THE RESURGENCE OF TUBERCULOSIS IN SOUTH AFRICA: AN INVESTIGATION INTO SOCIO-ECONOMIC ASPECTS OF THE DISEASE IN A CONTEXT OF STRUCTURAL VIOLENCE IN GRAHAMSTOWN, EASTERN CAPE.

A thesis submitted in fulfilment of the
requirements for the degree of

MASTER OF ARTS
Of
RHODES UNIVERSITY
By
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December 2006

Abstract.

This thesis is an investigation into the socio-economic constraints that influence the decisions of tuberculosis sufferers in the health seeking process and therapeutic management of tuberculosis in Grahamstown, the Eastern Cape. It is shown that structural violence influences experiences and perceptions of tuberculosis at all levels.

Management of tuberculosis in the formal health sector is explored at local levels and related to national and global strategies of health care. The role of health workers, and particularly voluntary health workers, is explored and it is shown that they work within a context of growing burden of sickness and co-infections and a lack of government commitment to deal with increasing TB and HIV incidences.

Kleinman's notion of explanatory models is explored and it is evident that although knowledge of the aetiology of tuberculosis is well-known to patients and general members of the communities, they are nevertheless victims of increased stigmatisation and marginalisation as a result of illness.

The importance of social support in curing tuberculosis is explored using Janzen's concept of therapy managing groups. Social capital is a fundamental component in adhering to biomedical therapy, but is commonly weak among the structurally poor. The availability of temporary social grants for people living with TB influences health seeking behaviour. In a context of structural poverty the sick are faced with what Nattrass terms "perverse incentives", having to choose between the right to health and the right to social security, both guaranteed in the South African Constitution, for him/herself and dependants.

Although adherence to biomedical therapy is essential in curing tuberculosis, it is shown throughout this thesis that ignoring wider structural causes of disease limits the patient's ability to get well. The ethnography shows that the right to health is a social and economic right which is not the reality for most South Africans.

Acknowledgements.

To the people living with tuberculosis and health workers in Grahamstown – this research would not have been possible had it not been for your willingness to give of your time and to confide in me.

My deepest and most sincere thanks goes to my supervisor in the Department of Anthropology, Penny Bernard, her patience has been admirable and her insights and assistance invaluable. Thank you.

Throughout my MA, the support and encouragement from Professor Valerie Møller at the Institute of Social and Economic Research has been extensive and much appreciated. My studentship was supported by SANPAD (South Africa – Netherlands Research Programme on Alternatives in Development). I also received support from and cooperated with Jan Bernheim from Freije Universiteit, Brussels, Belgium. I am forever grateful to Professor Michael Whisson whose extensive knowledge of – everything – has assisted me throughout my studies.

To Leigh and Daygan – I will sit on the third step with a bottle of wine, nice cheese and a silver bracelet. Monique – I am proud to share a history with you. The baby/lady group – a network of strength throughout everything. Bryan – the wait was worth it.

To Mira – who in addition to at times being a helpful research assistant, has shown an impressive maturity and given me space to work, while at the same time reminded me of the important things in life – hot chocolate and Roald Dahl books in bed on Sunday mornings.

List of acronyms and abbreviations.

ACSA	Anamnestic Comparative Self Assessment
AIDS	Acquired immune deficiency syndrome
ANC	African National Congress
ARV	Anti retro-virals
CD4	Count of a specific type of white blood cells
CHW	Community Health Worker
CMA	Critical Medical Anthropology
DG	Disability Grant
DHS	District Health System
DOH	Department of Health
DOTS	Directly Observed Treatment – Short course
DST	Drug Sensitivity Test
EC	Eastern Cape
EM	Explanatory Model
GDP	Gross Domestic Product
GEAR	Growth, Employment and Redistribution Programme
GFATM	Global Fund to stop AIDS, tuberculosis and malaria
HIV	Human Immunodeficiency Virus
IMF	International Monetary Fund
LSA	Local Service Area
MDR TB	Multi Drug Resistant Tuberculosis
MEC	Member of Executive Council
MSF	Médecins Sans Frontiéres
NTP	National Tuberculosis Programme
PHC	Primary Health Care
RDP	Reconstruction and Development Programme
SANPAD	South Africa-Netherlands Research Programme on Alternatives in Development
SANTA	South African National Tuberculosis Association
SANTAEC	South African National Tuberculosis Association Eastern Cape

SPF	Small Project Foundation
TB	Tuberculosis
TMG	Therapy Managing Group
TRIMS	Trade-Related Investment Measures
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UIF	Unemployment Insurance Fund
UN	United Nations
UNAIDS	United Nations
UNICEF	United Nations
WB	World Bank
WHO	World Health Organisation
WTO	World Trade Organisation
XDR TB	Extreme drug resistant tuberculosis

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Chapter 1.

