi and I surveyed 100 households split evenly between two different sections of Khayelitsha: Bluefalls and Cloverdale<sup>39</sup>. Participants were asked a series of open and closed questions. We walked on foot and approached people on the street as well as those who were sitting in front of their homes. Almost everyone surveyed knew someone who contracted TB in the past or was currently being treated for it.

Whereas sharing food is generally connected with relationships, conviviality and commensurability within close social networks, in this context it was considered a mode of TB transmission. Sharing food was an ITM presented through the survey: 66% believed sharing *both* food and drink with someone who had TB was a risk for transmission<sup>40</sup>. This is the direct link between an ITM and enacted stigma. Thus if sharing food put one at risk for TB, it was not done. Many patients I worked with spoke of family members refusing to cook for them or refusing food cooked by the patient. In other instances, separate food was prepared and cutlery, plates, bowls and glasses were allocated to the individual patient by family members. In one situation, Amandla's food was set on the floor by his wife. Another time she refused to cook for him altogether. Sometimes these circumstances would persist or worsen to the point of complete isolation. Other times, family members would relent after a visit by a Community Health Care Worker (CHCW) like Betty.

---

<sup>39</sup> See appendix for detailed summary of the survey.

<sup>40</sup> Refer to survey for specific results

## Dirty things

In addition to asking children about disease transmission and germs, children were asked to draw ‘dirt maps’<sup>41</sup>. Drawing on Gooskens’ (2006) ‘my neighbourhood’ exercise, children were asked to draw the dangerous and safe places in their neighbourhoods. I changed the parameters to dirty/clean places. The idea was based on their spatial understandings of their neighbourhoods in correlation with their perceptions of dirt. We worked with nine children from Thandi’s neighbourhood and permission was received from both guardians and the children themselves. They were three girls and six boys ranging in age from three to eleven years old.

According to the children we worked with, germs came from dirty water and ‘dirty things’. A germ ‘looks like a worm and it is really dirty.’ Children thought that coming into contact with dirty things caused one to get sick. Dirty water and touching inside rubbish bins were also vectors for sickness. ‘Dirty water came from drains and places where water taps were located.’ Dirty things were clarified as ‘things outside - the things we throw away.’ Also, if food was dirty there would be germs in the food which could make one ill.

Adults specifically aligned TB transmission with dirty things and an ill-kept home. One respondent said, ‘You get TB from having a dirty home.’ Another remarked, ‘Being around dirty things like rubbish.’ It was clear that illness transmission models for adults and children were very similar and, given the squalor of public spaces outside of personal residences, this was unsurprising to me.

Prominent features in the dirt maps were the location of children’s houses and how they depicted the interior space. In many drawings, the domestic interior was depicted as free of dirt, whereas the outside areas were ‘dirty’; oftentimes indicated through ‘x’ clusters or dots. ‘Clean’ was indicated with / / / /. Windows and doors to homes were closed to prevent the movement of dirt from outside to inside spaces<sup>42</sup>. In one illustration, a handheld broom was positioned inside the home to denote cleanliness. Conversations with adults elicited similar patterns; space was conceived as public/private, dirty/clean, external/internal. Private spaces were maintained while public areas were generally considered unkempt and dirty. I elaborate on this later in this chapter.

---

<sup>42</sup> Gooskens’ findings were slightly similar; home was considered ‘safe’ whereas other outside/unknown locations were unsafe (2006).

The children indicated that the ‘dirty places’ were near the *spaza* shop, the train station, and that all drains and water taps were dirty places too. One little girl observed that ‘all the streets in Khayelitsha are dirty’, and another added, ‘It’s really dirty by the informal settlements and where the dam is.’ One little boy asked us, ‘You know where those council containers are? Where those people from the informal settlement are – they put the rubbish in the black bags and then put it there, it is dirty there.’

These comments highlight water as an additional vector for TB transmission in children and adult ITMs. In the children’s exercises, the communal water taps and dirty water featured as both germ carriers and germ areas. The children explained that dirty water carried germs and they had been instructed by adults, parents and teachers not to touch this type of water<sup>43</sup>. Drains, too, were looked upon as ‘dirty’ areas, filled with discarded rotting food, nappies, litter and pieces of plastic. These ‘dirty things’ were all signifiers of disease and germs for the children. A few added that *tokoloshe* and *hillys* could ‘get you’ if you walked close to the drain openings.<sup>44</sup>

During an interview with Amandla, he added:

‘You can see in the mornings in many of these areas the drains are dirty and they are blocked because of the human faeces which are poured out there. There is dirty water and old food, nappies. And the sewage in the drains just sits. And there are children just playing there...inhaling and touching everything.’

The communal water taps were also areas of disease and germs for adults and children alike. In contrast to Ross’s work (2005:632-633) my data suggests that the water tap and the act of collecting water were more divisive than unifying. Participants were not enthusiastic about the water taps or adjacent spaces, often citing the disrespect of other water tap users. Antithetical to the oft-conjured symbolic properties of purification, nurturance and cleansing, water and water taps were considered dirty and dangerous to one’s health. One woman pointed out, ‘You know, I go there to fetch water. *Qha!* (That is all). I cannot stand to see women washing their children there, or tossing the old foods. It is disgusting man’. Water taps were contested spaces which served a necessary but risk-laden function. Although water

---

<sup>43</sup> These observations are shared by Snodgrass (2010 np) in her work in Mandela Park with children and waterborne illness.

<sup>44</sup> Different groups conceptualise particular beings as representative of dangers they may or may not encounter. The *tokoloshe* is representative of sexual and physical danger and is often invoked through conversation between adults and children. Although he does not appear in this work visually, he often lives under beds which are not raised. The *hilly* is represented through the drawings of children in this piece below. He lives in the drain and carries germs according to children interviewed.

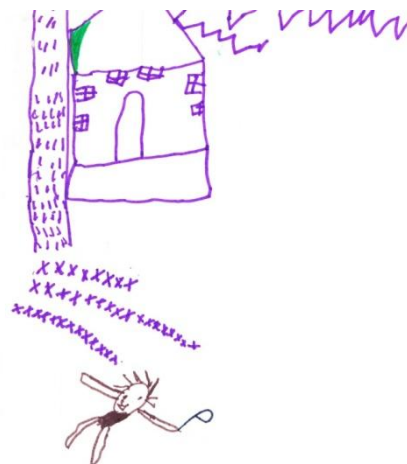
helped sustain life (and allowed for the washing away of personal and household dirt), the context and the act of water collection were unsanitary and contentious. It became yet another ‘dirty thing’ which had become dirtied through contact with ‘dirty’ users.

## Drawings and explanations

All children unanimously confirmed that their homes were ‘the cleanest’ places in their neighbourhood. Sweeping and washing the floors were ways to keep one’s home ‘clean’ and ‘TB free’. Ensuring the windows and door were closed also prevented dust and dirt from entering the home. Outside, public spaces were considered dirty because people and dogs defecated there. When I asked the children what TB looked like to them, almost all of the participants went quiet. One little boy ventured an observation, ‘It’s different. I don’t know how to draw it because I don’t know what it looks like – but it’s kind of white. You will be so sick’.

Through the drawing exercises and the accompanying explanations of the children we worked with, I gleaned insight into how children conceptualize dirt, disease and TB. TB was presented as ambiguous in our conversations, yet there were very distinct understandings as to what constituted ‘good’ and ‘bad’ hygienic practice and, later, moral behaviour. The correlation with housing and communicable diseases, however, was a strong one, and pertinent to the understanding of ITMs and stigma.

The following drawings are accompanied by explanations from their creators.



Here is my house and here is the road – the road is dirty and the house is clean. These little x's are *izinto zimdaka* (dirty things) – and the stick is the thing to beat people with...these other things are clean things.' (Boy age 6)

Another little boy says, 'Here is the clean things (pointing to the house and car). This heart



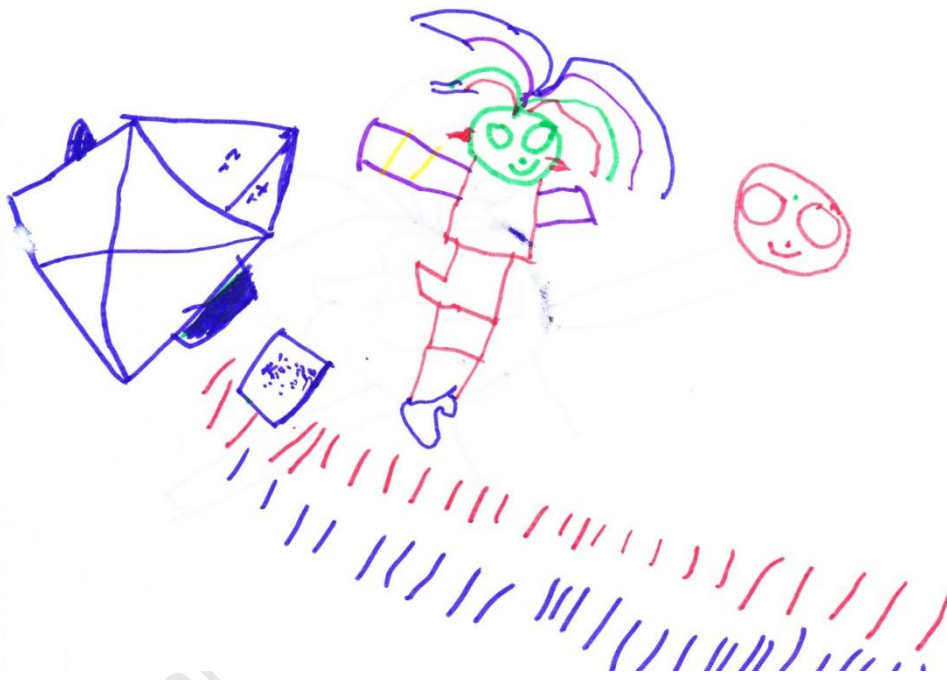
red thing is dirty. The little worm snake is the germ. Inside the house I'm small and I'm sitting. The 'hilly' is outside.' Here is the hilly and here is the *quthu* (a stick like thing) to beat people.'

The *hilly* is a little man who lives in the drain and who has a lot of germs. He survives on consuming dirty things, hence his infectious character. Hillys also only come out at night time.



Here are a few drawings of the *hilly*. All hillys are very small and 'bring germs.'

One little girl said, 'Here is the hilly...he lives in dirty places and dirty things...here is a germ and this is a coughing person - it is a *mama* (middle-aged woman).'



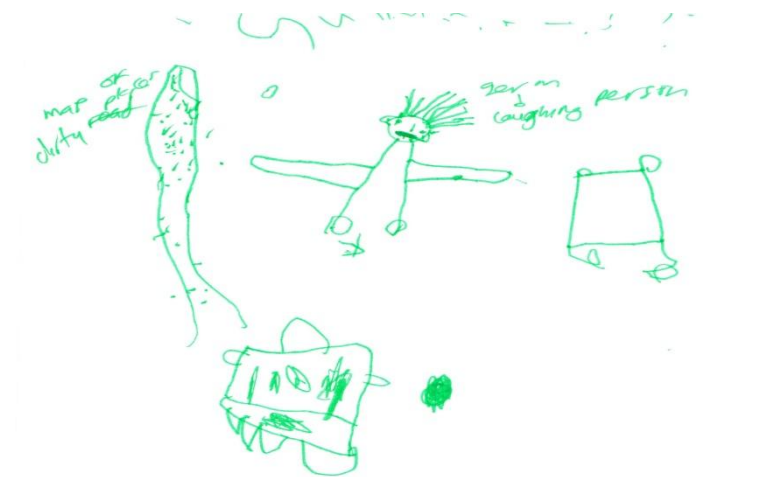
Another explained, 'Here is my house and here is a broom to clean the house. This is the door to the house and this is a window. The window is closed to keep the cold outside and the wind and the dirty things'.



'A window of the house is closed because there are dirty things outside. This is a laughing woman. And I forgot to draw the germ. Here is the house. Here are the dirty things...they are outside the house and the windows are closed at night'. (Boy age 8)



A little boy explained, 'Here is my germ - and here is the hilly. Here is my house and the road is clean here and the dirty thing is here. Here is my house with closed windows'. He explained further that it was night time, and if the windows were left open, 'the *tsotsis* (criminals) will come and the *tokoloshe* and the *hillys* will come for you.'



### **Dirty Habits make for Dirty People**

In this section I discuss the way that 'dirt' is attached and represented through bodies. Just as dirt may physically attach to one's body, there are stigmas that attach too. My data suggests that dirt and 'dirty habits' largely indicate 'dirty people'. The majority of the ITMs I heard about stemmed from perceived dirt or immoral habits like drinking and smoking. Eighty percent of respondents surveyed said they would not treat or perceive a TB patient any differently if they knew their TB status, yet in response to a similar question phrased differently, 67% stated that they would take precautions in the presence of someone they knew had TB. This indicates a complex interaction between taking precautions against infection and moralised judgments of the TB positive person.

Curtis and Biran (2001) use 'disgust' as an emotional indicator to trace the correlation between objects and events which evoke this reaction. They suggest that there is a mutual relationship between the routes of transmission, objects, and subsequent or perceived infection which elicit disgust or revulsion (2001:23). Additionally, disgust takes on social dimensions through moral orderings and judgements. They elaborate: 'If disgust began as

aversion to physical parasites, it may have come to serve an extended purpose, that of an aversion to social parasites' (2001:29). Thus, disgust is a significant verbal and visual indicator of stigma and abhorrence, a way to recognise the moral and hygienic discourses of others.

The Comaroffs (1997) have written on the 'civilizing mission' forced upon the Tswana people during the colonial encounter in Southern Africa. Notions of cleanliness were intimately connected to 'proper' and 'good' ways of doing and being in the world. Cleanliness as practice is therefore a benefit to the individual, while being a 'dirty' person warrants a lower social status, social judgement and potential stigma. This has also been noted in Hirschfield's work (2002) with children, whereby children employed stigmatising language and practices towards those they perceived as having germs or 'cooties'. Children labelled with a lower social status those who were perceived as being improperly bathed or unclean.

All children were in agreement that washing one's body will prevent the spread of germs and washing hands will also prevent sickness. An interesting trend emerged, however, when we asked about how an individual contracts TB. Adults generally produced the same responses as children in their conceptions of TB transmission. 'Doing bad things' to one's body included 'sharing cigarettes with someone who has TB', 'drinking too much' and spending time in *shebeens* (informal local taverns). One survey respondent said, 'Being around dirty people gives you TB' and another suggested that, 'If you live in a shack, you will get TB.' One little boy suggested, 'You get it from drinking and smoking...When you share drinks with someone who has TB'. Being an alcoholic and smoking *dagga* (marijuana) were also characteristic of someone with TB. I asked if smoking and drinking could cause someone to get TB and all the children responded 'yes' except one little boy. In the survey, 73% of all respondents believed TB is contracted because TB patients are (1) unhygienic, (2) have an unclean home and (3) poor lifestyle (drinking, smoking). Only 22% attributed airborne transmission to TB.

