Chapter One: On the Inside, Looking Out

Through the Gates

Mena¹ and I sat on the front stoep² sharing an apple. Sunlight streamed through the windows of the glass enclosed porch to Ward 3. We exchanged few words; Mena was too tired to go back to school. Suddenly, Gift³ burst through the doors without warning. Normally the buzzer would ring in the office, activated by a visitor outside the ward trying to enter. I hadn’t heard the buzzer ring, and yet, here stood Gift. He ran past us and into the main sleeping area for the older children. He fumbled around under the white steel bed frame and produced a pre-packed bag. Mena looked up at me and said, ‘He’s gonna go Kate’.

‘G, where are you going?’ There was no reply. ‘G? Nurse Jones? Gift is here.’ The older nurse walked onto the stoep from the office and asked, ‘Gift, please talk to me. What’s happening? Why are you crying?’

Gift refused to speak. My phone rang. It was my supervisor. ‘Hi, I can’t talk.’ Gift tried to push past me. ‘G, where are you going? Ok, I’ll call you later. Sorry, we have a bit of a situation here. One of my kids is trying to run away.’ I ended the call. ‘Gift? Boeti⁴, come here, let’s talk.’

What was the best course of action to take? Gift, at fourteen years old, was determined to leave. But where was he going to go? I had heard many accounts of runaway patients, but I had never witnessed it first-hand. Gift continued to fight against Nurse Jones, Mimi the cleaner and me as we tried to make sense of the situation. He would not speak, he just cried.

Nurse Jones persuaded me, ‘Let him go Kate, it’s better. The guards will get him. We’ll call them now.’ ‘Nurse, are you sure?’ ‘Yes, just let him be. They’ll speak to him. It will be good for him to speak to those men. You know mos⁵; he may need that right now.’

We stared out the windows of the enclosed stoep, through the chain link gate, and watched as the little boy hurried across the grassy, sandy expanse separating Ward 3 from the parking lot. He carried his bag and stumbled a bit on the mole holes that pocked the gritty terrain. Within less than a minute, the electric exit partition closed and security men clad in maroon and black

¹ A pseudonym  
² porch  
³ A pseudonym  
⁴ Vernacular isiXhosa or Afrikaans for ‘brother’.  
⁵ Afrikaans vernacular of ‘you know’.  

filtered out of the front gate kiosk. An older guard approached Gift just before he arrived at the entrance and brought him into a one-armed embrace. They spoke and the guard consoled him. They disappeared into the gate house. Mimi reflected, ‘He’s just a boy. What is he thinking? And to go where? What will happen to him in that big world out there? He has a mother and father, nuh? And then?’

Nurse Jones shook her head and replied flatly, ‘No, he can’t just run away. No one can.’

Mena finished her apple and I removed her back brace. When she was admitted, her TB meningitis (TB-M) was so severe doctors feared she was going to be paralysed. I tucked her in to bed and left Ward 3. As I looked back at the security kiosk, a wave of déjà vu washed over me. I remembered an initial trip to the hospital for my PhD research. As I left that afternoon, a female patient approached my car and implored me to ‘take her away’. When I asked where she was going, she replied, ‘Anywhere’.

The school sat on the opposite side of the complex. The wind whipped through the maze of lemon cream, red-roofed buildings, kicking up wisps of sand. Through the palisade perimeter fencing I saw the other children and teachers assembled on the front porch of the school. I unlocked the front gate and let myself in. I explained to the headmistress, Theresa, what had transpired. She explained that Gift had asked to use the toilet. Theresa speculated that he took the front door key from her desktop and snuck out. After locking the metal gate, he probably flung the keys back through the door, onto the floor, where she had found them. He arrived minutes later at Ward 3 at the Brooklyn Chest Hospital (BCH), my PhD research site.

Gift’s attempted escape was not an uncommon occurrence; it represented an accumulation of frustration, confusion and desperation some patients experience while living within the facility. In order to fully contextualise the events leading up to his attempted flight from BCH, it is necessary to read Gift’s story accompanied by those of other paediatric patients during the time of my research from November 2011 to 2012.

This research conveys a year in the life of a present day Tuberculosis (TB) sanatorium from the perspectives of child patients, doctors, nurses, and volunteers living and working at BCH. Throughout the introduction, I introduce the different ways in which TB has been configured epidemiologically, pathologically, historically, and finally within the context of South Africa. An analysis of the construction of the figuration of the child runs parallel to this. Children are

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6 Meaning: ‘No?’
imagined in unique ways, both globally and locally. They are shaped into categories: as patients, dependents, recipients of care, as well victims of circumstances beyond their own control. The following hospital ethnography illustrates the different ways children, time, and TB have been shaped and re-shaped throughout the ages and in different disciplines.

![Figure 1: entrance to BCH and signage](image)

**At the Foot of Table Mountain**

My interest in working with paediatric TB patients stemmed from my MA at the University of Cape Town in 2010. I worked with adults who were being treated for Multiple Drug Resistant-TB (MDR-TB) and Extensive Drug Resistant-TB (XDR-TB) in a decentralised ‘patient-centred’ treatment programme. During that time, I heard accounts of BCH or ‘Brooklyn’ as it was frequently referred to by patients both past and present. BCH was described as a ‘prison’ and others alluded to it as a place where one ‘goes to die’. It seemed to me, at the time, that the institution was shrouded in negative connotations. BCH’s reputation seemed to be built upon a robust collection of horror stories, urban myth and recycled facts, which may have mutated and twisted over time. Yet, amidst overtly negative accounts, there were stories lauding the knowledge gained through the experience of living in BCH. This alternative telling aligned experience with a necessary isolation from society. Isolation provided a lens with which to better understand treatment and the responsibilities beyond a prolonged (and sometimes repeat) stay at BCH. Some adult patients argued that an individual emerged equipped with skills ‘to cope’. I was intrigued with how patient experiences of Brooklyn lent themselves to increased drug adherence, stigma, perseverance, and other times despair and eventual re-admittance. In that body of research, my research experience with children was limited, but the interest was piqued nonetheless.
I had many unanswered questions. How would children formulate models of disease transmission and notions of trust, medicine taking and diet, and ultimately, responsibility to themselves as well as others? How did the understanding of a disease shift when one worked with children? This gradual line of questioning propelled my interest to work with paediatric patients living within a contemporary sanatorium. I wanted to understand the challenges they faced as minors, patients, children, and of school-going ages, isolated from everything that seemed ‘normal’. How would children’s understandings of their isolation experience differ from adult’s accounts? Who was responsible to ensure they received necessary treatment when they became ill? Who was deemed trustworthy and why? How do children make sense of circumstances which (in this case) were largely out of their control? How did children make a home in a foreign environment?

BCH is in a working class area in Cape Town called Brooklyn. In South Africa during Apartheid, populations were forcibly relocated to different geographic locations according to racial criteria. Brooklyn was an area reserved for impoverished or uneducated white populations. It was one of many ‘sandwich’ neighbourhoods on the periphery of Cape Town, in the Western Cape Province of South Africa. BCH sat on land which was originally a privately-owned farm. The farm eventually became a government run farm hospital which served white clientele only. Today, the facility accommodates the only specialised paediatric TB and DR-TB ward in the city of Cape Town and treats an entirely different demographic in comparison to its inception. While Brooklyn remains a working class area, there were more immigrants than previously. One nurse explained to me:

‘You know, back then it was poor whites. Now all the Nigerians is here, those people from outside, and Slamse. Even so, the drugs are worse. The tik Koppe. You can see the prossies on the corner. Maybe it’s changed, but not for the better. I certainly wouldn’t live here.’

Her observations spoke to the influx of immigrant populations, the increased availability of the drug tik and the sex workers who I saw daily as I drove to and from BCH. For her, Brooklyn, as a neighbourhood, was not ideal.