Introduction.

1.1 General aims of the study.

This study explores tuberculosis as a social disease in Grahamstown, a small city in the Eastern Cape, South Africa. Specifically, health seeking behaviour is investigated, particularly how it is shaped and constrained within the context of socio-economic conditions, social and therapeutic support and the broader effects of structural violence. The influence of therapy managing groups (including patient-provider relationships and social support), notions of stigma, as well as divergent explanatory models of illness in determining health seeking behaviour and adherence to treatment are considered. It is argued that tuberculosis and factors influencing health seeking behaviour must be considered in the context of the pervasive poverty and inequality in which it is found.

A note on the title: In South Africa tuberculosis is not a “resurgent” disease as such (see also Farmer, 1996). The infection rate has been high in South Africa since the disease was first knowingly imported into the country in the 1800s with British TB patients who were sent to South Africa to convalesce. However, I am using the term here not to argue that tuberculosis is reappearing in the country, but to show that both the prevalence and the context of the disease is changing due to a syndemic[1] of tuberculosis and HIV.

1.1.1 Notes on the general framework used.

The initial intention of this study was to focus on the experience of tuberculosis sufferers in Grahamstown through the application of the more “traditional” medical anthropological approach of ethnomedicine. I hoped to apply various models to health seeking behaviour, such as the explanatory models of illness approach adopted by Kleinman (1980), and the importance of therapy managing groups identified by Janzen (1978), but with a more critical and historical perspective in mind (Baer *et al.*, 1997; Singer, 1990). However, the enormous poverty related issues evident among the people studied were too great a factor to be treated as a confined topic in merely one chapter. It was a dominant theme that pervaded all the research findings. Thus, although an

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[1] The term is explained in chapter 2, section 2.12.

ethnomedical approach is adopted in this study, it is examined with a more critical and justice oriented perspective to make sense of the anthropological findings. It is argued that a too narrow focus on the experience of illness itself, and the causes and meanings attached to these illnesses, would obscure the fundamental social and political-economic realities and causes of suffering among people living with TB. Bearing this in mind, methods used are anthropological; individuals in communities are studied, and data is qualitative, however, the anthropological analysis is deeply influenced by Paul Farmer's application of the concept of structural violence (1999; 2004; 2005). The concepts and approaches mentioned above are explored in the next chapter.

The overall objective in using these approaches is that they will assist in understanding the reality in which the subjects of this study get sick, get well, or not, and live their lives. It is shown that people make strategic choices in terms of their illness and other responsibilities in life but that these choices are limited and constrained by structural relationships of power and access to this power, including economic benefits. Indeed, multileveled inequalities are a central theme in the ethnography presented. This is where anthropology can make a tremendous contribution to global efforts to combat social diseases such as TB. Hopefully this perspective will inform policy makers, epidemiologists and public health experts, who rely heavily on quick interventionist clinical fixes rather than acknowledging, or challenging, the broader structural inequalities that are the basis of the frightening exponential growth of tuberculosis. I am a firm believer in the responsibility of anthropology and anthropologists to challenge the systems of inequality that create marginalised and "voiceless" populations. Because people with tuberculosis act and react, indeed live their lives, in contexts of structural violence, it has become the single most important topic related to TB in this study and it is possibly the most dominant TB related topic which links the chapters in this thesis.

1.1.2 The link between HIV and TB.

> We can't fight AIDS unless we do much more to fight TB as well.
>
> Nelson Mandela, cited in WHO, 2005a: 2

Each year it is estimated that TB infects 8.7 million people and kills 2 million worldwide. It is a curable disease, yet it is a leading cause of death in sub-Saharan Africa. Of the approximately 25 million Africans now living with HIV, about 8 million of these are also infected by the TB bacillus. In the next two decades, the UN warns, a total of 35 million people could die of TB (Daily Dispatch, 2004: 7). These numbers are beyond imagination.