The group of children did not believe you could get TB from your parents<sup>45</sup>, nor could an individual contract it from sharing utensils or food. They unanimously believed that TB

---

<sup>45</sup> It was not made clear as to why children thought this. Perhaps it was because they thought of their parents as too clean, or incapable of spreading disease to them. A potential area of future study would investigate ITMs in terms of transmission between children and their parents.

could kill you if you did not take treatment or wash yourself. One little boy (age 9) explained that if his friend coughed on the table and he subsequently touched the table, he would contract TB. Another, Siso had drawn a 'drunk old man', who was living close to him. Siso thought because old men drink beer, they can get sick. He associated drunk men with the *mqomboty* (fermented sorghum beer) house across the street. He always saw drunks there. This house was also identified as a dirty place by other children. Amandla, too, thought that Bluefalls was a dirty place. He said, 'I stay away from Bluefalls on weekends. People drink a lot over there on the weekends. Drunks everywhere. There is not enough space. I think people's behaviour changes when there is less space.'

Children also believed that adult women were responsible for spreading sickness to men<sup>46</sup>. I asked if men could give women diseases and a little boy responded, 'No, that doesn't happen, the women give it to their men, and parents give the germs to their children.' I also asked if children could make their parents ill. Another little boy laughed at the improbability, 'Never! How could that be? Like when the old women want to give you little kisses and say 'My child! and they want a kiss and they smoke too.' The cigarette smoking in particular was connected with TB transmission and 'poor' behaviour, yet another indicator that an ITM can correlate with stigma. Saliva was also considered a conduit for TB transmission but only by adults. Some adults interviewed believed that the act of spitting and leaving saliva uncovered (by soil) would transmit TB to other people. Again, to echo Douglas (1966), body fluids were considered 'matter out of place' when they traversed the boundaries of the body. Saliva is not dirty by itself, rather 'dirt' is what is out of place. Ironically, one would have to cover the spittle with soil in order to avoid transmitting TB to others.

## **Concluding thoughts**

I became increasingly aware of the expectations (both hygienic and moral) which may have been implicit or explicit in conversations with different people. I remain uncertain as to where these expectations originated or how they were enforced. I was, however, more certain that there were connections between conformity to social conventions and deviation from them. If one deviated (or was seen to deviate) from a social expectation (whether through

---

<sup>46</sup> This statement is corroborated by the work of LeClerc-Madlala (2001) who found that AIDS is fundamentally gendered; women are often viewed as carriers of disease. Scorgie (2002) too, had similar findings in her work with virginity testing and the reoccurrence of the female body as a moralised symbol.

practice or speculation), one would be assigned a judgement. This casting of blame aligns neatly with personal habit or perceived hygiene.

Individual bodily boundaries and margins are held in constant tension with the larger boundaries which are crossed throughout township spaces, city spaces and beyond. Boundaries and spaces also lend themselves to understanding the transmission of disease. Samuelson clarifies my point about space: ‘Etymologically, to transmit means to send or pass from one person, place, or thing to another. Thus, transmission is about movements in space: it includes a process whereby something, whether physical or not, is put in motion in space or between spaces’ (2004:91). My data, however, suggests that while proximity and space are crucial to understanding TB transmission, infection and contagious disease are conceptually conflated. Lay understandings of TB transmission relied upon notions of shared spaces, moral (or immoral) conduct and the sharing of utensils and cleanliness. Again, the boundaries of both body and space, public and private realms are pertinent to understanding how TB transmission is conceptualised and how stigma is produced through contact with ‘dirty things’. Dirty things are linked to those who come into contact with them, creating a conceptual bind between contact, context and ITMs. ITMs and stigmatised notions are mutually reinforced because they are ordering mechanisms that define social conventions and norms.

The home space and the body were considered sites of control, cleanliness and order. The public areas outside of the home were antithetical to order. However, it seemed there was a shared expectation to maintain a certain degree of respectability and integrity within public areas, a quality Ross (2005) has referred to as *ordentlikheid*, an old Afrikaans word for decency or respect. This type of public/private dichotomy is reinforced in other works focusing on post-apartheid urban environments and identity formation (Salo 2003, Ross 2008, Cassidy 2010 np). On many occasions I saw people disposing of rotting food, faeces, plastic containers and countless other items into drains and gutters. In one instance I counted 37 different items fouling a storm drain. Therefore, the maintenance of the domestic space reflects the dirt-oriented insecurities and disease-transmission anxieties harboured in day-to-day realities in outside spaces. Coming into contact or interacting with dirt is potentially damaging not only to one’s reputation, but also to one’s physical health. Hygiene and notions of cleanliness not only reinforce ‘healthy’ practices and a healthy body, but enforce moral conventions which, if violated, induce stigmatisation and stigma.

### Chapter 3: 'Losing Face'

*The mask has a thick plastic bendable strip which creases and fits to the structure and contour of your nose and cheeks. The air you exhale is hot and steamy which makes the skin around your mouth (and your exhalation) very moist and warm. I had a tendency to adjust my breathing through my mouth almost exclusively, resulting in a visible inhale/exhale expansion/contraction movement of the woven pink fibres when you breathe. The strip constricts your nasal air flow-so you have this mask on (which looks like a glorified duck bill) and two blue rubberized straps over your head and one which goes over the small of your neck.*

*[Field notes]*

Prior to commencing fieldwork, we were provided with N95<sup>47</sup> respirator masks, donated through a non-profit organisation working in the area. A mask etiquette session detailed mask-wearing procedures and context-specific situations which necessitated the use of a mask. In the clinical space I gradually became aware of those who wore masks and those who did not. I was uncomfortable when I saw children not wearing face-masks or watching adults enter the clinic and walk past the handwritten 'Please wear a mask' sign, only to do the opposite. One day I forgot my N95 mask at home and panicked. I was scared to go inside Manzini clinic for the support group without an N95 mask, and I refused to wear the 'normal' masks – flimsy, tissue-paper thin things distributed for free inside the clinic. I would wear the N95 mask only because I had attended a mask 'etiquette' session. This session influenced my opinion that it was the best way to protect myself from potential TB infection. Other members arrived and agreed I should stay outside until Vuyi, a peer educator, came with a spare mask. So I waited. Retrospectively, I unconsciously came to embody certain biomedical and personal ideals through wearing an N95 mask. It was uncomfortable but felt safe; it was bulky but I felt protected. Without it, I felt as though my normal styles of interaction inside clinics completely disrupted.

There is a dearth of ethnographic work that concentrates on the clinical landscape of mask-wearing and its influence on social context and stigma production. Anthropological interpretations of masks associate the object with ritual, ceremony, or lineage. My objective is to examine the practical issues of wearing a preventative face-mask in relation to felt and enacted stigma. The symbolic and material aspects of the mask are parallel dimensions contributing to greater implications for mask use outside a South African biomedical

---

<sup>47</sup> See photograph on page 55.

environment. I incorporate my personal reflections and data from support groups in clinics and interviews. In doing so, I try to untangle the intricacies of the mask as a visible signifier of illness, perceived harm and potential threat, for both patients and non-patients alike. I argue that the paradox of mask-wearing is multi-dimensional: disrupting the normal order of social flows by their mere presence, yet ordering the individual patient's experience of illness. First, an explanation of mask etiquette to which I now turn.

University of Cape Town



**Figure 8: Front view, author wearing N95 mask**



**Figure 9: Side view, author wearing N95 Mask**

## Mask ‘etiquette’

The use of ‘etiquette’ is intentional. I first heard it used in the mask-fitting session, and it is used almost exclusively in a biomedical space. Etiquette can be defined as:

- (n) The customary code of polite behaviour in a society.<sup>48</sup>

And:

- (n.) The forms required by good breeding, or prescribed by authority, to be observed in social or official life; observance of the proprieties of rank and occasion; conventional decorum; ceremonial code of polite society.<sup>49</sup>

I came to understand etiquette as an embodied experience<sup>50</sup>. One embodies mask etiquette through mask-wearing – it is literally something one advocates through its use. Yet, etiquette became an instructive code which extended beyond my personal use of the mask. My own mask etiquette mirrored those who taught me the ‘right’ ways to wear a mask. Over time, I then duplicated their teachings by policing others. I was unconsciously embodying a medical ideal, simultaneously trying to keep myself protected from inhaling others’ exhalations and keeping others safe from mine. I immediately formulated opinions about those who did not wear a mask in clinics. I felt they were being reckless, irresponsible and negligent. If the patient did not affix a mask to their child’s face, I too would think negatively of them. They were, in my mind, not being a responsible patient or parent. They failed to subscribe to the etiquette which was condoned clinically to keep everyone as ‘safe’ as possible (i.e. from infection). Other patients and peer educators echoed my concerns and voiced their own. I had become a stigmatiser in my own right. Although I would never act on my opinions, I harboured them nonetheless until someone put on a mask.

## Protection and prevention for whom?

Environments deemed ‘high-risk’ necessitate mask-wearing by patients and health personnel alike. Clinics, hospitals, public transport and areas where there is little ventilation are high-

---

<sup>48</sup> Concise Oxford Dictionary 2011

<sup>49</sup> Webster’s Revised Unabridged Dictionary 2011

<sup>50</sup> Although beyond the scope of this paper, dimensions of embodiment and phenomenology as anthropological paradigms have been described by Bourdieu (1977), Csordas (1990,1994) and Merleau-Ponty (2007)

risk areas. Therefore, it is common to see people wearing masks in clinics and hospitals. However, the N95 respirator mask is not a 'regular' mask and it is not the same type of mask distributed in clinical environments. The physical appearance of someone wearing an N95 mask is immediately striking because it is not the 'normal' mask. Rather, it is bulky and imposing; covering roughly 60% of the wearer's face. The efficacy of mask use in a clinical and public space remains highly debated and is beyond the scope of this paper. The preventative aspects of mask-wearing are undermined because it is the mask people see, not necessarily the utility behind it. The negative opinion of the mask is translated to the wearer, the individual in effect becoming the target for scorn or aggression. The most obvious observation is that the mask wearer is sick with 'something' to the extent they must cover up their mouth and nose to prevent others from 'catching' their illness. Wearing a mask can produce another effect: the observers may think the mask wearer is protecting themselves from others whether or not the mask wearer is ill. This is a point I return to later.

While mask-wearing remains a common practice in some Asian countries (most notably Japan), 'mask culture' is largely absent from everyday life outside a biomedical environment in South Africa. This pronounced absence informed my decision to wear a mask in different contexts to gauge the responses of other people. It could also be argued that the pervasiveness of mask-wearing in Japan may be tied to a collective understanding of dirt and how 'dirty things' are transmitted through breathing or bodily contact (i.e. touch). Tomosada (1976) and Ohnuki-Tierney (1984) discuss the Japanese conception of 'dirt' and its relation to mask culture. Both believe that Japanese ideas surrounding 'dirt' are spatially oriented, and that 'cultural germs' or 'people dirt' are located 'outside' and 'below' (on the ground) (Ohnuki-Tierney 1984: 26-27). Therefore, it is common in Japan to see parents scolding or explaining to their children the hazards of touching things or sitting on the ground.

This conception of dirt from Japan is similar to the context in *Khayelitsha* I detailed in chapter two. The difference, however, is the relationship to mask-wearing. Whereas mask culture is present in Japan, in South Africa it is present *only* within clinical spaces. Therefore, the absence of mask culture in public spaces creates disruption and in some cases disorder to normal social processes. The presence of someone wearing a mask then creates disruption and initiates stigma and stigmatising practices.

In relation to face-mask use, Ohnuki-Tierney compares the intended purposes of doctors and medical personnel in the United States with those of the Japanese lay person. She observes

generally that, ‘...Japanese use it to prevent themselves from inhaling someone else’s germs, whereas American surgeons and patients use it to avoid transmitting their own germs to others’ (1984: 26). In this context, using the ‘normal’ paper masks would not protect the wearer; but theoretically stop the projection from a sneeze or a cough. The N95 mask allows the inhalation of air but has a fine enough filter to prevent inhalation of active TB particles. In my data, the divide between intention and perception is still skewed, however, because most people thought of the masks as preventative (to stop transmission from them to others) and protective (against others’ germs). In another study, Mahendra et al found that clinic personnel in India wore masks to prevent HIV infection from HIV/AIDS patients (2006).

I therefore seek to understand the practical issues of wearing a mask when one has MDR or XDR-TB and how the mask wearer experiences felt stigma or becomes a target of enacted stigma. Again, it is beyond the scope of this paper to debate the efficacy of mask-wearing in or outside a clinical environment<sup>51</sup>. The efficacy of respirator mask use can only be assessed with more research in the area of public health prevention and respiratory infections.

The following remark from Betty, a former health care worker, reflects the contention behind mask use.

K: Can people get TB in the clinic or hospital?

B: Yes for sure....The thing is you can get TB in hospitals...you are not safe there...you see when people are wearing the masks they will take them off when they are speaking, or wear them improperly...it defeats the purpose...I remember this XDR-TB patient I had- he was sent back home after being seen but we were in the clinic together and he removed his mask and I got very cross with him...because he could have infected everyone there...and sometimes someone has TB and they cough in the hospital and they spit on the ground and you scold them and then they get mad at you...

---

<sup>51</sup> For further discussion on this debate: Syed et al (2003), Wu et al (2004), MacIntyre et al (2009), Cowling et al (2010); for negative physiological side effects of masks see: Kao et al (2004), Lim et al (2006).

## Masks

Outside of a biomedical lens, masks have been interpreted differently in varying social contexts by art historians, archaeologists and anthropologists alike, however much less work has been afforded to how masks 'work'. Anthropologically, masks have found significance in the renowned works of Boas (1955), Levi-Strauss (1979) and Goldman (1975). These collective works analysed the symbolic meaning of masks and their uses in different cultural social contexts from the Kwakiutl to the Sua. Their insights are useful, but observations from Pollock (1995) and Tonkin (1979) are particularly salient. Pollock writes about the semiotic properties of masks and how they 'work' upon the face in meaningful and different ways; acting as 'indexes and icons of identity' (1995:581). He states that:

...identity is displayed, revealed or hidden in any culture through conventional means, and that masks work by taking up these conventional means, iconically or indexically. In semiotic terms, an icon is a variety of sign that bears a resemblance to its object; a diagram, for example, is an icon of that which the diagram represents. (1995:582)

I interpret this to mean that a mask can signal a change in identity or transform the identity of the wearer. This echoes Levi-Strauss's ideas on the type of identity one assumes after putting on a mask, be it a god, a deity or otherwise (1979). The presence of a mask outside the biomedical setting (e.g. in a public taxi) labels the wearer in many ways. Whereas the wearer is almost always labelled as 'sick', they too can be perceived as protecting themselves from others' imagined or imaginary germs as in the Japanese context. In the clinical environment, the type of mask one wears is the differentiating factor (because as previously stated most are masked). However, certain mask wearers become hyper-visible because they are wearing the N95, whilst others are less visible, wearing the 'normal' masks. Often times the partially disguised face is accompanied by a body which is diminishing in stature and fullness. The inherent paradox is that although the physical body is wasting away, the mask creates a heightened sense of presence because of the visible difference of mask type. Therefore, the mask wearer is simultaneously accumulating visibility and diminishing from view.