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7 White people
8 Vernacular for Muslims
9 A type of methamphetamine
10 Afrikaans for head- meaning ‘drug head’ or specifically, ‘tik head’
11 Sex workers
BCH housed 320 beds for TB inpatients, of which 60 were paediatric cases. The research involved over 50 children, all of whom were diagnosed with a severe form of TB, often complicated by a simultaneous diagnosis of HIV or other opportunistic infections. Most of the children admitted to the hospital came from troubled social backgrounds accompanied by impoverished circumstances, physical abuse, sexual abuse, drug addiction and alcoholism, to name a few. BCH housed two paediatric wards, Ward B and Ward 3. Ward B accommodated 40 beds for children under 5 years old and those classified as new arrivals or still infectious. Ward 3 housed older children, generally ranging from 5 to 15 years of age. Children 16 years of age and older lived within the exclusively male or female adult wards, which were classified along the severity and type of TB. The majority of the paediatric patients at BCH were admitted because guardians were not able to continue care for them, either through financial strain or inability. In addition to these factors, almost all of the children living there were extremely ill upon arrival. They required the extra care and support Brooklyn provided for all patients while they recuperated. BCH furnished patients with three meals daily, clothing, a bed, shelter and extremely expensive healthcare which would not otherwise be affordable or accessible. Most of my research time was spent with Ward 3 children. We did almost everything together: went to school, ate lunch or dinner, drank pills and played, a lot.

With infectious diseases like TB, statistics, WHO-generated data, historical texts, news casts and media coverage are readily accessible. The human experience of TB demonstrates the complexity and interconnectedness of many relationships, far beyond the ‘bug’ and its host. These relationships and links demonstrate the fractured social, historical, political and economic realities those in abject poverty experience in unequal proportions globally. Generally, adults occupied the centre of the TB discourse, to the extent that TB in children was a non-entity. Paediatric TB received little recognition from the WHO, much less the children who were living (and dying) from it in developing countries. The social experience of people who have TB is a vital starting point to locate significance and future implications within the lived experience of TB. Individual patient narratives in this sense offer a nuanced understanding of the challenges children in the developing world face daily; whether they are deemed ‘ill’ or ‘healthy’, by themselves or other qualifying bodies.

While there are anthropologists working in a variety of developing contexts addressing TB, this thesis focuses on the experiences of children hospitalised for TB in Cape Town, South Africa.

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12 A metaphor to describe the TB bacteria
Africa. There are different treatment paradigms and programs underway globally to address TB control. Erin Koch for example, (2011, 2013) examines Directly Observed Therapy-Short Course (DOTS) implementation in post-Soviet Georgia with attention to the way tuberculosis becomes a social disease. Ian Harper’s work in Nepal (2005, 2006) focuses on the experiences of patients, also within a DOTS program. These authors consider the social actors, transnational partnerships and powerful organizations that create standardised protocols which in turn are implemented for local TB patients. Their research sheds light on the regional specificity of TB, and what is at stake for patients. DOTS-focused research is central to an anthropology of TB, but is not the focus of this hospital-based ethnography. Inpatient treatment differs significantly from a DOTS approach, and the following thesis explains why that is, and what the implications are for child patients and their carers.

This research marks a departure from a DOTS-focused, or adult-centred inquiry through exploring the lives of children and those who work alongside them in a clinical environment. With my focus on the relationships between children, hospital staff, teachers and volunteers, a different area of inquiry is opened up. Additionally, a glimpse of the social realities children face outside of the institution are evidenced through their narratives here.

The analytical thread that runs through this thesis are the ‘figurations’\(^\text{13}\) of children and the figurations of Tuberculosis. The work of Annemarie Mol (2002) is essential in this regard, as it is the doing aspect that warrants merit and consideration. In her work with people suffering from atherosclerosis in a Dutch hospital, Mol (2002) addresses the ways in which a disease is acted upon, and conveys that this entity is different every time. She states: ‘…No object, no body, no disease is singular…’ (Mol 2002:6). Mol presents the plural nature, the multiplicity of atherosclerosis- as it may appear to a patient, how it may be treated by a doctor, how it may be translated in a diagnostic test, or a surgical intervention on an artery- all of these are different representations of the same medical condition. Although atherosclerosis is remarkably different from TB, Mol’s analysis is instructive. Following her lead, the sections below detail figurations of Tuberculosis; its pathology, its prevalence in children, the topography of TB, and lastly, the inequalities and urgency associated with curbing drug-resistant strains in South Africa.

\(^{13}\) Lending the term from Castaneda, ‘figurations’ (2002)
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).

TB is an ancient disease with known origins tracing back to 8000 B.C. (Reynolds 2010). As an airborne, highly contagious bacterium it is likely that more people have died from TB than any other infectious disease in history (Daniel 2006:1862). Although Robert Koch isolated the bacterium in 1882, it would only be some decades later that a first line cure, streptomycin, was developed. Despite this finding, TB has emerged with renewed vigour in recent years, once again establishing itself as the ‘grandfather’ of infectious diseases.

The prominence of TB in history is noteworthy. There is evidence of TB in the Biblical texts Leviticus and Deuteronomy (Daniel & Daniel 1999). The Greeks knew TB as ‘phthisis’, and it served as the basis for Hippocrates’ writings in *Book I, Of the Epidemics* (Daniel 2006:683). There has been abundant archaeological evidence of TB provided from mummy DNA and bone remains from the Americas, as well as Colombia, Peru and Egypt (Cave 1939). In India there is textual evidence of TB dating back to 3,300 years ago (Daniel 2006: ibid); in China literary references start around 2,300 A.D. (ibid). In northern Europe, TB was thought to be hereditary, whereas in the south, TB was considered infectious by its very nature (Daniel 2006:684).

**Pathology of TB: Figuration One**

To many, it is unimaginable that *mycobacterium tuberculosis* (the bacteria which causes TB infection) still exists in human populations. It is, for the most part, a bacterium which caused (and continues to cause) a forgotten disease. *Forgotten* because it has been treated successfully and on a large scale in the majority of the developed world. However, in the developing world, and in South Africa especially, TB is an extremely relevant, if not urgent, public health concern. South Africa has the second highest TB incident rate in the world, with the highest prevalence in urban and peri urban parts of the Western Cape Province (MSF 2008-2009, WHO 2010,

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14 Selgelid (2008:10)
National Strategic Plan to Stop TB 2012-2016). The co-existence of HIV and AIDS has contributed substantially to the continued presence of TB in Southern Africa. In South Africa specifically, 70% of those infected with TB are also co-infected with HIV (National Strategic Plan to Stop TB 2012-2016).

TB is airborne. One acquires the risk of infection through breathing. When aerolised particles of saliva containing *mycobacterium tuberculosis* are ingested, there is a risk for infection. These saliva particles are emitted and propelled into the air through sneezing, coughing, singing and even speaking (Wells 1955, Riley and O’Grady et al 1962, Schaaf and Zumla 2009). An airborne, primary infection is generally acquired via someone who has active pulmonary TB. If an acid-fast dye stain renders a sputum smear that is smear positive it means that the sample contains tubercle bacilli. Children generally develop TB differently; they develop primary progressive infections. This means that they may have been exposed to someone with active TB, but the infection may manifest within a year to two years of exposure. These cases are smear negative, meaning they have TB but are not considered a significant source of infection to others in their community. Adults are capable of providing sputum samples, i.e. coughing to emit a productive sample of sputum emanating from the lungs. Children are not always as able to perform this, making diagnosis tedious and often a very prolonged endeavour.