A low estimate of HIV prevalence among adults in South Africa in 2003 was 22% (WHO, 2005b). A study conducted in the rural district of Hlabisa in northern Kwa-Zulu Natal found that the TB incidence increased by 360% between 1991 and 1998. This coincided with the level of HIV infection which increased from 28% in 1993 to 65% in 1997 (Colvin *et al.*, 2003: S87).

It is emphasised that increased collaboration between HIV and TB programmes are needed at all levels (Maher *et al.*, 2005: 734). As will be shown later in this study, this is happening on the ground in Grahamstown, if not at system level yet. Issues of stigma related to this syndemic (Singer & Clair, 2003) will also be discussed.

The World Health Organisation confirms that TB programmes can be an important entry point for the administration of anti-retrovirals (ARVs), as through TB treatment a large number of HIV patients would already be in contact with the formal health system (WHO, 2005a: 5). Increased levels of co-infections also pose an increased risk of transmission of TB to the general community (Maher *et al.*, 2005: 734). With an estimated 8500 new people infected with HIV in Africa *every day* (Torrisi, 2005: 3), it is becoming increasingly important to increase efforts to combat TB and HIV jointly as a syndemic.

1.2 Tuberculosis in South Africa.

With the development of an effective cure for tuberculosis in the early 1950s, TB became a curable disease and eradication became a goal in international health discourse. However, throughout history it has been shown that improvements in socio-economic conditions have contributed more to the decline in TB prevalence in the industrialised countries in the last 100 years than have medical interventions (Grange, 1999: 13). As a result of a lack of a global commitment to improve socio-economic conditions, the developing countries are today carrying the burden of tuberculosis with 97% of TB cases and 98% of TB deaths in the world (Benatar, 2003: 227).

In 1993 the World Health Organisation (WHO) declared TB a global emergency and introduced DOTS (Directly Observed Therapy-Short course) to face this emergency. Although DOTS, which will be discussed to some detail in chapter 2 and 3, has improved the situation, there are certain fundamental shortcomings and TB was declared an emergency again in Africa in 2005. The reasons for this declaration are grave and many: There are 1500 TB deaths in Africa alone every day. In fact, in just 15 years, overall TB rates in Africa has doubled; tripled in areas with high HIV rates and quadrupled in countries worst affected by HIV and TB (WHO, 2005c: 127). South Africa belongs to the latter category.

Although tuberculosis has been common in South Africa since colonisation and early urbanisation, the notification rate has varied from around 50/100 000 in the 1920s before increasing to about 350/100 000 in 1965 followed by a decrease until 1988 when the notification rate was 172/100 000 (Strebel & Seager, 1991: 65). In 2004 the national incidence rate was an alarming 718/100 000[2] (WHO, 2006a: 119). The Eastern Cape has the second highest incidence rate in South Africa with over 674/100 000 (Health Systems Trust, 2002) in addition to the second lowest cure rate at 41% (Thom, 2006: 5).

1.2.1 History of tuberculosis in South Africa.

Structural violence has been at the very basis of the creation and maintenance of the state in South Africa. It still is. An anthropological analysis of any issue will be inadequate if this factor is not integrated into the analysis at all levels. The history of tuberculosis and its epidemiological profile in the country is an image of a history of structural violence based on racial discrimination, inequality, and labour exploitation associated with increased industrialisation (especially the migrant labour based mining industry) from the late 1800s onwards. Despite South Africa gaining democracy in 1994, the neo-liberal economic era and globalisation have led to the continuation of oppression and inequality,

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[2] WHO classifies incidence rates above 200/100 000 as a serious epidemic.

albeit in new forms. According to Farmer, “persistent social inequality is no doubt the primary reason that HIV has spread so rapidly in sub-Saharan Africa’s wealthiest nation” (2005: 45).

The mines have been the major contributing force to the spread of tuberculosis in the Southern African region. The moist, hot and poorly ventilated mine shafts and often cold outside temperatures combined with inadequate nutrition and overcrowding in the closed mining compounds are a perfect “breeding ground” for tuberculosis. Adding the system of migrant labour to the mix, the mine workers in turn spread tuberculosis to their regions and countries of origin. According to Packard, “the extent to which tuberculosis spread within any given rural area prior to World War 1 was directly proportional to the extent to which the area’s population had been involved in migrant labour and thus exposed to the risk of outside infection” (Packard, 1990: 100).