Tonkin states, 'Perhaps one's first thought about a mask in use is that it is a disguiser. Faces especially are covered by masks, but far from obliterating a face, the mask actually transforms it into a new form, the Mask' (Tonkin 1979:240). Here she is differentiating between the

physical object itself and the object in motion or object in use. The object alone is void of power or the ability to communicate without being appropriated in an action.

She adds:

A primary distinction proved to be necessary between mask (signalled here by lower case), that is the object by itself and Mask (signalled by upper case) which is the mask-in-action, that is when carried or worn by somebody, a complex unit, often of mask + costume + carrier. This is how masks work, namely as social phenomena, operators in communicative events. (Tonkin *ibid*)

In more recent work, Gibbons (2010 np) used masks as a creative method in her work with chronically ill people. Project participants were encouraged to decorate both the interior and exterior of a plain, white mask. The premise of the exercise was to make chronic illness 'visible' through explorations of hyper-textual images and the notion of self-scapes. The masks served to illustrate the complexities of internal and external experiences of chronic illness, and the challenges involved in representing the individual's lived experience thereof. Gibbons found that the exterior surface of the masks portrayed the sentiments of family and friends (the viewers) toward the patient. The underside (internal) surface of the mask conveyed the patient's (wearer's) feelings, thoughts and emotions. Here, the mask provided a bridge to a sensory experience which would allow the viewer entrance into the world of living with a chronic illness. Gibbons states, 'Connecting with a mask or an image requires the viewer to become personally involved removing distance between the viewer and the creator' (2010: 104). Gibbons continues, 'In entering into its world, by wearing the mask, the words and art touch the skin and can pass through that barrier to inform on the self-hood of the viewer' (2010:105).

Masks in my research were perceived quite differently. Gibbons' masks were colourful and aesthetic, whereas N95s are suited for a function, not for visual appreciation. Yet there is import in their appearance because they are so stark and imposing. Masks are integral to the lived experience of TB, or exposure to high-risk environments. My objective was to try to understand what it means to wear a mask from a practical, embodied perspective. It was therefore crucial to understand the relationship people had with masks and how they felt about them in different contexts. If I could be a part of that process, I would gain insight into an otherwise foreign experience of felt stigma.

## In the clinic

Every week, I met with different support groups. The Manzini support group was smaller in size and receptive to my presence. The group sat outside the clinic frequently, but we met inside if it was cold or windy. Manzini support group was the smallest I attended but it always felt like a productive space. Group members showed concern, were quick to advise others, and were forthcoming with personal issues.

One morning, we sat huddled inside the clinic waiting room due to the cold wind gusting outside. The waiting room buzzed with activity. We sat in relative silence for 10 minutes or so, the only back ground noise the murmur of others. I rarely initiated conversation – rather I listened and recorded the group conversations with their consent. My role was to listen and participate minimally, if at all. My mask was irritating my nose and I made a comment about it. The following conversation resulted. It demonstrates the discomfort (physical, emotional, mental) many people experience when wearing an N95 respirator mask. It also illustrates the anxiety MDR-TB patients must grapple with while their sputum is still ‘positive’ for active MDR-TB.

K: ‘God, this thing (mask) drives me crazy! Does it ever just make you itch!?’

Vuyi responds:

‘I just hate it. I hate it. I will be so happy when I don’t have to wear this damn thing anymore. The sooner I convert<sup>52</sup>, the better....I will never wear this thing again after that and when I am done with the meds.’

An older man added, ‘they are horrible...they are itchy. You cannot breathe...breathe deep like this Kate (demonstrates to me, and I emulate him). It is too difficult. I can feel the water<sup>53</sup> inside. It’s warm. It’s not right.’ He did not think that there should be moisture building up inside the mask. For him it was intolerable.

I asked other members how they felt about their masks. Everyone in the group hated them.

‘People always stare and say ugly things.’

‘People think you are so sick. I hate it. But if I take it off I could infect someone.’

‘My children are scared of it. I stopped wearing it at home.’

---

<sup>52</sup> To ‘culture convert’ is the process whereby one’s sputum no longer tests positive for active MDR-TB, however, the only surety in this process is to complete the entire duration of treatment while still receiving a negative sputum result.

<sup>53</sup> Clarified as moisture

## **‘This mask is different’**

It was not unusual to fidget with my mask in order to maintain the proper ‘fit’. I found that after wearing it for the first few days, I became accustomed to the pressure it exerted on my nose and the headache I would inevitably experience afterwards. I became comfortable in my discomfort. Most patients in the support groups complained about the masks, which were only worn inside the clinic. Often, I forgot that I had the mask on, but this occurred in support groups where we were all masked – it was ‘normal’. One eventually approaches a point at which it is no longer visible. I did not ‘see’ the mask of others when I was in a support group. Those who were not masked in a clinical space became identified as ‘others’; they were not ascribing to the ‘rules’.

In the support group a young mother explained how the mask ‘made her sad’. She wore it at home to protect her children and ‘to keep them safe from her.’

Another man, Sifiso, added:

‘That’s really the thing though *sis*<sup>54</sup>Kate. We wear these things and look! These (N-95s) are not like the other masks. See! (Pointing to ‘normal’ mask wearers). Those are different. Everyone wears those ones. You can see the face, you know? With these, they are different. Everyone knows you have something bad if you wear these ones.’

An older man observed that people looks like *tsotsis* (criminals) when they wear the mask.

Sifiso continued: ‘I mean...the mask look different man. You can see it? This mask (N-95)...you can’t see the face. You can see the eyes...not the noses, the mouth. Can you see me smile? Or can you see if I am not happy? How can you trust someone like that? The face is closed. You cannot see it.’

S: (laughs). ‘That’s what I can say is no one can see you! But they can see you, because of this damn thing. You are like a ghost standing up.’

K: ‘A ghost standing up?’

S: ‘Yes *sis* Kate. You can be a ghost and no one will notice. But when you stand, everyone will. This (mask)...it’s different...and it’s big, man. It means you must have a big disease. Yoh!’

K: ‘A big disease because it is a big mask? Is that what you mean?’

S: ‘Yes, That’s what I am saying to you. It’s a big disease this TB and the MDR. It’s big like a bed. For a big sickness, you must have the big mask, like this one. Not the other one.’

---

<sup>54</sup> Abbreviation of ‘sister’ in Xhosa

The ‘other one’ was the normal mask everyone wore in the clinic for protection. Sifiso explained for a ‘smaller illness’ you wouldn’t need a mask.

S: ‘The normal masks protect the people from us. Our masks protect them from us too...It’s like that...it’s not ‘number one’<sup>55</sup>.’ I am sick of these masks, this TB, I feel like some days I just can’t go on.’

## **Big Diseases, Big Masks**

This conversation demonstrates patients’ insecurities when faced with wearing a respirator mask, especially outside the clinical space. Again, the dichotomy of private space and public space is intrinsic to the perceptions that were shared in the support groups. The majority of the conversations related experiences of public discrimination initiated because the individual patient was wearing an N95 mask. As Sifiso states, TB is considered ‘a big disease’, requiring a ‘big mask’. He, like others, was convinced people would assume the magnitude of the disease was greater if one was wearing the N95. The magnitude of disease and the *presence* of disease is mimicked through the type and size of mask worn; as a result, one mask is considered ‘normal’, the N95 not. This signification extends to the wearer, too. Wearing a mask became a visible indicator of illness, something that was otherwise invisible, especially if you ‘looked’ healthy like Sifiso.

Sifiso made an additional distinction between the ‘normal’ mask and the N-95 masks. In Sifiso’s understanding the ‘normal’ masks were used to protect the other patients from the MDR and XDR-TB patients. He thought the ‘big masks’ also provided this type of protection. MDR and XDR-TB patients were protecting others from their forms of TB, but not themselves. His admission of suicidal thoughts was representative of how many patients felt. New(er) patients were generally disoriented in this new routine of daily medicine and mask-wearing. Older patients like Sifiso had tired of the routine. For Sifiso, the mask was yet another concern; even though he ‘looked’ healthy, he had to attend the clinic every day and still was unable to work. This process of visibility lent itself negatively to his day-to-day operation. Despite his pessimistic feelings towards the mask, it had become incorporated into daily biomedical ritual. It was a signifier of normalcy and ordered the disorder inside his body.

---

<sup>55</sup> ‘a good thing’

Everyday mask-wearing also influenced the relationships between mothers and their children, as stated through the comments of the women from Manzini support group. Fathers did not verbalise these challenges. One particular woman protected her children ‘from herself’ and from her disease. Her comment indicated a form of self-stigma. She was attributing negative aspects to her personal character. This type of stigma falls categorically under ‘felt stigma’, as it is an internalised state (Parker & Aggleton 2003, Scambler 2006, Scambler & Paoli 2008). The other mother refused to wear the mask at home; she saw it disrupting her relationship with her children and willingly took the risk. Often mothers would wear the mask outside if they were carrying their children close to their body. This arrangement created an awkward visual assemblage: a mother embracing her sleeping child, a kiss delivered to the baby’s forehead through a mask. In this instance, there is intimacy despite the barrier; the interaction occurs nonetheless. In other instances, the barrier prevents the understanding Gibbons affiliated with her mask method (2010). Wearing a mask creates uncertainty, ambiguity and anxiety for other people in the same social space.

Support groups used a vocabulary of size to describe MDR and XDR-TB. One morning a new patient joined the support group who displayed all of the visual signifiers attributed to a severely weakened, diminishing body. He asked if this was the ‘Big TB’ support group. He had not attended for months and had stopped taking treatment. The group welcomed him back (not without admonishment) and we continued.

This man, Jabulani, epitomised Sifiso’s metaphor of the ‘standing ghost’. The visible wasting of his stature and physique was exacerbated by the N95 mask which hung awkwardly; barely covering the ‘right’ parts of his face. I realized only when we met outside again how the mask transformed his face, how the mask had ‘worked’ upon the surface. Sifiso’s doubts about ‘being able to trust someone’ whose face is ‘closed’ is a valuable starting point.

### **Closed Faces and ‘Losing Face’**

In reference to her work with African masks, Tonkin cites the ambiguity inherent to the reality and the representation of mask users. She observes:

...Masks are comparable as operators in sequences of action which share properties of representation. Or is it of re-presentation? Are they recreations or re-creations? Re-productions or reproductions?... Although one can easily start with

the 'problem' that Mask users confuse image with reality, it soon appears that the English language does so too. Clearly this is an area of potent ambiguity. (Tonkin 1979:240)

In an effort to avoid conflating a mask's type with its purpose, we should take note of a shared premise behind the Mask. Whether it be a mask affiliated with dramatic ritual or theatrical performance or one employed for biomedical practice, there remains a sense of uncertainty. This ambiguity cannot be grounded in a particular or fixed aspect of the mask, rather it is just as ambiguous as the mask wearer is perceived. There is an element of trust which is fundamentally lacking because the face as a surface has been interrupted or 'closed' as Sifiso explained, substantiated by his and Tata's comments. Again, there is order instilled for the masked TB patient, they are following biomedical etiquette. The disorder stems from the productive absence of mask culture in South Africa and simultaneously the presence of a masked person.

The turn of phrase 'losing face' is both a descriptor and an active process in this context. In a study of moral social stigma in China, Yang et al found that:

Face represents one's moral status in the local community. One 'has' face, 'receives' face, and 'gives' face to respected others. When Chinese experience loss of face, they quite literally report the experience of humiliation as an inability to face others, as a physical crumbling of facial expression, a way of being faceless. (2007:1530)

I argue that 'losing face' extends the idea that the face is physically and visibly lost through the 'masking' process. As Sifiso articulated; when one is unable to recognize someone's facial expressions, one's face is lost. This double meaning also infers a loss of social status in accordance with others' judgements or stigmatisation of those wearing mask. Therefore, 'losing face' is both an embodied process as much as it is a social process. This also relates to Goffman's ideas on 'face work' and social interaction (1967). He states, '*Face* is an image of self delineated in terms of *approved* social attributes' (1967:5). In order to 'maintain face' in a social encounter, one must 'take into consideration his place in the social world beyond it' (1967:7). As Yang et al conclude, moral dimensions of stigma in China may be intimately connected to 'physical-emotional-sociocultural' elements (ibid). 'Losing face' is therefore what is 'at stake', both physically and socially. In the following section, I share similar personal experiences along the premise of 'losing face' myself.

## Provoking Stigma

I initially felt intimidated by the challenge of trying to research something which is not visibly ever-present. Wearing a respirator mask seemed to be the most noticeable way to draw attention to myself and note reactions from bystanders. Again, to draw upon the survey from chapter 2, 80% of respondents stated that they would not treat TB patients any differently if they knew the individual had active TB. The following excerpts come from what came to be referred to as the ‘Taxi Experiments’ because Thandi and I rode in public taxis alternately wearing N95 masks. Minibus taxis are significant and mobile research sites because in Cape Town it is estimated that over 40% of the population relies on this form of transport<sup>56</sup>. The intersection of mobility, disease transmission and space is of particular importance here as public transport has been cited as a potential vector for TB transmission<sup>57</sup> (hence the ‘STOP TB, Open a Window’ Campaign<sup>58</sup>). It is not unusual to see these stickers on taxi and clinic windows, only to find all of the windows closed, the taxi without ventilation.

Figure 10: Closed shebeen (tavern) window, Cloverdale



---

<sup>56</sup> Thomas 2009

<sup>57</sup> see Wu et al (2004)

<sup>58</sup> This campaign was initiated by the STOP TB partnership; a group of international NGO groups including USAID and the WHO.