It is also important to note that TB, as an aerobic bacterium, is oxygen-loving. This is a fundamental reason why TB usually infects the lungs as the pulmonary cavity is an oxygen-rich environment. This type of infection is called pulmonary TB, but there are many types of TB. Extra thoracic TB refers to TB outside of the brachial and pulmonary areas. TB-Meningitis (TB-M) is a term used to denote TB infection in the meninges of the brain. TB can manifest and ‘activate’ almost anywhere in a human (or animal) body. Other types of infection include glandular TB, TB in the bones (most notably spinal TB) and abdominal TB amongst others. There are also drug-resistant strains previously mentioned: Multiple Drug-Resistant TB (MDR-TB) and Extensive Drug Resistant TB (XDR-TB). MDR-TB is defined as a resistance to first line TB drugs, while a resistance to second line TB drugs characterises XDR-TB. Often these two are grouped and called Drug Resistant TB (DR-TB). December 2011 evidenced the initial emergence of Totally Drug Resistant TB cases in Italy, Iran and India.15

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However, most people exposed to TB do not develop disease. One can assume that their bodies mount a sufficient immune response so that the proliferation of bacteria is limited. In most cases, this *partial* immune response will lead to a long-lasting partial immunity for the individual. Partial immunity means that further infection will *most likely* not occur, and that any latent bacilli from the initial infection will remain inactive (Smith and Moss 1994 ci Bloom 1994). An individual who is administered a Mantoux\(^{16}\) tuberculin skin test will react because their body still ‘contains’ latent TB bacilli (ibid). This is not to say that those who have had TB in the past will never become re-infected. Re-infection is often attributed to a suppressed or weakened immune system, one’s body is not strong enough to eradicate the bacterial infection. An important point to make here is that adults, whether they are infected through a primary infection, a re-infection or a reactivation, are smear positive in 50% of cases (Styblo 1984). It is these cases that are the main source of disease in the population, the community and the family unit (Shaw and Wynn-Williams 1954). It is therefore absolutely vital to identify those who unknowingly are potentially smear positive (infectious) because they will potentially infect others (Styblo 1984). The other aspect to consider is the availability and efficacy of treatment available. Before chemotherapy was introduced on a widespread scale, two different studies produced similar findings. In Britain (Springett 1971) and in India, the ‘Madras Study’ (National Tuberculosis Institute, 1974) found that 50% of sputum-positive patients ‘died within 5 years of diagnosis, 30% “self-cured”, and the remaining 20% remained alive’ (Smith and Moss 1994:51). TB infection and treatment can be complicated in adult patients, but TB in paediatric patients presents its own set of unique circumstances.

**Paediatric TB: Figuration 2**

‘Because of the difficulty of confirming the diagnosis, the global burden of childhood tuberculosis in the world is unclear.’ (Kabra et al 2004: 387)

Children do not transmit TB but are vulnerable to infection, meaning they contract the illness from adults (Kabra 2004, Schaaf et al 2003). Children are more susceptible to various strains of TB because they have weaker immune systems, lacking the antibodies adults possess due to

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\(^{16}\) Refers to the skin test developed by Frenchman Charles Mantoux in the 1930’s, where immunity to TB is tested through injecting tuberculin into the skin. Diameter is measured of raised skin area if a reaction occurs.
age and exposure to illness (Feja & Saiman 2005). In comparison to adults, TB symptoms manifest differently in children, and also shift depending on which type of TB they have. In adults, TB infection is generally characterised by night sweats, loss of appetite, weight loss, constant coughing and fevers. The symptoms in children may be less visible and are often overlooked. For example, constant vomiting and headaches are indicative that a child is experiencing the stomach flu; but they also indicate potential Meningal TB infection. TB-M, if gone undiagnosed and untreated, can result in spastic paralysis, neural damage, brain damage and reliance on a gastro feeding tube for the duration of one’s life. Missed opportunities, a less than vigilant health professional, or a complete non diagnosis often render tragic consequences for children and their families.

In addition, current paediatric research demonstrates that childhood TB is difficult to diagnose as there is no ‘gold standard’. Its global epidemiology has been poorly documented (Kabra 2004, Feja & Saiman 2005, Marais et al 2005, Marais & Pai 2007). Epidemiological statistics gloss over children’s presence in the TB epidemic; they are recognised minutely, however statistics largely render them a ‘forgotten’ category. These patterns remain, despite the continued call for more emphasis to be placed on children as patients, statistical and social markers and as a ‘vulnerable’ population. Walls and Shingadia remarked that, ‘...the rates of TB in children are unknown. This is an epidemic that, in most of the world, is spreading unnoticed’ (2004:13). In the Western Cape Province of South Africa, ‘children under 15 years of age form between 15% and 20% of this TB burden’ (Soeters et al 2005:602).

For every person who becomes infected with TB, there is a TB ‘contact’ who doctors, nurses or social workers attempt to identify. This is not possible in all cases, but rather is an ideal scenario. The majority of the paediatric patients at BCH contracted TB from adult care givers, extended family or parents who had ‘defaulted’ on their medication, thus infecting their own children. Some, but not all, were infected before their TB contact was diagnosed or treated. Childhood TB prevalence can therefore be considered a ‘barometer of TB control within a specific community’ because children generally show symptoms within a year of exposure (Feja & Saiman 2005, Marais et al 2005:1310). This means that a community’s health is evident in the health of its children; therefore, their treatment and those of their families is a high

17 Pers comm.
18 Term used in biomedicine describe cessation of treatment

**Topography of Disease: Figuration 3**

The complex layering and interaction of political systems, social bodies, historical precedence and individual movements enable the transmission of TB. South Africa exemplifies the interweaving of various historical processes which continue to this day via issues pertaining to housing, service delivery, transportation, education, labour unrest and inequities in health and health care services. The South African Apartheid government instituted a migrant labour system which effectively displaced millions, industrialised a nation, reaped benefit to the minority, and spawned multiple public health concerns; two of the most visible being the emergence of HIV and the persistence of Tuberculosis (Kark 1950, Packard 1989, Campbell and Williams 1997, Marks 2002). Tuberculosis incidence and prevalence persists within the mining industry, migrant worker, and prison populations within South Africa (Packard 1989).

In addition, TB burden is still borne by the poorest of society living in the direst circumstances, globally.

In 1950 Stein recognised a positive correlation between poor housing conditions and TB. 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). Habib et al (2008) associated household overcrowding and poorly built houses with an increased risk of TB infection. Although substantial evidence highlights the correlation between inadequate housing, race, migration and TB (Veillers 1911, Stein 1950, Krieger & Higgins 2002, Sclar Garau and Carolini 2005, Strong et al 2005, Riley et al 2007), overall living conditions in South African cities have not improved dramatically since 1994. Nationally, many South Africans live in what is commonly referred to as ‘informal housing’, ‘townships’ or ‘locations’. Houses are constructed of scrap materials: zinc metal sheeting, plastic, insulation, wood or metal scrap and plastic. Sanitation, basic service delivery and potable water are not universally accessible. Krieger and Higgins (2002) observed that healthy housing and better civic planning lead to healthier people. In many South African cities and especially in Cape Town, the architecture of Apartheid leaves its legacy in the health of its people. TB is a ‘postal code’ disease; those living in informal areas are disproportionately affected by where they live.
In 1949 Dr. Sidney Kark cautioned, ‘The first line of treatment must be to remedy the unhealthy social relationships which have emerged as the inevitable result of masses of men leaving their homes every year...’ (1949 ci Marks 2002:18). Unfortunately, the fundamental catalysts for TB transmission persist: overcrowding, poor nutrition, lack of education, poverty, migration and the daily struggle to survive (Farmer 1996, 1999, 2003). Simply stated, ‘Tuberculosis is a social disease with medical implications’ (Madalakas and Starke 2005:100). No other infectious disease has so thoroughly helped shape and been shaped by the contours of changing social, economic and political realities; TB is an old disease with contemporaneous implications.