From the limited historical evidence available it can be seen that tuberculosis only occurred sporadically until populations settled in towns and cities, resulting in overcrowding and poor conditions of hygiene (Grange, 1999: 11). The emergence of tuberculosis among blacks in South Africa has been explained as a “virgin soil epidemic” where Africans were seen as vulnerable to the disease because they had no natural resistance to the bacilli. Randall Packard argues that there is evidence that TB may have existed in the region in pre-colonial times but it was contained due to good diets and limited stress factors. He also argues that this explanation does not take the conditions in the mines into account, nor can it explain why Africans who lived and ate well experienced the disease in similar patterns to the Europeans (1990: 30). Advocates of the “virgin soil epidemic” conveniently ignore structural causes.

Although TB infected individuals probably entered the Southern Cape from the time of the Dutch settlers in the 1600s, the first immigrant consumptives arrived in South Africa from England in the mid 1800s. From the 1870s it was thought that the dry Karoo climate was beneficial for the consumptives and TB afflicted immigrants soon came flooding to the Eastern Cape region to seek a cure at the various sanatoria that had sprung up to cater for their needs. Some of the poorer patients had to find employment and spread the disease to people working on farms and in small rural towns (Packard, 1990: 39-40).

Throughout the pre-apartheid period limited money was spent on health care for Africans and often “state intervention” was simply a form of enforced segregation so that diseases would not spread to the white population. Throughout the 1920s and ’30s TB control measures were based on a policy of exclusion (Packard, 1990: 194). This is linked to the wider national policy where the Native Urban Areas Act, for example, was introduced in 1923 together with other measures of influx control. In a report from the Tuberculosis Commission in Grahamstown in 1914 it was noted that: “There is no proper system of sanitation carried out in the locations” (cited in *ibid*., 1990: 55). Although insufficient sanitation does not lead to tuberculosis, it can result in diseases weakening the body and increasing the likelihood of TB infection turning into active disease. Poverty is rife in this environment, crime is often endemic and alcoholism rife, to mention a few factors that increase the risk of developing active tuberculosis. Theories that examine these connections are explored in the next chapter.

The situation deteriorated with the introduction of formal apartheid after 1948. One medical practitioner in the Transkei commented on “the never-ending stream of TB patients” (Jansen, 1973: 171). In the 1960s the housing situation for blacks grew worse and industry and people were moved to the overcrowded and poorly serviced “border regions” such as Mdantsane outside East London. The Group Areas Act meant that black people in the urban areas who were unable to work as a result of having tuberculosis, were forced to repatriate to “their” homeland areas, often far away from clinics providing tuberculosis treatment. The mining companies adopted a similar practice. In places where there were clinics, and Packard mentions Grahamstown as an example, the local authorities were not responsible for the cost of treatment (1990: 280 & 288). As a result, people discontinued their treatment and remained infectious. Thus, it can be seen that people’s failure to take their medicines properly was not from deviance as such, but, given the political-economic constraints in South Africa at the time, they were unable to continue. As will be shown throughout this study, this problem of non adherence is still very much a problem today.

1.2.2 Health care in South Africa prior to and during apartheid.

South Africa has a history of unequal access to health care and even before a formalised health care system was established, health care was segregated and inaccessible to some. The first hospital was built by the Dutch at the Cape in the 1600s and was only available to whites. In those early days the Cape was hit by a number of small pox epidemics which led to the first preventive measures to be taken in South Africa. Corpses were burnt, quarantine and notification were introduced and ships were examined at quay. Initially health care in the Cape colony was tied to the military, while missionary care, first practiced in Natal in the 1830s, was focused on the white population. The first civilian hospital was established in Somerset in what is now Mpumalanga Province in 1818. A hospital for "natives" was established in King William's Town in what is now the Eastern Cape nearly 40 years later (Gordon, 2001). The first black nurse was trained in 1908, 30 years after a nursing school for white women was established (Marks, 1994: 54; van Rensburg, 2004: 62). Thus, from the very beginning, access to health care in South Africa was based on a practice of racial exclusion embedded in the national political economy.

Between 1800 and 1900 there was an actual structuring and professionalisation of health care with the licensing of medical practitioners. However, there was no central control. This allowed for a number of epidemics to take their toll on the South African population. With the declaration of the South African Union in 1910 the practice of unequal access to health care became official policy and was legislated during apartheid and practised until the end of this era in 1994 (van Rensburg, 2004: 72).