Before commencing the taxi research I asked participants for input. I valued their thoughts because if Thandi and I chose *not* to carry out the research we would have been operating from a ‘felt/perceived stigma’ paradigm as opposed to an ‘enacted’ stigma experience. Whereas both paradigms are well founded, I wanted to understand and explore the embodied component of both felt and enacted stigma. None of my research participants thought it was a good idea. Betty’s daughter Trina speculated that because I was a ‘white girl’ it would ‘make things worse’ for me. Although Trina agreed with mask-wearing, she knew that people were afraid of masks and those who wear them. Betty also alluded to the basic issues with riding taxis in general:

Here people don’t care – for instance with taxis – you try to open a window and people cry of cold! They don’t want to be cold. And then you think, I don’t know what’s going on in this taxi if someone has TB or not, or if they even know that they are positive for TB. You have to tell people you have TB personally in order for them to open the windows and then people will be afraid of you! It’s a lose-lose situation. People stigmatize you but you want to protect yourself and other people<sup>59</sup>.

In anthropology, there is a debate over whether informed consent is needed when one researches within a public space. Whilst I still had reservations about conducting research in taxis, I felt impelled to do so because methodologically the experience was as close as one could come to feeling the stigma from others. It was necessary to insert myself directly into a situation where I could witness stigmatised actions as opposed to listening to post-event narratives about enacted stigma. I was scared because I was uncertain of others’ reactions, whether they were physical or spoken. Again, the survey stipulated that 80% of respondents would not treat or perceive someone with TB differently, and 76% recognised that covering one’s mouth would be an appropriate preventative measure. From my personal experiences, the survey reveals as much as it conceals, indicating the importance of complementary in-depth qualitative research such as this. Therefore, provoking stigma as a method outweighed ethical concerns I had about the well-being of others. I was not a carrier for active TB and therefore was not a threat to others’ health in the taxis. My own wellbeing gradually became more of a concern because people were extremely antagonistic, rude and aggressive towards Thandi and me.

---

<sup>59</sup> Personal correspondence

We rode from Khayelitsha and back on two separate occasions, once with me wearing a mask and the other with Thandi wearing a mask. The mask wearer would try to sit in the middle of the taxi while the other person would sit in back. We took notes via cell phone text and then stored the notes for review after disembarking from the taxi. We travelled a round trip from Khayelitsha to my home in Observatory, Cape Town. The excerpts below are from field notes detailing two different days of taxi riding and recording passenger reactions. The following section has *not* been edited as I felt it was important to include my initial reactions.

## **The Taxi Experiments**

*We jumped into the taxi and the gotchee [taxi guard] guy paid no attention. The first comment came from an older woman and she said 'Enkosi yam'(my god) and the other passengers in the taxi shifted away. It was strange that two rubber straps, a bendy strip and two pieces of tightly woven material could elicit such a physical and verbal response. The mask by itself has no power-but worn by an individual shifts it into a completely new translated space. It is no longer an object-it's a statement, a visible indicator that I am really sick, and allegedly VERY dangerous. It emphasizes and obscures-which perhaps lends itself to the mystery of the wearer's identity because only my eyes are visible. I sat in the middle of the cab and Thandi sat in the back row. The woman next to me leaned as far as possible away from me towards the window. Whispers soon ensued which she could hear-I could not. People were literally speaking behind my back. I felt the back of my head burning up. My face was hot and I was flushed perhaps out of embarrassment or because everyone was staring at me and making comments. A woman in the back row was praying and saying she had to get off the taxi as soon as possible because of me. Thandi recorded conversations by entering them into her cell phone. The older woman also was asking people what I had, how Thandi could live with a person like me and also asked if she was not afraid of getting what I have. She also covered her mouth throughout the duration of the trip to Cloverdale. She said she 'knew I wasn't healthy because she saw my hand when I was paying the gotchee'-(which was red because it was so cold outside)-and somehow the red hand further substantiated her speculations that I was sick. Someone also referred to my mask as the 'death mask'...*

*When we walked to the second taxi from Cloverdale to town people were visibly curious about the mask...we walked through a group of five men and all conversation ceased. I greeted them and they slowly greeted me. We got stuck sitting in the back of the taxi next to each other and there were empty seats near me, yet people opted for seats closer to the front. The smell of petrol was overwhelming and I could not breathe properly-I thought for a second to take off the mask but realized people would most likely have an adverse reaction to this. The man next to me leaned forward the entire trip-the woman in front of us with a baby did not seem to mind but women in the front most rows covered their mouths with either their hands or with scarves. The other strange thing is that all the windows were closed-one was open and a customer closed it-just like in the other cab. We got out in town and a woman*

*accosted Thandi. She asked if she knew me and if she lived with me. Thandi said she did know me and that I was her friend. The woman asked how could she stay with someone like me and asked the driver why he let me stay on the taxi-to which he did not respond at all. Another man (who we think was affiliated with the taxi association) confronted the driver and said he should not let people like me on the cab. We decided to leave.*

*On the way to Obs (Observatory neighbourhood) there were no real confrontations, the windows again were closed and the women behind us were speaking in Shona and staring at me the entire ride. At this stage my mouth area obscured by the mask was sweaty and very warm. I tried to tell the driver to stop on my street and he could not hear me-presumably from the mask. Thandi had to call out to him. This resulted in us being dropped 1.5 blocks from the house and so we walked to my house. People moved away from me and no one walked in our path.*

*On the way from Obs to Cape Town station, people stared on the street and the only open seat was next to me. The man who got on the taxi leaned away towards the window. We boarded the Bluefalls taxi at the rank and older women refused to get on the taxi when they saw me. Again-I sat in the middle, Thandi in the back. The windows were all shut. Before we left the drivers of other taxis going to Khayelitsha were speaking loud enough for us to hear. They were scolding and asking the driver why he let me on-he never responded. They said, 'What is she doing here hanging around us if she is so sick?' An older woman who refused to get on said, 'This one is scaring us, why is she covering her nose? What does she have?' The 'STOP TB Open a Window' sticker for the STOP TB Campaign was inside the taxi-yet no windows were open. This I thought was pretty ironic. What needs to be de-stigmatised is mask-wearing! There was one sympathetic comment from someone in the back who said; 'shame she looks so tired-she needs to rest'. When we de-boarded the taxi we walked through a section of Bluefalls. Thandi warned me that this is the street she was mugged a few weeks back and not to take out my cell phone. Five young men stared and said some nasty things to us and then one said 'Take that shit off your face'. Not sure what that necessarily meant-perhaps he thought I was protecting myself from them? Thandi is unsure if she will wear the mask-I'll give her some time to think about it. Judging from what we saw today, it is definitely not an option in her neighbourhood.*

Eventually, Thandi did decide to wear the mask. We emulated the same route we used when I wore the mask. Surprisingly enough, there was nothing negative said to her, or about her. In one instance, a young man was trying to speak to her and engage in conversation. This led me to think more about the racialized discourse which may have been perceived by those observing me. Perhaps other passengers thought that I was protecting myself from them or their germs? In the case of the group of young men and their emotive response towards me, I would say this was the case. Given the amount of attention I warranted merely walking down the street on a day-to-day basis, the mask amplified not only my presence, but a device people associated with negatively.

## **Negotiating spaces and proximity**

When I wore a mask, others would physically distance themselves from me. Although fellow passengers would sit next to me in the taxis, individuals would constantly lean as far away towards the window or other passengers as possible. Others would cover their mouths with scarves, shirt sleeves or jackets. In many instances potential passengers refused to enter the same taxi, opting rather to wait for another taxi. This is an ‘ordering mechanism’ which perpetuates stigma at the most basic level. The N95 mask (when worn) looks scary and the individual appears intimidating.

To understand how mask-wearing operated in other social contexts outside of Khayelitsha, I wore the mask from my home to the university campus and noted people’s responses. I also wore the mask in a classroom environment for a third-year tutorial group I facilitated. Many of the responses elicited were similar to the taxis and in Khayelitsha. In addition, I asked students to note their initial thoughts about my appearance<sup>60</sup>. Many of the students were concerned that I was very ill, or protecting myself from the H1N1 virus. Others equated the mask with those worn in parts of Asia. One student observed, ‘She looks like Daisy Duck.’ Lastly, one student remarked, ‘Needless to say one will usually find it difficult to understand why it (the mask) is being worn making it difficult to simply approach the person in a casual manner.’

## **Concluding comments**

In conclusion, although the mask is meant to be a preventative measure, it is not perceived as such. Masks are generally disliked by those who are indoctrinated into biomedical mask etiquette. Although mask-wearing is a component of the lived experience of MDR and XDR-TB patients, there is an absence of mask culture in South Africa relative to countries like Japan. This absence allows an exploration of the stigmas related to mask-wearing and indicators of disease. Different types of masks elicit different responses in different contexts. The type of mask and the person wearing it alter the manner in which it is received: the N95 mask is indicative of the magnitude of disease. ‘Losing face’ can be considered a ‘physical-emotional-sociocultural’ process hinging on a double meaning between social discredit and embodied humiliation. The data presented through the Taxi Experiments demonstrated the

---

<sup>60</sup> Consent was obtained through their permission and consequent participation.

embodied 'felt' stigma as well as the enacted stigma to which I was subjected. 'Provoking' stigma methodologically was an effective means to capture what it is like to be stigmatised by others. As a researcher this was a finite period of engagement, but I could not imagine the resentment and social adversity experienced by someone who had to cope with an extended 'masked' lifestyle. The next chapter argues that gossip perpetuates stigma and is triggered by envy. Again, enacted and felt stigma is indicative of the concerns everyday people have in Khayelitsha when they are infected with different forms of active TB strains.

University of Cape Town

## Chapter 4: Infectious Language: Gossip and Envy

‘You must be strong here. Otherwise if you are sick and you hear those rumours...you can die through those rumours. Not through your sickness, through the talk. People just know your problems without asking your problems. So if you are sick, the illness won’t kill you, the gossips will.’

Gossip can be understood as a ‘recreation of others’ disorderliness’ (Brenneis 1988:285). Another’s disorder is repeatedly called upon to order one’s own reality in ways that are damaging to those stigmatised. In her work on witchcraft accusations and violence in India, Macdonald observes that, ‘...by its very nature violence ruptures and produces disorder’ in the social fabric (2004). Although the intention behind violence may be to instil order, the opposite occurs. Gossip can be understood as indirect violence and thus, I argue, it has a similar intended ordering. Yet by its very nature as a form of violence, gossip produces rupturing and disordering effects. This line of argument may explain gossip, its intention and its (un)intended consequences.

But how does one explain remarks like the one above, which were common during my fieldwork? Gossip(s) were a focal point of discussion in support groups and interviews. The patients I worked with ‘gossiped about gossip’. It was a self-perpetuating cycle. Almost all participants described ‘their’ gossipers as being ‘jealous’ of them. This chapter unpacks ‘imagined envy’ as an organising image by suggesting that it serves a similar purpose of ‘bringing order to the disorder’ that gossip produces in the lives of a TB patient. The trajectory of gossip is extended when those who are objects of gossip express gossip in terms of envy. This chapter demonstrates the varying conceptions of gossip and rumour, envy and jealousy and draws parallels between enacted and perceived stigma.

### The Gossip Reel

Gossip has been studied extensively by anthropologists, especially in tandem with witchcraft accusations and rumour. As early as 1937, Evans-Pritchard examined the role of gossip in wizardry and witchcraft through a structural functionalist approach. He argued that witchcraft accusations were a means of dissolving or containing social strife within specific groups of people. Since his time anthropological conceptions on rumour and gossip have sufficiently

expanded. In attempting to dissect ‘the gossip reel’, it is pertinent to understand how gossip is disseminated, its purpose and who is involved.

Many theories of gossip recognise boundary-making techniques (us vs. them, you vs. I), moralised language, prestige and control. In the absence of other possible explanations, Herskovits (1937) concluded that gossiping served moral and social sanctions. Gluckman (1963) and Loudon’s (1961) theories are dominated by the notion of group membership and exclusion and consequently the reinforcement of group values. Colson’s *The Makah Indians* (1953), identifies social prestige and competition as characteristics of gossip, a social force equally divisive and cohesive. In Paine’s (1967) critique of Gluckman (1963) he proposes that gossip is strategic and manipulative disseminated largely in order to promote self-interest and control information. Gluckman proposed that ‘talking behind one’s back’ helps to maintain the unity of the community (1967:279). Paine rejects this claim on the grounds that gossip is not self-regulating (1967:280). Paine observes, ‘...gossip is a catalyst of social processes...’ and a ‘...powerful social instrument...’ (1967:238).

Lastly, Bleek’s work in Ghana identifies five major characteristics of gossip, all of which are pertinent (Handleman 1973 ci Bleek 1976:528):

- ‘1. It reinforces norms.
2. It is transmitted between members of one group.
3. It centres around people with whom a close social relationship exists.
4. To be the butt of gossip is an indication of social importance.
5. Gossip is utilised to forward personal interests.’

In the following section I elaborate on rumour and gossip to clarify the larger landscape of spoken stigmatising practices. In exploring the dialectic of both stigmatisers and the stigmatised, I distinguish between rumour and gossip and their function in local worlds.

## **The Rumour Mill**

There is significant conceptual ambiguity between gossip and rumour<sup>61</sup> and my collaborators used the terms interchangeably. Using DiFonzo and Bordia's definition, rumour can be defined as:

‘Unverified and instrumentally relevant information statements in circulation that arise in contexts of ambiguity, danger or potential threat, and that function to help people make sense and manage risk.’ (2007:19)

Rumours arise in contexts that are threatening, potentially threatening, or where a situation is ambiguous to those involved (DiFonzo & Bordia 2007:20). DiFonzo and Bordia define ambiguity as those in which ‘the meaning or import of a situation is not readily apparent’ (ibid). This ambiguity breeds insecurity and anxiety; consequently ‘people have an inherent need for acute security’ (ibid). The significant factor here is the *perception* of danger and the desire to understand what that danger entails. As argued by Fiske (2004), people have a core psychological motivation to understand what is happening around them. There is a *need to know*. One of the major differences between gossip and rumour is that rumours stem from making sense of something. Rumour is formulated individually and succeeded by collective consensus (DiFonzo & Bordia 2007:21). The development of rumour lacks moral and personal dimensions and can be formulated on a collective scale. By contrast, gossip is individually focused. Rumours are ‘sets of ideas’ which are transmitted *through* people and are not directed at or about them (2007:22).