**Inequality and Urgency: Figuration 4**

When DR-TB emerged in Tugela Ferry in the KwaZulu Natal Province of South Africa in 2006, 52 of the 53 patients reported died (Gandhi et al., 2006). Currently DR-TB affects populations in all regions worldwide (WHO 2013). TB is a disease of space; by way of airborne transmission it thrives in areas which are poorly ventilated, enclosed or overcrowded. Given the history of apartheid there exist huge social inequalities and class differences in South Africa. Social, economic, political and historical inequalities exacerbate adverse circumstances in health care accessibility (Farmer, 1996, 2005). South Africa has a highly politisised and publicised history of a co-existent HIV/AIDS epidemic. Many TB patients (although definitely not all) are also being treated for HIV. Patient non-adherence to TB drug regimens has also contributed to the spread of MDR-TB and XDR-TB. As Dye et al have noted, ‘Whatever the social, economic, and epidemiological context, TB control programmes rely on the health systems of which they are part’ (2010:861).

Central to the emergence of DR-TB, health officials started asking the question: how do we effectively ‘contain’ infected populations (Singh et al., 2007, London 2009, Harper 2010)? Ethical and human rights considerations are of paramount importance because involuntary patient isolation is an extremely contentious issue (Selgelid 2008, London 2009). Increased resistance to frontline TB drugs, inaccessible treatment options, migration, inadequate healthcare services, and patient ‘non adherence’ simultaneously spawned new forms of a

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curable disease, and generated multiple public health concerns, especially in urban areas\(^{20}\). Government facilities were also cited for a poor response to the TB situation in South Africa contributing to these issue through inappropriate drug regimens administered to patients and incompetent medical staff (Padayatchi & Friedland 2007, MacPherson et al 2009). The migration of many health care workers (HCWs) from public to private sectors exponentially increased the demand and strain placed on those who remain within the public health sector. HCWs within government clinics and hospitals are generally under resourced and underfunded; a case of infinite needs coinciding with limited supply (Bateman 2006, 2007). The larger discourse surrounding DR- TB did not seek to address the causes of drug resistance, but rather, containment and isolation of those infected in order to protect the larger population of civilians. Multi-dimensional ethical questions resulted, weighing the pros and cons of individual human rights versus the public good in South Africa.

The South African Department of Health (SA DoH) currently favours a centralised approach to DR-TB treatment through voluntary isolation of patients who both test positive for DR strains and who experience treatment complications. If an individual tests positive for ‘normal’ TB, medicines are administered via the World Health Organisation (WHO)-recommended Directly Observed Therapy-Short Course (DOTS). DOTS was first conceptualised in the 1980s by Dr. Karel Styblo and then formally implemented as a pragmatic intervention by the WHO in the 1990s. In this treatment control strategy, the patient visits the closest clinic to their residence and takes their medicine under the direct supervision of a health professional. Patients are guaranteed a standardised treatment regime overseen by a health care worker for a minimum of the first two months of treatment. In addition they receive a regular drug supply and their details are captured within a standardised system of recording and assessment. Many of the patients have migrated from rural areas in search of employment find themselves newly diagnosed with TB, patronising city clinic services within this treatment model.

BCH was different to the DOTS strategy in that it was a facility that housed in-patients within specific wards to (literally) ‘contain’ and cure the disease. All of the patients I worked with were in-patients, meaning they lived at BCH throughout the course of their treatment. They were allowed to go home every other weekend on two conditions. One: their home life had to

be assessed as ‘stable’ by the BCH social worker. Two: the child took their medicine without difficulty or complication. Child patients came from a variety of circumstances which in no way were homogenous. Generally, Brooklyn patients had extreme disease and came from troubled backgrounds. This manifested in various ways: previously defaulting on medication, abject poverty, were currently prisoners, lacked social support or could not provide for themselves. In-patients remained at the facility for the length of treatment duration$^{21}$. Treatment duration (and ultimately treatment success) hinged on numerous factors and varied on an individual basis. Again, fundamental to these challenges was the need to identify those who may have potentially infected others unknowingly, or through defaulting on treatment. It is estimated that an infectious TB carrier may potentially infect 10-15 people annually (Falzon & Aı¨t-Belghiti 2007:1266, MacPherson et al 2009, WHO 2011).

The following section looks at the language around the social diagnosis of Tuberculosis. The story of TB is one which provides a rare opportunity to see the ways a disease has shaped the contours of language and in turn been shaped by language; especially metaphor. The social landscape of TB romanticised a little understood disease and further sentimentalised those who suffered from it. As David Morens observed, it would seem that ‘...scientific knowledge of the disease seems to have displaced our interest in the patient’ (2002:1354). This is an apt point given that currently one third of the global population is currently infected with different forms of TB and new drug resistant strains emerge almost annually. With such miserable statistics, how can one qualify the lived experience of TB, much less the faces behind one of the greatest killers in history? In a bid to reclaim the human component of the TB epidemic over time, a valuable starting point is to examine the metaphors which saturated and gave life to TB ‘culture’.

Consumed by Metaphor: The Social Diagnosis of TB

Kearns described metaphor as ‘...the application of words or idea to something which it is imaginatively but not literally applicable...’ (1998:271). Metaphorical language originated from the human desire to give meaning to illness and the experience thereof. As different metaphors emerge, societal attitudes also shift accordingly. The understanding of TB has evolved from a point of epidemiological and biological investigation to incorporating

$^{21}$ Normal TB requires 6 months, MDR-TB requires a standardised treatment of 18 months, and XDR-TB 24 months—however this is not a strict guideline as other factors contribute to treatment adherence and success.
understandings of social stigma; however, the image of TB and TB sufferers has changed dramatically over time. Understandably, metaphors abound during circumstances of social, economic or political upheaval, and the continued presence of TB in human populations proved no different (Hanne 1996, Sontag 1978). Although metaphorical manifestations of TB often verge on the overly romanticised or poetic, Lakoff and Johnson (1980:5) noted that metaphor is pervasive in the everyday as a way of ‘...understanding and experiencing one kind of thing in terms of another’. In relation to TB, it is necessary to take inventory of these subtle nuances and their implications for those who are living with the disease.

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

Sontag’s observation demonstrates the deeply-seated poetic guise TB inherited through continued presence in human populations. Disease-related metaphors represented the prevailing values of different epochs. In the 19th century, TB was considered an all-consuming disease of passion and ‘inward burning’. A TB patient was deemed to possess more acute sensibilities: an enhanced emotional, creative and intellectual capacity. These qualities were also 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). Everyday descriptors became associated with those who had TB. Terms like ‘Lungers’, ‘consumptives’, ‘health seekers’ and ‘tuberculars’ represented this historical, categorical trend. The disease has often been described as ‘the white death’, ‘consumption’ and most recently, the ‘monster’ (Maxmen 2010). The employment of apocalyptic language continues to colour much of the TB social commentary since the co-prevalence and arrival of HIV (Upshur et al 2009). Again, language reflects prevailing social attitudes towards those who have TB, negatively shaping the disease and the afflicted patient.

Sontag was the most vocal critic of metaphors associated with illness, specifically cancer, TB and AIDS. She felt the person (patient) was stripped of their humanity and reduced to the disease (1978). Sontag argued against metaphor in her desire for illness to be ‘just an illness’, without negative associations attributed to the patient. In contrast, Susan DiGiacomo (1992) argued that metaphor is inevitable, and acts as a signifier which enables understanding. In response to Geertz’s observation of the limits of ethnographic empathy, she writes, ‘What we can legitimately claim to perceive is what others perceive with: the local categories and representations that constitute the common sense reality of everyday life’ (1992:111). In this
way, metaphors were an analytic tool to understand children’s perceptions at BCH. Disease will never be reducible to a cellular level because disease is a social, individual and collectivised process: one which continually challenges an engaged medical anthropology.