During apartheid "health care was allocated not in terms of need, but in terms of access to power" (van Rensburg, 2004: 79). Health care was, and still is to a large extent, based on private health insurance for whites and state care for blacks. Health care and rights to health care were, and still are, divided along geographical and racial lines upholding and contributing to social and economic inequities. Inequalities in the provision of health care were accentuated with the establishment of the homeland policy in the 1950s. This led to overcrowding, unemployment and poverty in the homelands, leading to an increase in social ills. In 1975 the Transkei had a TB notification rate of 489/100 000 whereas the rate in South Africa as a whole was 256/100 000 (*ibid*.: 81 & 91-92). These problems were exacerbated by the disproportionately low state government funding afforded to homeland health care systems.

During apartheid the different homelands, regions and provinces were each responsible for health and health care of their inhabitants. High-tech curative care received the largest amount of funds and resources were allocated unequally depending on the racial profile of those afflicted. As a result, health care was divided racially and geographically, leading to great inequalities in access to health care. Although there were sporadic efforts to address these issues, it was never the aim of the apartheid government to rectify or change these inequities. Instead, privatisation of health care was given focus and health was seen as the responsibility of the individual (van Rensburg, 2004: 90-96).

With the introduction of the concept of Primary Health Care after the WHO conference in Alma Ata in 1978, health care was to be more accessible for all, but this was not the case in South Africa. Health was still seen as a privilege and not as a right. This thesis shows that in many ways there is still need for a rights focus on health care in South Africa even to this day.

1.2.3 The end of apartheid.

With the abolition of apartheid there was a fundamental change in state aims and interventions, and also in the terminology used, in terms of health care from the 1990s and particularly post 1994. This coincided with an increasing international awareness and drive towards promoting “Health for all” through the application of comprehensive Primary Health Care (first officially endorsed at the WHO Alma Ata conference in 1978). “Equity” became a major aim in a comprehensive health care system shifting from a curative to a preventive focus, with community participation as an important tool in achieving health for all. Whereas a curative focus takes the attention away from structural causes of disease, prevention and health promotion has the potential to deal with underlying structural causes such as poverty and inequality. However, this fundamental change in health care could only come with a change in society in general (van Rensburg, 2004: 99). Prior to 1994 this was not easily achievable. However, with the new democracy, it became the main priority.

The new democratically elected government created reforms in South Africa aiming at dramatically changing the health system. This was expressed both in health specific policy documents, as well as in the Bill of Rights in the new Constitution. A rights perspective on health, which also dealt with poverty related issues, was finally adopted in South Africa, in theory at least. This was reflected by the endorsement of the inclusive WHO definition of health which reads that “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”[3] Later this is discussed in relation to a rights perspective to health.

Post 1994, a district based Primary Health Care programme was introduced focusing on:

- an extended definition of health for all
- redressing the harmful effects of apartheid
- equal importance of all health care workers and emphasizing teamwork
- ensuring respect for human rights in health
- international norms, standards and ethics in the provision of health care
- community participation and empowerment in health care
- reduction in burden and risk affecting the health of all South Africans

(van Rensburg, 2004: 420)

The District Health System (DHS) was introduced as a vehicle for PHC delivery. It was also a means to address the previously racially based fragmented health care system. The two concepts, DHS and PHC, are closely linked. Municipalities within the districts were given more power in terms of responsibility for health services. This new decentralised system was seen as a way of overcoming the fragmentation of services which had been apparent during the apartheid era as well as encouraging a democratic delivery of health services based on need. In order to implement the inclusive definition of health used, intradepartmental collaboration is necessary. Local accountability, equity in the provision of and access to services were aimed at being reached through community involvement.

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[3] Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organisation, no. 2, p. 100) and entered into force on 7 April 1948. http://www.who.int/about/definition/en (accessed 05.06.06).

The state was seen as serving both as “provider and purchaser of health services” on the basis of equity, efficiency and assessment of local conditions” (*ibid*.: 134-5).