## **Gossip as Narrative Event and Social Drama**

‘Conflict is a process, not a state.’ (Brenneis 1988:281)

Gossip assumes the shape of a ‘story’ format. The narration and dissemination of the event *is* the narrative event. As Brenneis’ work with conflict management in Fiji demonstrates, the narrative event comprises a narrator and an audience (1988:280). There is purpose and expectation(s) (ibid). Assuming the role of narrator increases one’s social prestige and moral or political stature. Stories may not necessarily be tools to provide clarity, rather they are

---

<sup>61</sup> See Ojha 1973 .

implements for ‘obscuring, hedging, confusing, exploring or questioning what went on, that is, for keeping the coherence and comprehensibility of narrated events open to question’ (Bauman 1986:5-6 ci Brenneis 1988:280). In telling stories, there is a ‘reconstruction of reality’ (Berret and Feldman 1981 ci in Brenneis 1988:286). However, as Brenneis so aptly observed, ‘speculative fictions are consequential realities’. Thus, reality is being constructed for the first time (1988:286).

In contrast to Brenneis’ work, conflict in Khayelitsha is not resolved, it is an ongoing process. Unlike Brenneis’ data, there is no one authoritative account, nor is gossip necessarily publicly mediated. The story may be public property because it has been disseminated multiple times, but authorship constantly changes. The story is forever *unfinished*. A piece of gossip is temporally resilient. The story can be drawn upon or invoked, altered and reconstructed by new authors. Das remarks that past events can be recycled and remoulded, thereby shaping the present in unexpected ways (1998). Gossip is malleable and resistant to the inscriptions of time.

As Bleek (1976) suggests, an unfortunate event generally precedes the production of rumour or gossip, thus drawing the social web tighter. Bleek proposes that the more sensational the gossip, the more self-important the narrator feels (1976). His conclusions challenge the literature that links causality solely to socio-economic conflicts. Quite simply, ‘gossip is fun’ for many<sup>62</sup> (Brenneis 1988:284) and a certain ‘voyeuristic pleasure’ is derived from gossiping about others’ misfortunes (Das 1998:123).

## **Nosabata and the Gossips**

In my work with Amandla, our relationship was based on a ‘school project’ because he was worried about others’ speculations. The topic of my research was revealed only to his immediate family and his neighbour, Nosabata. After becoming better acquainted, we started a Friday lunch routine. After attending the Manzini support group I drove to his home with groceries. As I prepared lunch, we spoke about our week, the support group, his school assignments and family life. One day we had finished lunch and Amandla suggested we meet

---

<sup>62</sup> The performative aspects of gossip are beyond the scope of this paper; see Bleek (1976), Brenneis (1988), and Das (1998).

Nosabata, his neighbour. She had had 'normal' TB in 2001 and Amandla thought a conversation would help my research.

We discussed Nosabata's move from Bluefalls in 1993. The house in Manzini was 'much better than Bluefalls.' She also explained, 'Life in a house is better than in a shack. I was living in an informal settlement in Bluefalls. It was dirty there, people were everywhere.' Her father and brother had both died from TB in 1999 and 1997. She described her shock when she was told she had TB. She displayed none of the visible signifiers<sup>63</sup> of TB, she felt healthy. She went to Manzini clinic because it was close. She explains how people gossiped about her:

N: 'You can only imagine... People spoke so much. They gossip a lot. With this HIV/AIDS and TB...they will laugh at you. They say different things. If you have TB without the AIDS, when they hear that you have TB – They say 'Obvious, you have AIDS'. People by the location they see you thin and you lose your weight – they assume you are sick. Maybe you are stressed or poor. Maybe you have no food to eat. They just assume and talk. They want to see you fail. When people would see me coughing all of the time my neighbours just talk, they gossip. In 2001, I had a swollen gland here (she points to her neck). The neighbours saw it and started talking about it, saying I had HIV. I had to just stay in my shack. It was very difficult. I closed my door and stayed inside. I did survive through all of that. It's hard in our locations<sup>64</sup>. If they see you and you are not well, they will spread those rumours.'

K: 'Is it different in different areas? Is there more gossip in some places versus other places?'

N: 'No it's not different. All our locations, we black people. We stay like that. We spread rumours.'

Amandla adds: 'It's jealousy.'

N: 'That is exactly what it is. Like my neighbours. I go outside, I do my washing and then when I am finished I come back inside and I close my door. I sit here and that is it. They are jealous because I am not a gossip. I keep to myself. This man is the only one<sup>65</sup> (indicating Amandla). You don't choose your neighbours.'

A: 'It's better to distance yourself. You are always behind doors.'

Nosabata described her constant fear of re-infection. 'These TBs now – the MDR and the XDR and you never know. And you never know where it came from...You can't see it. You just get it. You can't put the blame, but people blame you. Even with HIV it's always blame.'

---

<sup>63</sup> As per Nosabata: 'I wasn't *thin*, I wasn't *weak*.'

<sup>64</sup> Colloquial word for 'township'.

<sup>65</sup> Clarified that he is the only one she can relate to.

## Visible signifiers of the body, presence and mobility

Visible signifiers of illness often spark gossip, as evidenced by Nosabata with her lump in her neck. When she was diagnosed she, too, was surprised because of the absence of visible symptoms. As many theorists have noted, the dwindling and continued wasting away of the physical body are often linked to TB or HIV/AIDS (Sontag 2002, Henderson 2004, 2005, Steinberg 2008). Weight loss, discoloration and flaking of skin, weakness and a gaunt face are commonly associated with both illnesses.<sup>66</sup> There is a visible absence of health and an overwhelming presence of disease. In this context, spoken stigma is most powerful.

The presence/absence, public/private dyads are also illustrated in an individual's shrinking away from social realms. Individuals will move to a private space or home of a family member. This signifies again the parallels between the disappearing body and the progression of illness. Henderson's research in rural South Africa demonstrates similar findings (2004). In relation to AIDS patients, Henderson observes, 'The visible paring away of the body – its substance and efficacy in the world – is often mirrored by a paring away of benign social relations in relation to the person afflicted' (2004:5). An individual's absence from public spaces and increased presence<sup>67</sup> can elicit public conjecture (Colvin and Swartz 2010 np). The hyper-visibility of a wasting body is produced through the absence of flesh and the reduction in stature. This image creates a visible, salient paradox. Gossip becomes a reaction to these visible disorderly effects of a wasting body. Gossip brings order to gossips; those who perceive disorder in a sick body.

Amandla's reflections on a support-group session demonstrate my observations:

'The doctors do not understand the stigma or the disclosure issues. They don't understand what the person is going through. They don't know because perhaps they have never been a victim of stigma. They just give you medication. Because I don't have a car like most poor people, so people *might* see me out in the open. People see you. But you can always hide behind something if need be. But doctors and rich people can drive around in their cars and hide that way. That is why I want to get a car and move away, so I can be far away from this place. If you don't have your own transport like me, you are in the eye of the public and you are much more stigmatised. In the car you can hide. Rich people can stay away from poor areas. That is why in the future I want a better salary so I can go away...most of them here know about my

---

<sup>66</sup> This is substantiated by a conversation with Fundiswa, his sister, 'My cousins said they could see he was unwell...with the weight loss and the gaunt face. And the pimples on his head'.

<sup>67</sup> In the case of job loss, or a medical leave of absence.

status...through my wife...this TB stuff. It will be much more comfortable for me. I can be free. They say 'Ahhh this guy is not working'...'

Freedom of mobility (the car), not working and 'being out in the open' were all concerns of support-group members. In Amandla's case, he attended a support group in Bluefalls because he did not want anyone from Manzini seeing him at the clinic ten minutes from his home. For him, paying the taxi fare to Bluefalls was a better option than walking to Manzini. Amandla's scenario was extreme and unique. Other patients could not afford to pay extra fare. However, given the way his status was disclosed, I understood and respected his choices and his fears.

## **Disclosure and the Temporality of Gossip**

Amandla and I first met at a Kentucky Fried Chicken after a support group. He explained how he settled in Manzini and how he found out that he was both HIV- and MDR-TB positive. He had lived in Bluefalls for years. He eventually built a house in Manzini, although he wanted to move at the time of research. He would 'never go there' to Manzini clinic. He had used his health insurance, but it expired. He then went to a public, government facility.

'At Manzini there is a nurse there...she used to stay next to me. In fact she took my information to a neighbour before I knew my test results and she was the one who spread the message that I was HIV and MDR. She went to my wife and asked her to come collect a parcel. She disclosed my status before I even knew the results...I found out I had this MDR-TB and HIV the same day. I can never go back there. I use my old address in Bluefalls to access treatment; in fact my old shack is still there. I can afford to go that side every day by the train or taxi, many others do not have this option. Talk about stigma... It makes me go somewhere else! That is the problem really...Out here you are surrounded by those who may be poor, they may have nothing, not even an education. They see you progress, they gossip to bring you down. I consider myself a role model because of my level of education and others do not like to see you progress so they talk to make themselves feel better. When you go out of your door...there are people talking about you...and then perhaps a neighbour will approach you and say 'Do you know what they are saying about you?' It's hectic. People are bad... I think the gossip is the worst with women<sup>68</sup>...'

Disclosure stories like Amandla's were common: many patients worried they were unable to disclose on their 'own terms'. Disclosure was associated with risk, anxiety and fear. The

---

<sup>68</sup> Gossipers were almost always identified as female, and it was generally considered a 'woman activity' propelled through jealousy. Gossip as a gendered activity is reinforced by the work of Macdonald (2004), and Dreby (2009).

reactions of friends and family were uncertain. Most who had disclosed their TB or HIV/AIDS status employed distinctive, premeditated strategies. In Amandla's case, he was too afraid to disclose his HIV-positive status publicly. He feared losing his job. He disclosed his TB status instead. I consider his TB disclosure to be a 'supplemental disclosure' because, as he told me, 'It's more acceptable than HIV.' During our time together he was on leave from his job, which was granted because of his active MDR-TB. At the time of research he had ongoing marital problems and volatile arguments with his wife and her family because of his HIV status. Again, he had no control over the disclosure process. His wife had been a narrator to an audience. Amandla's disclosure story was thus a narrative which escaped temporal stricture.

Other thoughts on disclosure illustrated inherent risk. Disclosure was always coloured by remarks of 'social distancing', 'stigma' and 'being labelled in a negative way.' One support group member said:

'Sometimes that's why people decide just not to divulge or disclose their status, just keep on taking the treatment cause that's also discouraging. Where you stay or where you are taking your treatment, that institution, change people to go somewhere else.'

Other support-group members substantiated his concerns and told me freedom of mobility was a key factor in stigma, as was post-disclosure reception from family. TB seemed tainted with a reputation of death and burden. One man suggested, 'It's not fatal, it's just a chronic disease if you take your medicine. People must know that.'

### **'Social Diagnosis', Betty and Disclosure**

Betty used to be a Community Healthcare Worker (CHW) assisting people in the area with TB treatment and anti-retrovirals (ARVs). This is how she thought she got TB. Betty has been HIV-positive for ten years. She explained to me her disclosure process and the way her family received her. It started with two people from her support group living in her area. Against her wishes, they told her mother she was HIV-positive. Her mother 'said nothing',

but had been influenced by ‘Manto Tshabalala and the garlic’<sup>69</sup>. Betty continued to find beetroot and African potatoes in the kitchen stores. She decided to speak to her aunt.

‘When I arrived over to her house, my whole family was watching a program. The program was about AIDS sufferers and so I asked them how they would feel if someone had AIDS was in the family. They said they wouldn’t be able to live with someone like that, that they would be afraid to be around them and they would not eat their food, they would be scared...the cousins and everyone were saying these horrible things. I asked them how would you feel if you had AIDS or HIV and someone treated you like that. One of my cousins said they would go to the train (commit suicide), I wouldn’t want to live. So everyone was so negative about it. After that situation I disclosed to everyone. They were shocked and crying and screaming and people came in from off the street.’

Betty also described how people felt threatened by her disclosure and how her body was fat and healthy, antithetical to the ‘typical’ TB- or HIV-positive patient. Her neighbours commented when her daughter, Trina, wore nice clothes. They taunted her and said, ‘ah ha you are wearing clothes bought with an AIDS grant.’ She explained how ‘people used to talk all the time.’ She confronted them. ‘You keep talking about me *like I went to ShopRite*<sup>70</sup> and purchased my sickness...so what are you doing here? You think you are better than me.’ Betty’s strategy was to confront gossipers and stigma.

Colvin and Schwartz (2010 np) describe diagnostic language employed by third and fourth parties outside the diagnostic, clinical relationship of practitioner and patient. As they explain, disclosure is no longer rare but is often present in the form of ‘social diagnosis’. Obscure terminology implies one’s positive status and consequently social visibility (2010). These terms are often negative, obscure and cryptic. Betty’s own diagnostic language demonstrated her visibility (fat, healthy) and rejected the ‘normal’ symptoms (skinny, weak, etc.) associated with HIV and TB. She grappled indirectly with her family’s prejudice (through the television programme) in order to assess the ease of disclosure. Inevitably, their attitudes sparked her rebuttal and her disclosure. She also explained that disclosing HIV helped her to disclose TB. This experience was vastly different from Amandla’s. Not only were their diagnostic chronologies temporally different, Betty appropriated discriminatory remarks to her advantage. She related her family’s prejudice to an intimate occasion (her own HIV status), one to which they would respond emotionally. By disclosing her status she

---

<sup>69</sup> A former South African Minister of Health, Tshabalala is widely considered to be one of the most prominent AIDS denialists along with former President Mbeki, advocating garlic, beets, olive oil and other foods as remedies for AIDS.

<sup>70</sup> A grocery store

shortened the perceived distance between the people (on the television) and her family. In this way, I think stigma processes may have beneficial peripheral effects, but more research is necessary in this area.

## **Jealousy and Envy**

As demonstrated by both Amandla and Nosabata's experiences, notions of jealousy and envy are constantly employed. Amandla and others never understood the gossip directed at them to emerge from a real fear of infection. Instead, research participants constructed narratives about others' gossip about them around the organising image of envy. Amandla, as the target of others' gossip, imagines his gossipers to envy him. Many of the project participants used jealousy and envy interchangeably. There is a considerable difference between the terms and it is important to understand the contexts in which they arise. I maintain that envy (not jealousy) prompted much of the gossip about gossip.

Foster (1972:167-168) uses the Oxford Dictionary to differentiate the two:

**Envy:** 'To feel displeasure and ill-will at the superiority of (another person) in happiness, success, reputation, or the possession of anything desirable; to regard with discontent another's possession of (some superior advantage which one would like to have for himself).'

### **Jealousy:**

'Zealous or solicitous for the preservation or well-being of something possessed or esteemed; vigilant or careful in guarding; suspiciously careful or watchful'

[and ]

'Troubled by the belief, suspicion, or fear that the good which one desires to gain or keep for oneself has been or may be diverted to another; resentful towards another on account of known or suspected rivalry.'