Although Sontag’s critique of disease-related metaphors was a salient project, it assumed a very specific patient group, and an even narrower definition of TB. Her evaluation was limited to the white TB patient of the Victorian era in Europe. In her understanding, TB was experienced on behalf of those white, city dwellers in western industrialised countries. She most certainly relied upon the literary imaginations of the time more than any ‘real world’ experiences. Her critique fell victim to the very metaphors she wished to dismantle; in this instance, fiction is stranger than reality. In addition, her desire for disease to be reducible to biomolecular and biological processes will forever remain unrealised because metaphors are significant nodes in understanding the disease and those who experience it first-hand. To eradicate metaphor is not only impossible, it forecloses on the human experience of suffering and ways that humans, whether patients or caretakers, make meaning from experience. In this way, metaphors that patients employ provide valuable insight into arduous, if not life-changing circumstances.

Yet, the malleability of language, disease and body(ies) vacillates with the time and place from which they originate. In the United States for example (1880s-1940s), TB became a political and geographic agenda; one steeped in surveillance of the individual body and isolation of infection (Reynolds 2010). Americans with TB-like symptoms were oftentimes considered demented (Grineski et al 2006:604). Others who may not have been infected were enveloped into the fold, as TB had achieved catch-all status to describe chronic weight loss and persistent cough (Ott 1996). A positive TB diagnosis resulted in very specific social costs and as a result patients experienced the costs of social stigma (Abney 2010). TB patients were forced into isolation from urban areas, living alone without even the companionship of a domestic pet (Grineski et al 2006:604). ‘TB was also added to a list of eugenic defects that could prohibit a couple from marrying. Similarly, married women with TB were told not to get pregnant’ (Ott, 1996 ci Grineski et al ibid). The focus now shifts to the history of TB in South Africa.

The History of TB in South Africa

There is a dearth of historical information about the emergence of TB in Southern Africa prior to the 20th century, and the accounts provided emanate from missionaries and travellers.
Reports of TB first appeared at the end of the eighteenth century, and were directly linked to contact with European colonists. The mining industry too played a pivotal role in the spread of TB (Packard 1989). South Africa as a ‘health resort’ mirrored the growing trend of the sanatoria movement in Europe. The dry, high altitude, warm ‘climate cure’ appealed to the many people who sought respite in the Cape. What emerged was a threefold contribution to the economy in the form of increased tubercular tourism, railroad development (fed by the mining companies) and a robust steamship trade to transport potential patients. As South Africa became more urbanised with the discovery of gold and diamonds, city centres were filled with an influx of migrant labour. In the 1920s, the influx of worker populations far exceeded available housing, and living conditions deteriorated. In 1924, a doctor by the name of Peter Allen made the link between high mortality rates caused by TB and poor living conditions (Coovadia and Benatar 1991:27).

Many of the sanatoria in South Africa were guest farms which benefitted from the wealth of their overseas visitors. These types of institutions were established in places such as Beaufort West, the Karoo Desert, and Bloemfontein.

**The Architecture of TB: The Sanatorium as Treatment Paradigm**

[Figure 2: Patients resting in BASF sanatorium for consumptives (1892) (Dannenfels, Germany) (Campbell 2005:483)]

The ‘spatialisation’ of TB through the construction of TB sanatoria illustrates the social, political, economic, and health concerns in specific times and places. For the greater part of the 18th and 19th centuries, TB was woven into the social fabric of much of Europe and the Americas. As Craddock (1999) maintains, the production of bodies, disease and place are
inseparable elements; sanatoria and preventoria exemplify these elements brilliantly. The sanatoria approach was (and is) not without controversy or critique (Harper 2005, 2010 London 2009). In the multiple mediations of the best and most appropriate treatment strategies available, scientific diets, warm places, the countryside, convalescence and sunshine factored high as depicted in Figure 2 above.

Sanatoria were first developed in Germany during the mid-19th century (Fairchild & Oppenheimer 1998). This model was based on isolation from the city and climate therapy. The original sanatoria reflect an ideology nuanced by the ‘natural’ and idyllic, as depicted in Figure 3 and Figure 4 on the following page. This ‘romanticised landscape’ (Cosgrove 2004) is one of remote, alpine bliss: replete with pine trees, crystal clear bodies of water and an abundant supply of fresh, crisp air. As early as 1898, physicians recognised South Africa’s climate as ideal for TB treatment (Hillier 1898, 1899). This system of isolation arguably contributed to the linguistic, social, political and economic figurations of TB and by default, the TB patient. The intake of fresh, country air, graduated labour, convalescence, exposure to sunshine, exercise regimes, and healthy diet were integral to recovery of tuberculars (ibid). In Britain, the sanatorium emerged in the late 19th century because previously physicians had championed the ‘open-air’ method over isolation (Bryder 1988). However, not all sanatoria fulfilled this naturalist vision. Describing the sanatoria at the turn of the 19th century in New York, Rothman argued, ‘institutions...were too prisonlike to be hospitals and too hospital-like to be prisons’ (1992:72). Rothman’s observations are substantiated by Foucault’s (1973) early writings detailing the dualistic nature of surveillance and reform inherent in medical facilities.

Figure 3: Haus Caselva (1905), formerly Villa Merula, Davos, Switzerland
Landscapes of Health and Hospital Ethnography

Mitch Rose suggests that [the landscape] ‘is sustained not through something inherent within it but through the everyday practices and activities that surround it’ (2002:456). The landscape here is one which comes to be and is made meaningful through the rhythms of those inhabiting it. Therapeutic landscapes have emerged within recent years as more than places of healing (Gesler 1992, 1998, 2004), but also places which promoted well-being and health (Williams 1998). According to Lakoff and Johnson (1980:29), the concept of a therapeutic landscape can be considered a ‘container metaphor’. Situated sites of healing imply boundedness and clearly delineated borders; that which is not ‘in’ is necessarily ‘out’. This presents a paradox in regard to BCH because not all healing can be considered to take place within an institution, denying the fluctuation of support from friends and relatives who may visit the individual patient.

Van der Geest and Finkler (2004) suggested that hospitals are often characterised as monolithic, biomedical entities which are globally uniform in structure and function (2004:1995). Alternatively, they propose that, ‘...biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view’ (2004:1996). This position mirrors that of other theorists (Lock & Schepher-Hughes, 1987, Feierman & Janzen 1992, Helman 2001). After the 18th century, hospitals evolved from welfare care centres for the poor, and became educational institutions (van der Geest and Finkler 2004:1997). As Foucault observed, hospitals became places of instruction and surveillance, whilst patients became the foci of observation (1973).
Living within a hospital is often equated to living in a world separate from reality ‘out there’. In a TB treatment facility, with its locked gates, security guards, buzzers, entrance and exit kiosks, one can feel very isolated from the routine of daily life. In contrast to this observation, hospital-based ethnographies shed light on how biomedicine is practised, but also how those who are the focus of healing feel about the procedures, tests, and routines they experience uniquely as patients. Schneider’s (2001) work in China shows that there are intricate continuities between life in the hospital and life outside of it. A variety of authors (Tanassi, Gibson, Zaman 2003 ci Schneider 2001) support the claim that life within a hospital is far from being divorced from ‘the real world’. Rather, hospital life is ‘shaped by everyday society’ (van der Geest and Finkler 2004:1998). Rosemary Blake’s work (2009) with paediatric cancer patients and their families also substantiates this point. Livingston’s (2012) work in an oncology ward in Botswana is an exemplary ethnographic gesture. She explained:

‘Ethnographers recognise that the hospital is an intensive space where critical moral, political, and social questions arise regularly and with great urgency, and where broader political, social and moral forces in society can be witnessed in a condensed fashion’. (Livingston 2012:25).

Her observations are also shared by a small corpus of hospital-based ethnographic work22, most notably Mulemi’s patient-centred research in a cancer ward in Kenya (2008).

‘Saving’ Children, Preventing TB

Figure 5: The Kellerberrin Preventorium (Grose 2011:98).

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22 See Lock (2001), Kaufman (2005), and Rouse (2009)
The concept of the *preventorium* emerged as an institution to protect vulnerable children in Australia (Connoly 2000, Grose 2011). The TB treatment became a biomedical mission encased by a larger social cause: to protect, and to rescue children from the ills of the city and society. The ‘natural’ landscape as ascribed and promoted by preventoria fit neatly with the ‘natural’ figuration of the child in 19th century discourse. The following quotes demonstrate some opinions of the time:

One physician noted, ‘Children do better than adults as they will submit to discipline, they are unconscious of their danger, and have no worry’ (1923:343 ci Connoly 2000).