The core standards of the PHC package were spelled out in the 2001 document called “The primary health care package for South Africa - a set of norms and standards” (Department of Health, 2001). Here, standards of patient education, health care provider competence, intersectoral collaboration and community and home-based activities were spelled out. Additionally, specific norms and standards were stipulated for specific programmes and diseases, including tuberculosis (Department of Health, 2001). Ostensibly, a top down approach was abandoned and specific PHC programmes were introduced at District level. This focus on programmes has the potential to enhance interdepartmental collaboration and has the potential to incorporate wider issues of health care such as access to water and sanitation, education and social security. Disease then, in theory, is seen as both social and biological. On the other hand, the reality is that the division of programmes is based on biomedical ideas of separation of the mind and body, from the social and economic, where for example TB curative care and health promotion are allocated to different programmes with separate budgets and priorities. These two issues are closely linked, and still pose many challenges for effective implementation, so they must be dealt with together if sustainable outcomes are to be reached. Examples of these challenges are presented in the second chapter of this thesis.

The aim was that this comprehensive package should have been implemented at all PHC facilities by 2000. This proved to be overambitious, although in fact most Districts, if not facilities, could provide the comprehensive package by 2004 (van Rensburg, 2004: 431). The types of facilities providing these services are PHC clinics, including mobile and satellite clinics, community health centres (day hospitals), outpatient departments at hospitals and special PHC facilities focusing on particular issues such as maternal health, oral hygiene and school health services (*ibid*.: 432).

However, more than 10 years after the transformation of the health system was initiated, there are certain unresolved issues in the District-based PHC service. Many Districts, and certain individuals in Cacadu district express this clearly, have a lack of trust in the Province they fall under. In addition, it is not always clear which responsibilities fall under Province and District respectively. Province is not responsible for supplying health care directly to the people *per se*. Rather, in addition to making sure that national policy is implemented, their role is to manage, coordinate, guide and support the Districts (van Rensburg, 2004: 129). In many cases, the flow of funding is unregulated and uncertain, and services as well as staff are duplicated both at Provincial level and the level of the District (*ibid*.: 152). Legitimacy and authority at Provincial/District and municipal levels are often both confused and contested. In addition, organisational culture and behaviour have not always been transformed as successfully as many would have wished for (van Rensburg, 2004: 365). This bureaucratic and, at times, inefficient culture is examined in some detail in the second chapter.

Since 1994 equity in access to care has been a main governmental focus (*ibid*.: 422). More money is spent on health in South Africa than in most other middle income countries in the world. The problem is, however, that money is not spent equitably and efficiently across provinces (McIntyre & Doherty, in *ibid*.: 378). Although homelands do not exist anymore, their legacy still persists. The provinces which have incorporated areas previously belonging to homelands, such as the Eastern Cape, are still experiencing inequity in health care. In fact, a study which looked at a number of indicators such as quality of care, access to services, rural/urban disparities and race inequalities, concluded that the Eastern Cape is the most *in*equitable province in the country concerning health care (Ntuli *et al.*, 1999: 45, in *ibid*.: 437).

Much has been achieved in terms of health care in South Africa in the last 10 years. The most important achievement is the availability of free comprehensive health care for *all* South Africans. However, with the rapidly increasing burden of TB and HIV, challenges facing health care in South Africa are perhaps more imminent and urgent than ever before.

At the time of writing, the Eastern Cape Province has announced that it is intending to take over the responsibility of Primary Health Care delivery from Makana sub-district. It is not yet clear how or when this is going to happen. However, the Provincial Health Department is unfortunately not known for its efficiency, and it is feared that this will decrease efficiency, loyalty and accountability towards the local clinics. PHC is seen as being administered most successfully at local levels.

1.3 The setting.

The public health sector dealing with tuberculosis in Grahamstown was my main research ‘site’. A map (see appendix 4) is included and locations of the clinics and hospitals are highlighted. The map clearly shows that whereas private health care is good in Grahamstown West, under resourced government health care is providing the poor and overcrowded areas of Grahamstown East.

All the municipal clinics treat tuberculosis patients and people are required to go to the clinic nearest to their home to get treatment. This makes patient tracing easier for clinic staff, particularly the Community Health Workers who walk around in the community. The exception is Town Clinic, which is used mainly by people employed in town. As tuberculosis is a disease mainly affecting the poor and unemployed, the clinics in Grahamstown East have a significantly higher number of tuberculosis patients than Middle Terrace Clinic and specifically Town Clinic. Settlers Day Hospital does not have a lot of TB patients as they have other responsibilities such as mental and oral health.

Initially, I did not wish to focus the research on patients at the TB hospital, Temba, as they are very sick, and many died during the period of this fieldwork. However, it proved to be easier to meet patients at the TB hospital as they were in-patients and thus easier to arrange appointments with. For those who did make a recovery, by the time they were discharged, our relationship was strong enough for them to allow me to be taken to their homes and to meet their families. The members of staff were exclusively geared to nursing TB patients and thus could provide me with useful insight into their patients’ problems and needs.