Envy comes from desiring *something* someone else possesses. Jealousy arises when an individual already possesses something which they are afraid of losing to another. Foster makes a useful point: 'It is important to note that an envier is not envious of the thing he would like to have; he is envious of the person who is fortunate enough to have it. The possession is the trigger, but not the target, of envy' (1972: 168). Lastly, as Schoek suggests,

‘Envy is a directed emotion; without a target, without a victim, it cannot occur’ (1969:7 cf Foster 1972:168). This is a similar quality I associate with gossip: both gossip and envy require a target. Thus, envy is the operable term and emotion which initiates stigma through gossip. I suggest that imagined envy became a way for collaborators to position themselves in opposition to their gossipers.

Ironically, the target of gossip may gain some benefits thereby. On the one hand, we can understand that the gossiper is ‘making order’ in their own lives out of the perceived disorder of another (their illness or wasting body). By its very nature, this process produces rupture and disorder. However, being spoken of creates ‘social legitimacy’ (Bleek 1976:540). The opposite of social legitimacy is social death. In short, the fact one is spoken of at all imbues one with social relevance (albeit in most cases the gossip is judgemental and damaging). To understand the gossip as triggered by another’s envy allows the TB patient to rationalise the ‘indirect violence’ directed at them.

## **Indirect Violence and Gossip**

In this final section I reiterate the similarities of violence and gossip. Violence is intended to create order out of a disorderly world, but instead creates rupture in local worlds (Macdonald 2004). Gossip can be read similarly through Macdonald’s theory (2004). Whereas rumour tries to make sense of TB, gossip targets an individual and becomes a form of indirect violence. Gossip as ‘indirect violence’ affects the individual and their social networks. In Pocock’s (1973) research of the evil eye he contends that envy is bound to a certain realistic limit: ‘We do not really envy, that is truly covet, something that is not within our reach. What affects us more closely are the things which seem to just elude our grasp’ (1973:28). Thus, envy arises in those who are in a similar situation to those they envy, in this case Betty’s neighbours. The thing they envy may be of only marginally better quality, but the envier feels deprived nonetheless. Envy is an organising image which helps make sense of gossip –the targets of gossip imagine their gossipers as envious of them. To gossip is to try to make order out of disorder. To imagine others as envious creates order in the lives of TB patients. Gossip then renders them socially relevant.

In one of our last interviews, Betty, Trina and I spoke about stigma generally. It was if I had been trying to uncover some fundamental answer to why or how people gossiped.

B: 'Even though there is all of this information about TB or HIV, people just assume if you have AIDS you are promiscuous, if you have TB you are a bad person...you smoke too much or drink too much or go to the *shebeens* all of the time...or whatever...they never think that maybe you were in a committed relationship and your partner was unfaithful and infected you.'

K: 'And TB?'

T: 'They say you are a smoker and an alcoholic. It is about being a good person or being a bad person. Either way....it's not like that, but they make it out to be like that.'

K: 'Why do people do that?'

B: 'Yoh... I don't know.'

Trina observed:

'One of the reasons I think that people do the gossip thing and stigmatising thing...is that we are neighbours. It doesn't mean we like each other or care about each other...it was the setup of apartheid. We are all forced to stay here. Just because you live next to someone doesn't mean you like them. Sometimes you don't like the next person.'

She explained how my presence created gossip: neighbours questioned why 'a white person comes to this house because you all are so poor.' People had made accusations that I was 'feeding them.' I felt awful. I apologised. Betty brushed it off and confidently said, 'That is how people are in the township. Everyone knows everything even if it is a lie...They don't know, they don't come to ask and we will not go to them.' Ultimately, she and Trina thought gossip stemmed from hatred, contempt, and jealousy.

## Conclusion

I return to my observation that people 'gossip about gossip'. These conversations are narrative events which serve two functions (Brenneis 1988). First, employing envy as a lens through which to make sense of gossip gives order to disorderly events in the lives of those like Amandla and Betty. Imagined envy helps make sense of gossip by positioning the gossiper as the envier. Second, those who are envied create reality for the first time through re-authorship of the story (Brenneis 1988:286). Gossip takes many forms, but ultimately the gossip from my data was malicious and re-interpreted. These characteristics exemplified both the 'narrative event' (Brenneis 1988) and the 'social drama' (Bleek 1976). Gossip is timeless, transcending temporal ordering and chronological specificity. Although many theorists have

remarked on the inherent pleasures of gossip, stigmatised language as gossip has potentially damning implications for those with active strains of TB. Gossip and envy demonstrate ‘what is at stake’ within the landscape of stigma. Gossip conveys the fragility of an unfinished social world subjected to the authorship of the past and the future (Das 1998:126).

University of Cape Town

## Chapter 5: Conclusion

### A time of need: Identifying ‘what is at stake’

There are many ways to think about stigma. TB-related stigma and stigmatisation serve the purpose of ordering otherwise disorderly worlds. This process is executed through moral discourses. Organising images are useful tools for recognising recurring themes in a larger landscape of stigma (Das 1990). Investigating the keywords used frequently by both patients and non-patients assists an understanding of the circumstances in which stigma and stigmatisation emerge. My research suggests further investigation into the moral dimensions of stigma in the daily rhythms of a local world. My data identifies the ways in which TB transmission is conceptualised locally and how these ideas may translate into stigma and stigmatising acts within Khayelitsha.

Many of my initial research questions remain only partially answered. I propose that theoretical expansion and methodological improvisation are necessary to articulate succinctly the adversity some TB patients contend with daily. ‘Provoking’ stigma, however ethically contentious, is a method whereby the researcher experiences stigmatisation first-hand. ‘Provoking’ stigma probes for further insight within public spaces and confronts the anxieties of both researchers and those researched. As a researcher, rendering oneself vulnerable to others’ scrutiny is an essential process – it is, in effect, ‘practice as data’. This method yielded a comprehensive perspective through witnessing acts otherwise expressed only in post-event narrative accounts.

The theoretical implications of this work are exciting for a number of reasons. Using different bodies of literature has created a broader understanding of the ways that stigma and stigmatisation are activated. I suggest that the absence of mask culture in South Africa may be a fruitful area of further research to understand the way masks (and those who are masked) are received in their communities. This research suggests that mask-wearing may be implemented as a public-health strategy to ‘normalise’ mask-wearing and reduce potential transmission in high-risk environments like public taxis. An understanding of local Illness Transmission Models ITMs may help to raise issues that can be addressed in future by urban planning, local government, public health initiatives and stigma theorists alike. It is imperative to understand how everyday people understand everyday disease and how those ideas translate into daily practice.

My findings demonstrated that treatment-seeking behaviour is influenced by both ‘felt’ and ‘enacted’ stigma. The residents I interviewed in Khayelitsha were highly mobile, meaning they moved frequently in response to employment and housing opportunities. In addition, TB patients were acutely aware of the challenges they faced in seeking treatment ‘closer to home’ or within their identified neighbourhoods. Although the majority of the respondents in the survey stated they would not stigmatise TB patients, the same majority provided insight into ITMs and potential areas of stigmatisation. Most of the ITMs provided were based on poor hygiene and lifestyle choice. Thus, I argue that local notions of TB transmission directly inform stigma ideas and acts of stigmatisation. Lastly, TB patients were shrewdly cognisant of the potential moral judgments of others were they to be ‘seen’ in a number of scenarios. Some of these situations include: wearing a mask, being perceived as unemployed, failing to maintain a clean home, or looking ‘dirty’. Yet these are the very things which are *at stake*. One’s integrity, job security and social standing within the community are crucial elements in a daily routine. We (as theorists, academics and practitioners alike) must shift our focus if we are to address the dangers perceived and experienced by those who are stigmatised. It is with this consideration I return to the idea of stigma as indirect violence.

Hoffman (1989:144 ci Macdonald 2004:275) suggests that ‘violence [in this case stigma as violence] educates [one] to the inescapable reality of others’; it helps one ‘gain a perspective broader than, and independent of, [one’s] particular self’. This ‘inescapable reality’ is educational and consequential. It is educational because these worlds are constantly being re-negotiated through ever-shifting patterns of ordering and disordering. It is consequential because disruption is temporarily resolved through re-ordered accounts (as in the case of ‘gossip about gossip’).

In this work I have attempted a representation which resounds for reader and research participants alike. This perspective lends immense insight to the violence people experience: are subjected to, and persevere against *every day*. Understanding stigma as indirect violence makes it visible, a characteristic which may be obscured in other accounts. This approach also makes stigma and stigmatisation a tangible experience that can be felt, often deeply. Lastly, understanding violence as a theoretical device allows the acknowledgment that ‘what is at stake’ are universally shared concerns. It is impractical and dangerous to assume these challenges have been surmounted. The reality and *their realities* are far from resolution. I leave the last word to my research participants:

*'It's hard to be the support too...You want to be there, and you are...but he (Amandla) has been fighting lately with his wife. Maybe it is the stress, or she is afraid. I don't know. It's life-changing. The gossip is too much.'*

(Fundiswa, Amandla's sister)

*'For me to go back to my workplace is a problem. I'm going to be stigmatised. I cannot work at full capacity. They will say I am lazy. I'm not lazy. It's the tablets, they make me tired and drowsy. I have to have rest, if I don't have rest I will become stressed and get sicker. If I pretend I am feeling better I am putting myself at risk. I cannot carry a bag of potatoes right now. If I am under my blanket I cannot pull it over myself or find a comfortable resting position.'*

(Amandla)

*'I don't know why... but it [stigma] is powerful. It's easier to talk nonsense about something you know nothing about. I do know why the TB stigma doesn't stop though. Poverty has a lot to do with it. People are hungry and poor. They go through the bins and eat old food from the streets. People can get TB this way too. Children are touching all of these dirty things and playing in the streets and they'll catch it as well. It's an unending circle.'*

(Betty)

## Appendix 1: Survey questionnaire

Hello, We're conducting a survey to investigate the attitudes about TB stigma and how people get sick. We are researchers from UCT and this is a student project. It is an anonymous survey and it will take 5 minutes.

Senza uphando lokujonga indlela abantu abasibo ngayo isifo sephepha nendlela abantu abacinga ukuba situmaneka/sisuleka ngayo esi sifo. Igama lakho lizakufihlwa koluphando kwaye ukuphendula kuza kuthatha nje imizuzu emihlanu.

- 1) Do you know someone with TB? Y\_\_\_N\_\_\_ Ukhona umntu omaziyo one sifosephepha okhnaye owakhe waba nesifo sephepha?
- 2) Is this person a) friend?\_\_\_b)relative\_\_\_c)social acquaintance?\_\_\_d) self? Ingaba lomntu waye a) ngumhlobo b)isizalwane c) okanye umntu nje omaziyo? D) wena?
- 3) Do you think people disclose their status if they have TB? Y\_\_\_N\_\_\_ Ucinga ukuba abantu baye bazichaze ukuba banazo isifo sephepha?
- 4) Do TB patients ask for assistance (i.e. food, child care, lifts to clinic) Y\_\_\_N\_\_\_ Abantu abanesifo sephepha ingaba bayelucela ncedo (umz; ukutya, ukugcinelwa abantwana, okanye ukusiwa esibhedlele)?
- 5) If so-would you help someone with TB? Y\_\_\_N\_\_\_ Ukuba kunjalo, wena ungamnceda umntu onesifo sephepha?
- 6) If someone has TB do you see them /treat them differently? Y\_\_\_N\_\_\_Xa umntu enesifo sephepha, ingaba umbona ngendlela eyahlukileyo?
- 7) Do you take precautions if you are around a TB patient? Y\_\_\_N\_\_\_Ingaba zikhona inzame zokuzithintela ozithathayo xa uphakathi komntu onesifo sephepha?
- 8) If so-How? Explain:Ukuba kunjalo cacisa:
- 9) How do you catch/find/get TB? Sifumaneka njani okanye sisuleleka njani isifo sephepha?
- 10) Can you get TB by sharing food or drinks?Ungasifumana isifo sephepha ngokwabelana ngokutya nomntu okanye ukusela nomntu na?
- 11) Can you get TB by sharing a cigarette? Ungasifumana isifo sephepha ngokutshayisana icuba nomntu na?
- 12) How did you learn about TB? Ulufumene njani ulwazi onalo ngesisifo?

## Appendix 2: Survey and Quantitative Data

### ‘Attitudes about TB and Transmission Models’ Survey

Total number surveyed from both neighbourhoods: 100 people in total; 50 respondents from each neighbourhood. 58 women in total were surveyed and 42 men. Sampling was random. Ages surveyed ranged from the youngest 11 years old to the oldest respondent 78 years old. The data was not broken down according to gender or age.

Bluefalls: 28 men and 22 women, 4 potential respondents refused the survey

Cloverdale: 14 men and 36 women, 2 potential respondents refused the survey

#### 1) Do you know someone with TB?

Neighbourhood	Yes (in %)	No (in %)
Cloverdale	42	8
Bluefalls	38	12
total	80	20

#### 2) Is this person a) friend? b) relative? c) social acquaintance? d) self?

Neighbourhood	Friend	Relative	Social Acquaintance	self
Cloverdale	18	24	6	2
Bluefalls	30	12	5	3
total	48	36	11	5

#### 3) Do you think people disclose their status if they have TB?

Neighbourhood	Yes	No	Some do, some don't
Cloverdale	15	19	16
Bluefalls	10	22	18
total	25	41	34

#### 4) Do you think TB patients ask for assistance if they need it (i.e. food, child care, lifts to clinic)?

Neighbourhood	Yes	No	Some do, Some don't
Cloverdale	31	16	3
Bluefalls	28	19	3
total	59	35	6

**5) If so-would you help someone with TB?**

Neighbourhood	Yes	No
Cloverdale	49	1
Bluefalls	49	1
total	98	2

**6) If someone has TB do you see them /treat them differently?**

Neighbourhood	Yes	No
Cloverdale	12	38
Bluefalls	7	42
total	19	80

\*one respondent clarified that if the TB patient is on treatment, they would not treat them any differently than before the diagnosis, if they were not taking treatment, they would treat them differently.

**7) Do you take precautions if you are around a TB patient?**

Neighbourhood	Yes	No
Cloverdale	39	11
Bluefalls	28	22
Total	67	33

**8) If so, how? Please Explain**

The following responses were divided amongst the first initial response amongst those surveyed; meaning the responses listed were the first responses provided by the individual respondent.

Neighbourhood	Cover mouth with something: toilet paper, hand, shoulder, mask	Open windows of taxi	Stay away from them	No precaution necessary
Cloverdale	39	7	2	2
Bluefalls	37	3	8	2
Total	76	10	10	4

**9) How do you think one catches/finds/gets TB?**

The following responses were divided amongst the first initial response amongst those surveyed; meaning the responses listed were the first responses provided by the individual respondent.