The same physician also recommended the following measures for paediatric TB cases:

‘Again, change of air is most desirable. And in my opinion (given sanatoriums under equal supervision) a patient should hardly stay longer than six months at one sanatorium. If a dozen children's sanatoriums were established in different parts of England, and the children (that is, pulmonary cases) moved every three or six months, I believe that such changes of air would shorten the two years' cure by at least six months.’ (1923:343, ibid)

In 1931, childhood TB specialist Dixon observed the differences in paediatric TB and that of adults. He wrote, ‘It follows, therefore, that the family as a whole, and not the (child) patient alone, should be the unit for investigation and continued supervision’ (Dixon 1931:637).

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Figure 6: Postcards depicting preventoria as ‘healing landscapes’ situated in landscapes: beach, fields, mountains etc. Grose 2011:100).
The Right to Write: The Historiography of TB

There has been extensive literature published on TB, but the majority of this body of knowledge stems from the health sciences and those writing under the rubric of medical history. However, given the abundance of scientific historical accounts there remains a dearth of anthropological literature which focuses specifically on those most affected by the disease, especially in Africa, and South Africa. The following section details the international TB literature, which concentrates on the United States and Great Britain. These accounts are framed within a ‘science as authority’ hegemonic voice, championing expert knowledge over the narratives of TB patients themselves. The following work attempts to bridge these gaps, and contribute to anthropological investigations within clinical spaces and paediatric patient experiences.

Lyle Cummins was a leading expert in TB research in the mid twentieth century, and assisted in enhancing medical understanding of the disease. His work, *Tuberculosis in History: from the 17th Century to our own Times* (1949), focused on the medical practitioners who worked in the TB industry. He wrote for biomedical practitioners and noted the progress achieved, highlighting significant contributions made by various clinicians. His style suggested a linear progression towards the eventual conquer of TB in infected populations. In 1953, Dubos and Dubos released their study *The White Plague: Tuberculosis, Man and Society*. This was a meaningful work because it marked the departure from an essentialised, purely biomedical understanding of TB. Their work provided a comprehensive overview of the disease including the political, social and economic components embedded in the emergence of TB. They provided multiple perspectives on TB and those living (and dying) with it, in addition to the social construction of disease via lay populations in westernised contexts. Dubos and Dubos initiated the dissection of socially constructed disease metaphors relating to TB. They also analysed how metaphorical language shaped the understanding of illness and the perception of TB patients. This in part paved the way for Sontag’s influential work (1978) which I discuss in the following section. Dubos and Dubos’ analysis was far more nuanced than that of

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(a) Preventorium at Bugeaud, Algeria, [http://encyclopedie.afn.org/images/8/81/Bugeaud_preventorium.jpg](http://encyclopedie.afn.org/images/8/81/Bugeaud_preventorium.jpg)

(b) Preventorium dela Combe, Senones, Lorraine, France, Image is a postcard; date unknown.


(d) St. Edouard’s Sanatorium for sick children with TB (off centre left) in the village of Stoumont, Liege, Belgium, (Cole, 2000:350 cf Grose 2011:100)
Cummins’ work (1949), however, it still relied upon the experience of white populations within the west.

Another influential, if not controversial, work was McKeown’s *The Modern Rise of Population* (1979). Again, his focus was on Wales and Great Britain and the gradual decline of TB incidence from 1838 onwards experienced there. Like many of the previous works discussed, the public health interventions in use during the pre-chemotherapy era were the largest discussion point, as opposed to social interventions to improve standard of living and preventative approaches to TB infection. The sustained dichotomy between these schools of thought continue throughout other historical accounts of TB, and do not radically shift until the mid-1990s. This, despite much advocacy for preventative measures in the form of social and economic reform.

Linda Bryder’s work *Below the Magic Mountain* (1988) analysed the anti-TB campaign in Great Britain in the early 20th century. She, too, traced the pre-antibiotic era through political responses to TB leading up to the discovery of chemotherapy. Bryder also examined Britain’s attempts at curtailing the spread of TB infection via the sanatoria movement, surgical interventions and public health safety campaigns. She concluded that sanatoria and treatment regimens were not effective in curbing TB mortality and infection. Unlike many of the previous theorists mentioned, Bryder consistently featured patient narratives throughout her work and explained that, ‘…a history of tuberculosis is not complete without considering the experience of those who contracted the disease, including the impact of the anti-tuberculosis campaign in their lives’ (1988:3). Bryder, like the historians before her, failed to recognise the impact of TB outside industrialized nations.

In the 1990s and the first decade of the 21st century there was a renewed interest in TB. In 1993, Hardy published *The Epidemic Streets. Infectious Disease and the Rise of Preventative Medicine 1856-1900*. As the title implied, Hardy analysed the most prevalent infectious diseases of the time occurring in Britain, including TB, and compared the preventative public health campaigns attendant to each disease and its efficacy. Unlike the aforementioned theorists, Hardy focused on the sanitary approach to treatment and containment, thus suggesting that sanitary measures lent themselves to lowered TB mortality rates. Medical Anthropologists Marcia Inhorn and Peter Brown (1997) contributed to existing knowledge of infectious disease, and rightfully note that the emergence of AIDS and subsequent research endeavours have restored interest in TB. From the 1990s the historical literature starts to
highlight the relationship between HIV/AIDS, TB and the social landscape of health and disparity. Again, these ideas were nothing new; doctors and social activists observed as early as the mid 1850’s that TB was ‘a social disease with medical implications’. With the arrival of the 1990s and the increase in AIDS deaths, TB came ‘back onto the scene’. However it is pertinent to add, TB had never actually retreated in the first place.

In *Bargaining for Life* (1992), Barbara Bates recounted the history of TB in the Unites States during the pre-antibiotic era. The author focused on the relationships between medical health personnel, patients and care givers from 1876-1938. Similar to Bryder, the narratives provided originate in white middle class patients and their experiences with TB whilst living in different TB treatment facilities. She focused on the prominent TB physician of the era, Dr. Lawrence Flick, and his work with TB patients. Whereas Bates concluded that the sanatoria movement was largely insufficient and ineffective in meeting the demands of the TB epidemic, she recognised a few benefits that patients illustrated through their experiences. Patient narratives demonstrated that sanatorium living was accompanied by a sense of patient autonomy, relief from financial burdens and poor living environments, and nurturing relationships forged with medical personnel (1992:321).

In 1996, Katherine Ott published *Fevered Lives: Tuberculosis in American Culture since 1870*. Her work further strengthened the breadth of North American TB historiography. Ott provided an intersectional analysis of the social construction of illness, medicine, history and society. Ott’s work was significant because it was the first to draw upon both medical anthropology and literary history. *Fevered Lives* (1996) emphasised the long-standing interaction between human populations and TB through rhetoric employed to describe these relationships over time. *Fevered Lives* critiqued contemporary reports and stated that as opposed to speaking about how ‘Tuberculosis is back’, it would be far more appropriate to state ‘Tuberculosis is back in the news’ (Ott 1996:157). She also emphasised that the rhetoric used was based on archaic 19th century discourse: ‘medical authority conquers all disease’ mentality. Ott’s work documented a history of TB inclusive of attitudes and understandings, and how different understandings influenced ways of talking about TB. One such example is when Ott demonstrated how ‘phythisis’ became ‘consumption’, which eventually morphed into ‘tuberculosis’ (1996:1-2). This linguistic chronology charted the ways Americans signified the disease from 1870 onwards.
Ott’s work stands in contrast to the previous works mentioned because her analysis benefits the South African context. *Fevered Lives* (1996) illustrated the negative assumptions and values socially associated to TB sufferers in North America. Immigrant populations, ethnic groups, minorities and those from lower economic classes were negatively aligned with the disease, thus emphasising the socially constructed meanings people attributed to TB sufferers. As TB references changed, so did the social meanings attached to TB. A parallel can be drawn to the South African context where TB originated in white, European populations and eventually disseminated into impoverished populations, migrant labourers, and black South Africans.