1.3.1 Selection of informants.

Key informants were selected according to a variety of criteria and were classified into two main groups:

1) TB patients and their families.
2) Health workers and other formal health care givers.

Eight people with tuberculosis were selected from the eight municipal clinics in Grahamstown and from the local TB hospital. Initially I went with the District pharmacist, to whom I had previously been introduced by my thesis supervisor, to all clinics to introduce myself and explain the purpose of my study. It was through the cooperation of the staff that I was able to select informants. This was done as nurses on the ground knew the patients, how long they had been on treatment, if they could speak English, and if they would be willing to share their experiences of illness with me. Thus, a random selection process was not adopted. The sampling was purposive.

It is possible that through using such an approach some bias may have occurred as the nurses may have chosen the ‘good’ and ‘compliant’ patients rather than patients labelled as ‘unreliable.’ If this is the case, the problems presented concerning non adherence, as serious as it is in this context, may still be underrepresented.

I also spent time doing participant observation in the clinics prior to selecting key informants in order to gather information on care giver/care receiver interaction as well as for patients to get used to seeing me in the clinic setting. I went with Community Health Workers (CHWs) on their ‘rounds’ in the community, DOTing (directly observing the treatment of) patients. This was a useful way to get some insight into the living conditions and family support of TB afflicted patients. I was also able to observe the health workers’ interactions with tuberculosis patients in the patients’ home setting, and interviewed many of them (both patients and CHWs) on several occasions.

In selecting patients I did not differentiate between patients who were co-infected with HIV, were on retreatment, and had MDR (Multi Drug Resistant) TB or tuberculosis for the first time. The main illness related criteria was that they had recently started treatment. This allowed me to follow their treatment for a substantial amount of time. I am still in contact with these patients, although some of them are cured. It is important to note that of necessity the research became multi-sited since patients would move from one health care institution to another or from hospital to home. Patients I met in the clinic were transferred to Temba, or Jose Pearson, the Provincial Multi-Drug-Resistant (MDR) hospital located in Port Elizabeth, as their diagnosis or course of disease changed. Some people were cured and left hospital. Some people moved houses. I attempted to follow them throughout these various treatment phases. As will be discussed later, these movements are part of the experience of illness and have a great influence on illness management and therapeutic outcomes.

Six out of the eight key patient informants were male. Although the TB prevalence is slightly higher among males than females, the selection of a higher ratio of male to female informants was largely as a result of language competencies, both mine and theirs. I speak minimal isiXhosa and the men in most cases were able to speak better English than were the women. Most of my informants were unemployed at the time the research was conducted. As men have fewer commitments in the domestic sphere than women do, and it is seen as more acceptable for men than for women to spend time outside of the home, it became clear that men were more easily accessible as informants than women. Thus, there were cultural factors influencing the gendered nature of informant selection. Although I am aware of gendered differences in coping with illness as well as varying stigmas concerning certain diseases, the case studies in this thesis show that there are a number of common factors, at a variety of levels, influencing illness experiences.

I also attended meetings at the sub-district or Local Service Area (LSA) and at Settlers hospital. I attended the weekly Anti-Retroviral (ARV) Review meetings for HIV/AIDS patients at Settlers Hospital, and the Primary Health Care Programme’s meetings at the Makana sub District every second week. These were meetings where the PHC Programmes in the LSA met to discuss challenges and plan strategies and activities. I attended the ARV meetings at Settlers Hospital so as to be able to see how the syndemic (see section 2.12, chapter 2) is dealt with at this level. In addition, I attended meetings at the Makana sub-district where the World TB Day was discussed and planned in addition to meetings between CHWs and their ‘employers’.

1.3.2 Brief profiles of the most important participants in this study.

Ronnie: In 2005 Ronnie was diagnosed with TB for the second time. He had TB for the first time in 1984-85 and was cured. He was also HIV positive, a virus he said he probably contracted recently from one of the many girlfriends he confessed to have since his wife left him for another man in 2001. Since then he had been living on his own and felt increasingly lonely in his RDP house.[4] He had a son who lives in Port Alfred, whom he had not seen for years nor had he told him of his illnesses. They had no contact as Ronnie did not want to burden his son with his illnesses and unhappy life. Thus he dealt with his illness alone. I met him during the initial phase on his retreatment schedule and was immediately charmed by his sense of humour. We shared some amazing months together going for walks, shopping, meeting old friends of his, chatting and laughing. He was born in Grahamstown in 1956 and died alone at Temba hospital in July 2005.