Neighbourhood	The air	Not being a clean person, i.e. not bathing/grooming (unhygienic)	Dirty home: not sweeping, mopping or cleaning 'enough'	Inhaling dust, smoke, being cold (work oriented)	Lifestyle (drinking, smoking)	witchcraft
Cloverdale	12	13	14	2	8	1
Bluefalls	10	11	10	1	17	1
total	22	24	24	3	25	2

**10) Can you catch/find/get TB by sharing food or drinks?**

Neighbourhood	Yes to both	No to both	Only drinks	Only food	Only alcohol
Cloverdale	32	0	15	0	3
Bluefalls	34	0	2	2	12
total	66	0	17	2	15

**11) Can you catch/find/get TB by sharing a cigarette with someone who has TB?**

Neighbourhood	Yes	No	I don't know
Cloverdale	39	8	3
Bluefalls	48	1	1
total	87	9	4

**12) How did you learn about TB?**

Neighbourhood	Clinics/Hospital/outreach organisations	Former patient	School	Knew someone with TB and the patient taught me about TB
Cloverdale	6	2	3	39
Bluefalls	7	3	4	36
total	13	5	7	75

## **Appendix 3: Summary of Survey Results and Discussion**

### **TB visibility**

80 % of respondents knew someone with TB, while 20% did not. Respondents were more intimately related to the person they knew who had TB; 84% were either friends or relatives. While 5% were self identified patients and 11% comprised social acquaintances that were not classified as friends or family.

### **Disclosure**

41% of respondents said that people do not disclose their TB status, while 25% said that they do disclose their status. 34% of respondents were unsure; replying that ‘Some do disclose, some do not disclose’.

### **Assistance and Compassion:**

59% of respondents said that TB patients ask for assistance, while 35% said they do not. 6% were undecided; replying ‘Some do, and Some do not ask for assistance’. An overwhelming 98% of respondents replied ‘Yes’ they would assist a TB patient, or help them in some way if they were approached. While 2% said ‘No’.

### **Prevention:**

19% of respondents answered ‘Yes’, they would treat them or perceive them differently if they knew someone’s TB status, while 80% replied ‘No’, they would not treat them differently. In direct contradiction to the previous question (q. 7- Do you take precautions if you are around a TB patient? 67% Yes, 33% No), once the question ( q. 8-If so-How?) was re iterated and clarified; 76% replied that covering their mouth with an implement (hand, tissue paper, sleeve, mask) would prevent TB transmission, 10% would either stay away from the TB patients or open windows in a taxi, while 4% continued to maintain ‘no precaution’ necessary.

The moralised/hygienic responses in Cloverdale differed only slightly from Bluefalls. 35% of Respondents in Cloverdale believed that lifestyle and hygiene were responsible for TB transmission, while in Bluefalls 38% thought the same. Witchcraft amounted to 2% in total of ITMs, while 22% believes it was airborne and 3% in total believed TB to be transmissible through inhalation of dust, cold air or smoke from a braai.

## **Food and Drinks**

66% of respondents in both neighbourhoods believe that sharing food and drink would result in TB transmission potentially. In Cloverdale, sharing non-alcoholic drinks accounted for 15% and alcoholic beverage 3%. In Bluefalls by comparison, 12% believed that sharing alcoholic beverages could transmit TB. 87% of respondents from both neighbourhoods believed that sharing a cigarette with someone who has TB would transmit TB; this may suggest a connection to the idea of sharing saliva; as sputum samples are tested to assess a TB diagnosis. 75% of respondents learned about TB from someone he/she knew who had TB in the past or the present. 13% said they received information from local clinics, the Day Hospitals or medical outreach organisations.

## **Conclusions:**

TB is widespread in both Cloverdale and Bluefalls, and people have a tendency to state that they would not treat TB patients differently if the individual patient would disclose. However, the ITM employed by the individual may imply that TB patients receive different types of treatment from other people depending on how those individuals perceive the mode of TB transmission. There are visible moral and hygienic discourses woven into ITMs and it is not possible without further research to deduce to what magnitude these attitudes operate. In addition if 66% of respondents believe that sharing food and non-alcoholic beverage with someone who has TB is a danger, then it is hard to deduce in what ways those ideas translate to practice without further investigation. My data reflects some stigma translating into practice (i.e. active, 'enacted' stigmatisation) whereby patients are served food separately, have separate cutlery or are not cooked for or served food at all. Again, the sample size is relatively small and further research is required to make solid conclusions.

## Bibliography

Bateman, C.

(2006). 'Living the TB resistance nightmare'. *South African Medical Journal*. 96(10):1014-1016.

(2007). "'One shot' to kill MDR-TB - or risk patient death'. *South African Medical Journal*. 97(12):1233-1235.

Bayer, R. & Fairchild, A. (2002). 'The Limits of Privacy: Surveillance and the Control of Disease'. *Health Care Analysis*. 10: 19–35.

Bleek, W. (1976). 'Witchcraft, Gossip and Death: A Social Drama'. *Man*, New Series, 11(4): 526-541

Blendon, R. J., & Donelan, K. (1988). 'Discrimination against people with AIDS'. *New England Journal of Medicine*. 319:1022–1026.

Blendon, R. J., Donelan, K., & Knox, R. A. (1992). 'Public opinion and AIDS: Lessons for the second decade'. *Journal of the American Medical Association*. 267: 981–986.

Boas, F. (1955). *Primitive Art*. New York: Dover Books

Boonzaier, E.

(1985). 'Choice of Healer: An important area of interest for general practitioners'. *South African Family Practice*. August: 237-241.

(1988). 'Understanding Disease: Are "First World" and "Third World" patients fundamentally different?' *South African Family Practice*. November: 77-78.

Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge: Cambridge University Press

Brenneis, D. (1988). 'Telling Troubles: Narrative, Conflict and Experience'. *Anthropological Linguistics*. 30 (3/4): 279-291.

Brown, Trujillo, & MacIntyre, (2003). 'Interventions to reduce HIV/AIDS stigma: What have we learned?' *AIDS Education and Prevention*. 15: 49-69.

Castro, K.G. & W. Jaffe, H. (2002). 'Rationale and Methods for the National Tuberculosis Genotyping and Surveillance Network'. *Emerging Infectious Diseases*. 8(11): 1188–1191.

Cassidy, A. (2010). 'Community Health Workers: Just a Foot in the Door?'. Unpublished Honours Thesis, Department of Social Anthropology, University of Cape Town South Africa

- Chapple, A. Ziebland, S., & McPherson S. (2004). 'Primary care: Stigma, shame, and blame experienced by patients with lung cancer: qualitative study'. *BMJ* . 328:1470-1472
- Colson, E (1953). *The Makah Indians*. Manchester: University Press.
- Colvin, C. and Swartz, A. (2010). "A House in Virginia": Diagnosis and Interpretation in the Age of the "Chronic" HIV Epidemic'. Unpublished paper from the School of Public Health and Family Medicine at the University of Cape Town, presented at the ASA conference East London, South Africa 2010
- Comaroff, Jean and Comaroff, John. (1997). *Of Revelation and Revolution II: The Dialectics of Modernity on South African Frontier*. Chicago University Press: Chicago
- Cowling, B.J., Zhou, Y., D.K.M., Leung, G.M. and Aiello, A. E. (2010). 'Face masks to prevent transmission of influenza virus : a systematic review'. *Epidemiological Infections*. 138:449-456.
- Csordas, T.J (1990). 'Embodiment as a Paradigm for Anthropology'. *Ethos*. 18(1): 5-47
- (1994). *Embodiment and Experience: the existential ground of culture and self* (ed) T.J. Csordas. Cambridge University Press: Cambridge.
- Curtis, V. (2007). 'Dirt, disgust and disease: a natural history of hygiene'. *Journal of Epidemiological Community Health*. 61:660–664
- Curtis V. & Biran, S. (2001). 'Dirt, Disgust and Disease-Is hygiene in our blood?'. *Perspectives in Biology and Medicine*. 44(1) :17–31
- Das, V.
- (1990). *Mirrors of Violence* (ed). Delhi: Oxford University Press.
- (1998). 'Specificities: Official Narratives, Rumour, and the Social Production of Hate'. *Social Identities*, 4: 1, 109-130.
- Das, V. And Poole, D. (eds) (2004). *Anthropology in the Margins of the State*. Santa Fe: School of American Research Press.
- Deacon, H. (2005). *Understanding HIV/AIDS stigma*. Cape Town: HSRC Press.
- DiFonzo, N & Bordia, P. (2007) . 'Rumour, Gossip and Urban Legends'. *Diogenes*. 54: 19
- DiGiacomo, S. (1992). 'Metaphor as Illness: Postmodern dilemmas in the representation of body, mind and disorder'. *Medical Anthropology*. 14:109-137.

Douglas, M.

(1966). *Purity and Danger*. Routledge: London.

(1992). *Risk and Blame: Essays in Cultural Theory*. Routledge: London.

Draus, P. (2004). *Consumed in the City: Observing Tuberculosis at Century's End*. Temple University Press: Philadelphia.

Dreby, J. (2009). 'Gender and Transnational Gossip', *Qualitative Sociology*. 32:33–5

Ecks, S. & Sax, W.S. (2005). 'The Ills of Marginality: New Perspectives on Health in South Asia'. *Anthropology & Medicine* 12(3) (2005), pp. 199–210.

Evans-Pritchard E. E. (1937). *Witchcraft, Oracles and Magic among the Azande*. Oxford: Oxford University Press.

Falzon D. & Ait-Belghiti, F. (2007). 'What Is Tuberculosis Surveillance in the European Union Telling Us?'. *CID* 44: 1261-1267.

Farmer, P.

(1992). *Aids and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press.

(1996). 'Social Inequalities and Emerging Infectious Diseases', *Emerging Infectious Diseases*, 2(4):259-269.

(1999). *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.

(2005). *Pathologies of Power: Health, Human Rights and the New War on the Poor* University of California Press: Berkeley.

Fiske, S. T. (2004). *Social Beings: A Core Motives Approach to Social Psychology*. Hoboken, NJ: John Wiley & Sons.

Fitzpatrick R, Hinton J, Newman S, Scambler G, Thompson J, Scambler G. (1984). 'Perceiving and coping with stigmatizing illness', in Fitzpatrick R, Hinton J, Newman S, Scambler G, Thompson J (eds.) *The experience of illness*. London: Tavistock, 203–26.

Foster, G. M. (1972). 'The anatomy of envy: a study in symbolic behaviour'. *Current Anthropology*. 13:165-202.

Gilbert, L. & Walker, L. (2010). 'My biggest fear was that people would reject me once they knew my status...': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health and Social Care in the Community*. 18(2):139–146

- Gluckman, M. (1963). 'Gossip and scandal'. *Current Anthropology*. 4: 307-15.
- Gibbons, R. (2010). 'A Table of Metaphors: The Visual Representation of chronic Illness'. Unpublished Masters Thesis, Massey University, Albany, New Zealand
- Goffman, E. (1963). *Stigma. Notes on the management of spoiled identity*. New York: Simon and Schuster, Inc.  
(1967). *Interaction Ritual: Essay on Face-to-Face Behaviour*. Chicago: Aldine Publishing Company
- Goldman, I. (1975). *The mouth of heaven*. Seattle: University of Washington Press
- Gooskens, I. (2006). 'Boundaries and Crossing Points: Children, Geography and Identity in the Fish Hoek Valley'. *Social Dynamics*. 32(1): 135-168.
- Gray, D. (2002). 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism'. *Sociology of Health & Illness*. 24(6):734-749
- Green, E.  
(1998). 'Etiology in human and animal ethnomedicine'. *Agriculture and Human Values*. 15: 127-131.  
(1999) *Indigenous theories of contagious disease*. Walnut Creek: Altamira Press.
- Gustafson, P., Gomes, V.F., Vieira, C.S. (2004). 'Tuberculosis in Bissau: incidence and risk factors in an urban community in sub-Saharan Africa'. *International Journal of Epidemiology*. 33(1):163-172.
- Habib, R.R., Mahfoud, Z., Fawaz, M. (2009). 'Housing quality and ill health in a disadvantaged urban community'. *Public Health*. 123(2):174-181.
- Harper, I.  
(2006). 'Anthropology, DOTs and Understanding Tuberculosis Control in Nepal', *Journal of Biosocial Science* 38: 57-67.  
(2010) 'Extreme condition, extreme measures? Compliance, drug resistance, and the control of tuberculosis'. *Anthropology and Medicine*. 17(2):201-14.
- Heijnders M. and Van Der Meij, S. (2006). 'The fight against stigma: An overview of stigma-reduction strategies and interventions'. *Psychology, Health & Medicine*. 11(3): 353-363.