Another work which contributed to the analysis of the South African context focused on the Firland sanatorium in Seattle during the pre-antibiotic, post-World War Two era. *Contagion and Confinement: Controlling Tuberculosis along Skid Road* (Lerner 1998) was a return to re-framing TB as a social disease. This work questioned the social and physical environment which impacted TB incidence and prevalence. Because Seattle, like Cape Town, had a high migrant labour population, the comparisons made are acute. Lerner critiqued the on-going debate between social and medical treatment efforts through his examination of coercive Skid Road facilities. Unlike the South African context, immigrants and transient workers were forcefully detained and isolated within these establishments until their schedule of medicine was complete. Again, the human rights discourse of individual rights versus the greater public good arose, yet in different contexts.

In *Tuberculosis the Greatest Story Never Told* (1992), Frank Ryan provided an overview of the leading medical practitioners, physicians and researchers who raced to ‘find a cure’ for TB. He included important dates in his detailed analysis of the mini epidemics which had ‘re-emerged’ in Paris, New York City and other ‘modern’ cities. Undoubtedly, his work was an important contribution to medical history, yet, it too evoked the traditional (medical historical) format based upon a hegemonic, westernised, biomedical focus. The doctors and physicians mentioned are all white, of European descent and almost exclusively male. Given that Cape Town is considered not only a ‘world class city’, but also a TB ‘hot spot’, it is strange that Africa or even South Africa were not considered within this analysis. Again, there is a tendency towards a ‘temporal hiccup’, framing TB as a disease which appears and disappears; a non-cognisance of the continued presence despite what Kilpatrick (2002) referred to as ‘public amnesia’.
Another assessment of TB with a specific demographic focus was Johnston’s *The Modern Epidemic: A History of Tuberculosis in Japan* (1995). The ‘public amnesia’ of the disease occurred after TB incidence dropped dramatically post-World War II. Johnston’s work detailed the decline of TB in Japan, but when it is applied to the South African context, there are astounding parallels in relationship to collective memory, and the ways people speak about disease. During Apartheid, the infected populace shifted from white Europeans to predominantly black South Africans. Given the infrastructure (and overt objectives) of Apartheid governance, the medical needs of miners were not a top priority. Many were repatriated to the homelands, and many white people ignored the presence of TB because it no longer affected them on a daily basis and it was not a part of their lives, thus aiding in this ‘public amnesia’ featured in Kilpatrick’s work (2002:24).

In *Consumed in the City: Observing Tuberculosis at Century’s End* (2002), Paul Draus provided a sophisticated exploration of TB in New York City during the late 1990s. Drawing upon his public health care experiences, the work successfully incorporated ethnographic perspective within public health. Draus depicted the social challenges related to TB through ethnography. Draus was a public health care worker and his participants come from impoverished backgrounds: immigrants, welfare recipients, alcoholics, drug users, sex workers, and single-parent households struggling to make ends meet. This work was a distant cry from lauding the accomplishments of white European male clinicians. Rather, Draus questioned the efficacy of treatment and the realities of living in inner city New York. Through a political economy lens, Draus illustrated that TB treatment success largely hinged on social issues often beyond the individual patient’s control. He concluded that it is impossible to treat TB without treating the social inequities and disparities which underlie the disease, a sentiment shared by humanitarian academics like Paul Farmer (1996, 2003). Unlike other works previously mentioned, there was a humanitarian thrust at the heart of Draus’ work, once again presenting TB as a timeless, cyclical, social disease. Draus also alluded to the postulate that perhaps there is little to celebrate even in light of new technology, drugs or diagnostics.

A more recent publication, *The Ailing City* (Armus 2011), drew on extensive sources - oral history, media, literature, statistical information, the arts and medical journals - to illustrate how TB became a national narrative in Buenos Aires, Argentina from 1870-1950. Armus’ intent was not to provide a comparative study, but rather to emphasise the similarities between other countries and major cities which experienced rapid industrialisation, economic change, labour and population influx, and TB. Unlike the aforementioned theorists, Armus dedicated a
chapter to the figure of the child. He analysed the assumption that children were predisposed to TB and the impact this supposition had on public health care programmes and preventative measures. Most significantly however, Armus’ writing highlighted that despite the roll out of new treatments, public health campaigns and new medical knowledge, the majority of those afflicted with TB were not able to access these measures, nor were the implemented programmes sufficient to cope with seemingly endless demand. Therefore, the history of TB in Buenos Aires is strikingly similar to that of Cape Town, and potentially other areas in the Global South. It was, and continues to be, a story which is timeless: the never-ending cycle of infinite need and demand for treatment, limited supply of appropriate health care services and social resources.

Lastly, Helen Bynum’s *Spitting Blood: The History of Tuberculosis* (2012), provides a sweeping and exhaustive historical account of TB and its relationship to humankind. Bynum traced its existence from ancient Greece into the contemporary moment. Bynum weaves together political and economic processes; industrialisation, world wars, urban poverty and public health campaigns in a bid to provide a comprehensive understanding of the emergence and re-emergence of TB. Her message is cautionary because TB remains an epidemic disease in many parts of the world, and one which is still being treated with drugs developed in the middle of the 20th century. Unlike other texts, Bynum acknowledges that as the ‘conquest of TB’ came to a prematurely triumphant end in the developed world, (thus slipping from public memory and public health campaigns), the incidence and burden of TB increased in other parts of the developing world. With the arrival of HIV/AIDS, the disease cycled back into public consciousness in places like New York City as an opportunistic infection. Her work is a call to activism, thus prioritising TB as an ever present infectious threat to human health globally.

**Writing from the Local**

Again, the ethnographic work from South Africa has been sparse, and is dominated by the confluence of primarily North American and British studies and historiographies. It is pertinent to note that medical anthropology has only briefly touched on some of the possibilities for TB as a stable area of inquiry in South Africa, and the literature available focuses heavily on the political economy of disease.24 Again, this thesis contributes to the experience of TB from the perspective of children and hospital staff in an inpatient treatment facility and seeks to expand

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24 See Marks and Rathbone (1982) for a good example.
the growing corpus of hospital ethnography amidst a social, economic and political landscape specific to South Africa.

Packard’s *White Plague, Black Labour* (1989) is rightly heralded as the most important contribution to the knowledge and history of TB in South Africa. An American writer, Packard focused on the migrant labour system, mining and miner’s health in the Gauteng Province. Whereas his approach was politically economy driven, what resulted was a thorough analysis which detailed South Africa’s TB epidemic and the unevenness of TB burden. Packard associated the perpetuation of TB in poverty-stricken populations with the intensity of industrialisation, however his study remained limited to the Johannesburg area and surrounds due to the mining focus. It is pertinent to note that as of yet, there has not been a work as influential in the context of Africa or South Africa in relation to Tuberculosis.

*A Century of Tuberculosis* (Coovadia & Benatar 1991) was a multi-author edited volume aimed at bringing together perspectives from different fields on the topic of TB. During the time of publication, South Africa was undergoing a radical change in government in a bid for a new democratic South Africa and Nelson Mandela had just been released from prison. The collected works included epidemiological information, historiography of TB, connections to migrant labour and incidence and discussions on different types of TB. The authors rightfully acknowledge that, ‘…the contours of health and disease have rarely been as profoundly shaped by social and political realities anywhere, as they have been in this country’ (ibid: i). Unfortunately the volume does not include any anthropological studies which would enrich the scope of their inquiry. Rather, the numerous TB case studies presented are sanitised through dependence on statistics and biomedical language. Without inclusion of individual narratives, there is no ‘face’ to the TB epidemic and history described.

Fiona Kilpatrick’s work (2002), although a historical thesis, focused on the Chapel Street Clinic in Cape Town. In this work, Kilpatrick discussed the history of the Cape Town City Council’s efforts to manage TB through the efforts of the Chapel Street Clinic. Thus, the localised context is set within an international historiography to provide a larger theoretical framework. Kilpatrick too relied upon the medical response to curbing the disease in Cape Town and the various public health initiatives of the period. Largely missing are the stories and histories of individual patients and their families. Although black South Africans were the most affected by TB during this time period, Kilpatrick focused on those from administrative and governmental positions during the Apartheid regime. It is no coincidence that the narrative is
dominated by those who benefitted the most from the political institution; thus history provided is also a by-product of white privilege.

*When Bodies Remember* (Fassin 2007) focused on the historical imprint on the political present in South Africa: lack of access to treatment, governmental and institutional denialism. Whereas Fassin, a medical anthropologist, concentrated primarily on HIV/AIDS and its effects through the narratives of patients and their families in South Africa, he provided some insight into the TB epidemic. The analysis of TB incidence in South Africa draws on Packard’s work (1989) and the social and political commodification of bodies; in this case migrant labour and the mining industry. As Packard asserted, at the beginning of the 20th century, the mining industry was deeply invested in trying to protect their labour pool from infection, because a decrease in available labour would adversely affect production. Varying hypotheses as to why TB was more rampant in black populations than white populations relied heavily on ‘cultural’ explanations which exoticized black Africans as being ‘natural’ or ‘closer to nature’ (Fassin 2007: 139). With the influx of black labourers into cities, they were unaccustomed to city life and the ‘proper’ way to live. Varying examples included wearing damp, or sweaty clothing which had not been dried sufficiently (ibid). This theory replaced others like the ‘virgin soil’ hypotheses which posited lack of immunity resulting in increased vulnerability to TB.

In the second decade another theory was put forward, one suggesting that susceptibility was inherited. Therefore exposure to tuberculosis was something that was contingent on natural selection and gradual exposure to the disease. This was a convenient enough (if not criminal) explanation for those in the mining administration, and allowed them to hire workers for months on end, only to send them home for ‘rest’ when they appeared infected. Fassin’s point was this: although the ‘native’ body was the primary object of concern, the health of Africans was not what was at stake. Medical screenings, slum clearance, and segregation were implemented in order to protect white populations. Environmental and social factors were replaced by ‘cultural’, racial, or biological explanations. Fassin accurately correlated the co-presence of AIDS as an epidemic in South Africa, but also explained the historical precedence of TB long before the arrival of AIDS. As it was in the past, so it continues to be here in South Africa. Recently, Minister of Health Dr. Aaron Motsaledi called upon the mining industry and prison system to provide more efficient case recognition and provision of medicines to those identified as tubercular. The strength of *When Bodies Remember* is not just its eloquence, but the power Fassin brought to the narratives of patients and their families as a cautionary reminder of the lessons history can teach.
Thus far I have established how TB and children have been figured in different ways, in different epochs. As society changed, conceptions and responses fluctuated accordingly. This work demonstrates the different figurations of children, TB and understandings of time within a hospital environment. I investigate these varying figurations: imperfect and episodic, not as permanent or fixed, but merely as flashes of interaction, agreement and contestation. These figurations build on the larger discourse presented in this introduction and will continue to figure into a broader engagement with TB, history and society.

**Thesis outlook**

The following chapter discusses the methodological limitations and ethical considerations throughout the fieldwork process. In contrast to the figuration of the child as an *ideal participant*, much of the research required a reconceptualization of the ethnographic tool kit. Most of my research participants wanted to participate on their own terms, and in their own way. ‘Traditional’ qualitative methods were not useful for these ‘non-participants’. One of the main arguments put forth in chapter 2 is that non-participation should not be viewed in a negative light. Often in child-centred literature which focuses on methods with child research participants, non-participants are edited out of the final research product. I also problematise the language which pervades most of child studies literature and reflect on the impact on methodologies used (or not) in the fieldwork process.

Chapters 3, 4 and 5 introduce the actors who helped animate one year in the life of a hospital. While child-focused, this thesis is not solely about working with children in a clinical environment. The relationships forged between teachers, nurses, doctors and overseas volunteers help to describe and give shape to various forms of care experienced by child patients. These relationships; between practitioner and patient, nurse and teacher, child and volunteer breathe life into Brooklyn as a thoroughly social, but also clinical space. Chapter 3 introduces the processes which indoctrinated children into the role of paediatric or child patient within the hospital. Doctors and nurses cyclically figured the paediatric patient with every new admission; however the homogenizing processes and tasks of biomedicine are not without exception, loopholes or flaws. Although myriad actors and processes are involved in figuring the child patient, thick bureaucracies, diverse care practices and uncertainty penetrated BCH. Nurses, doctors and children themselves grappled with the entanglements of sluggish bureaucracy, and rigid routine, thus lending to the social life of a hospital. Nonetheless, a specific, regimented ‘patient lifestyle’ is constructed with the understanding that patients must
conform, take their pills and abide by these powerful protocols and biomedical rituals. Visual ethnographic material produced by children is presented to help elucidate the ways children embodied life in Ward 3 and the space of Brooklyn Chest as patients.

Chapter 4 considers pedagogy at the fringe: the productive chaos of a school that is both (paradoxically) a school and not a school. Teachers explained the challenges of a hospital school that is not registered, yet simultaneously acts as a pivotal interface for the BCH teachers, their new students and the continuity of life ‘on the outside’ whilst being a patient at BCH. The hospital school, and the teachers employed there, acted as an anchor of support, care and encouragement. Attending school daily helped to provide stability and consistency for child patients, which was oftentimes lacking in their ‘home’ school. Children within the school were figured very differently because they fulfilled the additional role of student. Their personalities were disambiguated, their hopes, fears and personal circumstances were brought to the fore in a way different than within Ward 3.

In Chapter 5, the phenomena of service education tourism touches down at BCH. Overseas volunteers brought with them baggage which did not seem to fit within the confines of a suitcase: personal philosophies of paternalism packaged within good intentions, ‘white guilt’, and civilizing missions. Through interviews and conversations, I explored volunteer intentions through their work at BCH in addition to their motivations for working with ‘sick children’. Here, Brooklyn is simultaneously being created as a space for education and service, of care and tourism. Five volunteers reflected on their time spent at BCH and their imaginings of Africa, their figuration of the ‘vulnerable child’ and their pre conceptions and ideas of working with paediatric patients in a hospital environment. Although temporary fixtures in the hospital, volunteers and their interactions with children influenced patients’ views of foreign visitors and their intentions of working in Africa, thus contributing to a landscape of care in the hospital.

Chapter 6 discusses the malleability, significance and the detrimental effects of time in patient narratives and the use of time as a metaphor. These perspectives lend themselves to filling the gaps in the history and the re-telling of TB because time is crucial to the lived experience of illness. Time references were used by children and hospital staff, metaphorical associations helped convey multiple messages. Time became a way to speak to burden, anxiety, pain and ‘not-knowing’. Time, and the ways people speak to time, gently contest the stringency of biomedical temporality and Sontag’s (1978) desire for the understanding of disease to remain sanitised within a biomedical explanation. Disease cannot be stripped of its social
underpinnings, exoskeleton or substance. Diseases may manifest in a biological manner which is identifiable through various biotechnologies, but the entire experience of disease is thoroughly grounded in social processes, relationships and experience. At every level, those who treat tuberculosis, those affected by it and infected with it give meaning and dimension to the experience of living with the disease. Although treatment contexts and healing spaces may vary both locally and globally, it is the social experience imbricated with the biological manifestation of TB that create, question, and ultimately remake our understandings of this timeless infectious disease.