- Henderson, P. (2004). 'The Vertiginous body and social metamorphosis in a context of HIV/AIDS'. *Anthropology Southern Africa*. 27(1 &2): 43-53.
- (2005). 'Mortality and the ethics of qualitative research In a context of HIV/AIDS'. *Anthropology Southern Africa*. 28(3&4): 78-90
- Herek, G. M. (1999). 'AIDS and stigma'. *American Behavioural Scientist*. 42(7), 1106–1116.
- Herek, G. M., & Glunt, E. K. (1991). 'AIDS-related attitudes in the United States: A preliminary conceptualization'. *Journal of Sex Research*, 28, 99–123.
- Herek, G.M., Capitano, J. P., & Widaman, K. F. (2002). HIV related stigma and knowledge in the United States: Prevalence and trends, 1991–1999. *American Journal of Public Health*, 92, 371–377.
- Herskovits, M. (1937). *Life in a Haitian valley*. New York: Knopf.
- Higgins, J. (2007). "It's Literacy, Stupid!": Declining the Humanities in National Research Foundation (NRF) Research Policy'. *JHEA/RESA*. 5 (1): 95–112
- Hirschfeld, Lawrence. (2002). 'Why Don't Anthropologists Like Children?'. *American Anthropologist*. 104 (2):611-627
- Jenkins, R. (2008). *Social Identity*. New York: Routledge.
- Kao, T-W, Huang K-C, Huang Y-L, Tsai T-J, Hsieh B-S, Wu M-S (2004). 'The physiological impact of wearing an N95 mask during hemodialysis as a precaution against SARS in patients with end-stage renal disease'. *J Formos Med Assoc*. 103:624–8.
- Kleinman, A. (1980). *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press.
- (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Kleinman, A., Das, V., & Lock, M. (Eds.) (1997). *Social suffering*. Berkeley: University of California.
- Krieger, J. and D.L. Higgins (2002). 'Housing and Health: Time Again for Public Health Action', *American Journal of Public Health* 92 (5): 758-768.
- Leclerc-Madlala, S. (2001). 'Virginity Testing: Managing Sexuality in a Maturing HIV/AIDS Epidemic'. *Medical Anthropology Quarterly New Series, Special Issue: The Contributions of Medical Anthropology to Anthropology and Beyond*.15(4): 533-552

- Levi-Strauss, C. (1979). *The way of the masks*. Seattle: University of Washington Press.
- Lim E.C.H., Seet R.C.S., Lee, K.H., Wilder-Smith, E.P.V., Chuah, B.Y.S., Ong B.K.C. (2006). 'Headaches and the N95 face-mask amongst healthcare providers'. *Acta Neurologica Scandinavica*. 113:199–202.
- Link, B. G., & Phelan, J. C. (2001). 'Conceptualizing stigma'. *Annual Review of Sociology*, 27, 363–385.
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). 'Measuring mental illness stigma'. *Schizophrenia Bulletin*, 30(3), 511–541.
- London, L. (2009). 'Confinement for extensively drug-resistant tuberculosis: balancing protection of health systems, individual rights and the public's health'. *International Journal of Tuberculosis and Lung Disease*. 13(10):1200–1209.
- Loudon, J. (1961). 'Kinship and crisis in south Wales'. *British Journal of Sociology*. 12(3): 33-50.
- Mac, J., Solis, A., Martinez, G., & Dujardin, B. (2006) 'An exploration of the social stigma in five "municipios" of Nicaragua to reflect on local interventions'. *Health Policy*. 74 : 205 – 217.
- Macdonald, H. M. (2004). 'Resolution and Rupture: The Paradox of Violence in Witch Accusations in Chhattisgarh, India'. Unpublished Ph.D dissertation. School of Oriental and African Studies, University of London.
- MacDonald, M.E., Rigillo, N. and Brassard, P. (2010). 'Urban Aboriginal Understandings and Experiences of Tuberculosis in Montreal, Quebec, Canada'. *Qualitative Health Research*, 20(4): 506–523.
- MacIntyre, C.R., Simon Cauchemez, Dominic E. Dwyer, Holly Seale, Pamela Cheung, Gary Browne, Michael Fasher, James Wood, Zhanhai Gao, Robert Booy, and Neil Ferguson (2009). 'Face Mask Use and Control of Respiratory Virus Transmission in Households' *Emerging Infectious Diseases*. 15(2): 233-242.
- Macintyre, S., Ellaway, A., Hiscock, R. and others. (2003). 'What features of the home and the area might help to explain observed relationships between housing tenure and health? Evidence from the west of Scotland'. *Health & Place*. 9(3):207-218.
- MacPherson, D.W. and Brian D. Gushulak, William B. Baine, Shukal Bala, Paul O.Gubbins, Paul Holtom, & Marisel Segarra-Newnham (2009). 'Population Mobility, Globalization, and Antimicrobial Drug Resistance'. *Emerging Infectious Diseases*. 15(11): 1727-1732.

- Mahendra, V. S., L. Gilborn, B. George, L. Samson, R. Mudoi, S. Jadav, I. Gupta, S. Bharat, & C. Daly. (2006). 'Reducing AIDS-related stigma and discrimination in Indian hospitals'. *Horizons Final Report*. New Delhi.: Population Council.
- Malkki, L (2007). 'Tradition and Improvisation in Ethnographic Research', in Cerwonka and Malkki (eds), *Improvising Theory: Process and Temporality in Ethnographic Fieldwork*. Chicago: University of Chicago Press. Pp. 162-187.
- Mak, W.S., Phoenix K.H. Mo, Rebecca Y.M. Cheung, Jean Woo, Fanny M. Cheung, & Dominic Lee (2006). 'Comparative stigma of HIV/AIDS, SARS, and Tuberculosis in Hong Kong', *Social Science & Medicine* 63 : 1912–1922.
- Mawadza, A. (2005). 'Metaphor, Stigma and HIV/AIDS Discourse in Zimbabwe.' Unpublished article.
- Merleau-Ponty, M.(2007). "From Phenomenology of Perception" in Lock, Margaret and Farquhar, Judith (eds.), *Beyond the Body Proper: Reading the anthropology of material life*, Duke University Press: London
- Mengoni, I. (1996). 'Conceptions of Tuberculosis and Therapeutic Choices in Highland Chiapas, Mexico'. *Medical Anthropology Quarterly*. 10(3):38 1-401.
- Munch Z.; Van Lill S. W. P.; Booysen C. N.; Zietsman H. L.; Enarson D. A.; Beyers N. (2003). 'Tuberculosis transmission patterns in a high-incidence area: a spatial analysis.' *The International Journal of Tuberculosis and Lung Disease* 7(3): 271-277.
- Murdock, G. P. (1980). *Theories of Illness*. Pittsburgh: University of Pittsburgh Press.
- Newman, D. & Passi, A. (1998). 'Fences and neighbours in the postmodern world: boundary narratives in political geography'. *Progress in Human Geography*. 22: 186-207
- Oelefse, C. and Dodson, B. (1997). "Community, Place and Transformation: A Perceptual Analysis of Residents' Responses to an Informal Settlements in Hout Bay, South Africa" in *Geoforum*. Vol. 28. (1) pp. 91-101.
- Ogden, J. and Nyblade, L (2005). *Common at Its Core: HIV-related Stigma Across Contexts*. International Center for Research on Women (ICRW).
- Ohnuki-Tierney, E. (1984). *Illness and Culture in Contemporary Japan*. Cambridge: Cambridge University Press.
- Ojha, A. B. (1973). 'Rumour Research: An Overview'. *Journal of the Indian Academy of Applied Psychology*. 10: 56–64.
- Padayatchi N., & Friedland, G. (2007). 'Managing multiple and extensively drug-resistant tuberculosis and HIV' . *Expert Opinion Pharmacother*. 8(8):1035-1037.

- Paine, R. (1967). 'What is gossip about? An alternative hypothesis'. *Man* (N.S.) 2, 278-85.
- Parker, P., & Aggleton, P. (2003). 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action'. *Social Science & Medicine*. 57: 13–24.
- Perdue, W.C., Stone, L.A. & Gostin, L.O. (2003). 'The Built Environment and Its Relationship to the Public's Health: The Legal Framework' paper submitted for American Public Health Association.
- Petersen, A. (2009). 'An Exploratory Study on the Occurrence of Pulmonary Tuberculosis among residents of formal and informal dwellings: A case study of households in Uitsig, Cape Town'. Unpublished Honours thesis. University of Cape Town E.G.S. department.
- Pocock, D. (1973) *Mind, Body and Wealth. A Study of Belief and Practice in an Indian Village*. Basil Blackwell: Oxford.
- Pollock, D. (1995). 'Masks and the Semiotics of Identity'. *The Journal of the Royal Anthropological Institute*. 1(3): 581-597
- Price, V., & Hsu, M. (1992). 'Public opinion about AIDS policies: The role of misinformation and attitudes about homosexuals'. *Public Opinion Quarterly*, 56:29–52
- Riley R, Mills C, & Nyka W (1959). 'Aerial dissemination of pulmonary tuberculosis—a two-year study of contagion in a tuberculosis ward'. *American Journal of Hygiene* 70:185–96.
- Riley L, Ko, A. Unger, A. & Mitermayer R. (2007). 'Slum health: Diseases of neglected populations'. *BMC International Health and Human Rights*. 7(2): 1-6
- Rogerson, C.M. (1999) 'Local economic development and urban poverty alleviation: the experience of post-apartheid South Africa'. *Habitat International*. 23(4):511-534
- Ross, F.
- (2005). 'Model Communities and Respectable Residents? Home and Housing in a Low-Income Residential Estate in the Western Cape, South Africa'. *Journal of Southern African Studies*. 31(3): 631-648
- (2010). *Raw Life, New Hope: Decency, Housing and Everyday Life in a Post Apartheid Community*. Juta Press: Cape Town.
- Salo, E. (2003). 'Negotiating gender and personhood in the new South Africa: Adolescent women and gangsters in Manenberg township on the Cape Flats' in *European Journal of Cultural Studies*. 6(3):345-365.
- Samuelson, H. (2004). 'Illness Transmission and Proximity: Local Theories of Causation among the Bissa in Burkina Faso'. *Medical Anthropology*. 23:89–112

- Scambler G. (2004). 'Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions'. *Social Theory & Health*. 2:29–46.
- Scambler G. (2006). 'Sociology, social structure and health-related stigma'. *Psychology, Health and Medicine*. 11: 288–295.
- Scambler, G. & Paoli, F. (2008). 'Health work, female sex workers and HIV/AIDS: global and local dimensions of stigma and deviance as barriers to effective interventions'. *Social Science and Medicine*. 66: 1848–1862.
- Scheper-Hughes, N. (2003). 'Keeping an eye on the global traffic in human organs'. *Lancet*. 361(9369): 1645-8.
- Sclar ED, Garau P, Carolini, G. (2005). 'The 21st century health challenge of slums and cities'. *Lancet*. 365(9462):901-903.
- Scorgie, F. (2002). 'Virginity Testing and the Politics of Sexual Responsibility: Implications for AIDS Intervention'. *African Studies*, 61(1): 55-75
- Sheuya, S., Howden-Chapman, P. & Patel, S. (2007). 'The Design of Housing and Shelter Programs: The Social and Environmental Determinants of Inequalities'. *Journal of Urban Health*. 84:108.
- Sibley (1995). *Geographies of exclusion: society and difference in the west*. London: Routledge.
- Singh J. A., Upshur, R, Padayatchi N. (2007). 'XDR-TB in South Africa: no time for denial or complacency'. *PLoS Med* . 4(50).
- Snodgrass, K. (2010). 'Water-bodies and Anti-bodies: Perceptions of Water among Children in Mandela Park', Unpublished Honours Thesis. Department of Social Anthropology. University of Cape Town, South Africa.
- Sontag S. (1978). *Illness as Metaphor*. New York: Farrar, Strauss and Giroux.
- Spiegel, A. (1994). 'Struggling with tradition in South Africa: the multivocality of the past' in Bond, G.C. and Gilliam, A. (eds) *Social Construction of the Past, Representation as Power* pp. 185-199.
- Stein L. (1950). 'A study of respiratory tuberculosis in relation to housing conditions in Edinburgh; the pre-war period'. *Br J Soc Med*. 4:143–169.
- Steinberg, J. (2008). *Three Letter Plague*. South Africa: Jonathan Ball Publishers
- Stipp, H., & Kerr, D. (1989). 'Determinants of public opinion about AIDS'. *Public Opinion Quarterly*. 53: 98–10

- Strong, K., Mathers, C., Leeder, S., Beaglehole, R. (2005). 'Preventing chronic diseases: how many lives can we save?' *Lancet*, 366(9496):1578-1582.
- Syed, Q., Sop, W., Regan, M., & Bellis, M.A. (2003). 'Behind the mask. Journey through an epidemic: some observations of contrasting public health responses to SARS'. *Epidemiological Community Health*. 57:855–856.
- Thomas, W. (2009). 'Corporate Engagement to accelerate local Business Development in Khayelitsha (Cape Town) University of Stellenbosch Business School, Paper to be presented at the International "Base of the Pyramid" Conference, Gordon Institute of Business Science, Johannesburg
- Tomosada, K. (1976). 'A phenomenological approach to childrearing', In *Cultural Interpretations of Childrearing*, Kazuko Honda and Shin Tsumori, eds. Tokyo: Koseikan. pp. 94-126
- Tonkin, E. (1979). 'Masks and powers'. *Man* (N.S.) 14: 237-48.
- Tshitereke, C. (2009). 'There shall be Houses, Security and Comfort' ISS Paper 196, August
- Veillers, L. (1911). 'Housing and Health', *Annals of the American Academy of Political and Social Science*, 37(2) special edition: *The Public Health Movement* pp. 13-25
- Waisbord, S. (2007). 'Beyond the medical-informational model: Recasting the role of communication in tuberculosis control', *Social Science & Medicine* 65: 2130–2134.
- Weiss, M. (1997). 'Signifying the Pandemics: Metaphors of AIDS, Cancer and Heart Disease', *Medical Anthropology Quarterly* 11(4): 456-476.
- Weiss, M.G., Ramakrishna, J., Somma D. (2006). 'Health-related stigma: Rethinking concepts and interventions', *Psychology, Health & Medicine*, 11(3): 277 – 287.
- Werner, D. (1993). *Where There Is No Doctor: A Village Health Care Handbook for Africa*. London: MacMillan
- Western, J (1997). *Outcast Cape Town*. Berkley: University of California Press.
- Winterton, L. (2010). 'Finding Meaning Behind Noise: The Soundscapes of Response-Ability'. Unpublished Honours Thesis. Department of Social Anthropology. University of Cape Town, South Africa
- Wu, J. and Fujie Xu, Weigong Zhou, Daniel R. Feikin, Chang-Ying Lin, Xiong He, Zonghan Zhu, Wannian Liang, Daniel P. Chin, and Anne Schuchat (2004). 'Risk Factors for

SARS among Persons without Known Contact with SARS Patients, Beijing, China' *Emerging Infectious Diseases* 10(2): 210-216.

Yamada, S. MD, MPH, Caballero, J. MPH; Matsunaga, D.S. MPH; Agustin, G. RN; and Magana, M. PsyD (1999). 'Attitudes Regarding Tuberculosis in Immigrants From the Philippines to the United States', *Clinical Research and Methods*. 31(7):477-481.

Yang, L.H., Kleinman, A., Link, B., Phelan, J. Leed, S., and Goode, B. (2007). 'Culture and stigma: Adding moral experience to stigma theory' in *Social Science & Medicine* 64 (2007) 1524-1535.

Zimmerman, D.H and Wieder, D.L. (1977). 'The diary: Diary-Interview Method', *Journal of Contemporary Ethnography*, 5(4):479-498.

### **Electronic resources:**

MSF Khayelitsha Report 2008-2009 'Providing HIV/TB Care At The Primary Health Care Level' accessed online 8.3.2010 at : <http://www.msf.org/msf/tags/en/reports.cfm>

WHO 'Multidrug and extensively drug-resistant TB (M/XDR-TB) 2010 Global Report on Surveillance and Response' accessed online 22.3.2010. WHO/HTM/TB/2010.3

Fact sheet number 104 November 2010, accessed online at:  
<http://www.who.int/mediacentre/factsheets/fs104/en/>

'2009 Stop TB update' accessed online 27.6.2010 at:  
[www.who.int/tb/.../2009/tbfactsheet\\_2009update\\_one\\_page.pdf](http://www.who.int/tb/.../2009/tbfactsheet_2009update_one_page.pdf)

'2010 TB update' accessed online 28.7.2010 at:  
[www.who.int/tb/.../2010/tbfactsheet\\_2010update\\_one\\_page.pdf](http://www.who.int/tb/.../2010/tbfactsheet_2010update_one_page.pdf)