Thando: Thando is 23 years old and lived with his mother and sister when I started my research. His mother works as a parking guard and earns R 500 per month.[5] This is the only income in the household. She will soon be on an old age pension (R 780 pr month). In 2001, within the same month, both Thando's sister (who had AIDS) and father (who had cancer) died. The father was the "social glue" in the household and the family has to some extent disintegrated in his absence and as a result of increasing poverty. Thando matriculated in 1999 and studied at Damelin College in Port Elizabeth in 2000 and at Rhodes University in 2003 (passed) and 2004 (failed). He is now unemployed.

Thando realised that he was ill in January 2005 and started TB treatment in June the same year after passing out at home and taken to Settlers Hospital where he was diagnosed with TB and HIV. He was at Temba for two months, before being discharged to the clinic where he finished his treatment. He was no longer living with his mother and sister, but isolated, living in a one-roomed house belonging to the family. He survived on his temporary disability grant. Two months after TB cure, he was reinfected and admitted to Settlers Hospital. He also has HIV, but is in denial and is not receiving ARVs. Just like they did not visit him at Temba Hospital, his family did not come and visit him at Settlers Hospital.

Nozithembiso: Nozithembiso is now 15 years old and lived with her aunt Lindelwa and 4-year old cousin Kuhle in a room behind Lindelwa's aunt's house when I first met her in

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[4] An RDP house is usually, and in this case, a 2-roomed freestanding house, owned privately but subsidised wholly or partly by the government and allocated on a needs basis. This is part of the ANC government's housing policy as part of the Reconstruction and Development Programme enabling poor people to own a house.

[5] The official poverty line is R1028 per month for a household consisting of three adults. http://www.sarpn.org.za/documents/d0000990/index.php (accessed 08.08.06).

April 2005. She was then at Temba Hospital with TB and HIV. She has been on ARV treatment since April 2005, two months after she started her TB treatment. They later moved to Port Elizabeth. They live off Nozithembiso's disability grant (DG),[6] and Kuhle's child grant. In Port Elizabeth, they lived for a while with Lindelwa's husband who works as a mechanic, making R 200 per week. Nozithembiso's mother died of an AIDS related sickness when Nozithembiso was 6 years old and she was lying at her mother's side in the hospital bed at Settlers when she died. Nozithembiso was discharged from Temba in June 2005, cured of TB having doubled her weight from the day she was admitted.

Although their little family unit (Lindelwa, Nozithembiso, Kuhle) finds strength in one another, they depend entirely on social grants and goodwill. Apart from Lindelwa's younger sister, who lives in Grahamstown and sometimes phones Lindelwa, they have no contact with other family. Sadly, conflicts have arisen within the family due to the social grants which many family members wish to secure some access to. In order to escape increasing demands from family, Lindelwa moved to Port Elizabeth with the girls.

Moses: Moses was 33 years old when I met him in early April 2005. In January that year he tested positive both for TB and HIV. He worked as a security guard, but has now lost the job due to his illnesses and long hospital treatment. He lives with his mother, sister and brother, and sometimes a cousin or two. His mother owns an RDP house and they have also added on two rooms at the back where Moses and his brother sleep. His mother sells vegetables on the street and his sister has a disability grant. She is HIV positive and is receiving ARV treatment. She has had TB, but is cured. Moses's brother is unemployed, but has not finished school as the family did not have money to pay the fees at the beginning of the year. He will continue with his schooling next year. The family is very supportive of Moses. Now Moses also has a disability grant. He was at Temba Hospital from March to November 2005 when he was (at last) diagnosed with multi-drug-resistant (MDR) TB and sent to Jose Pearson TB hospital in Port Elizabeth where he spent four months. He now takes his MDR treatment at his local clinic and lives at home.

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[6] The nature of the DG will be explained later. Suffice to note here that it is a valuable resource in impoverished areas and is given temporarily (often for 6 months) to TB patients and HIV positive people with a CD4 count below 200.

Lionel: Lionel developed MDR TB due to non adherence. He had run away both from Temba Hospital and Jose Pearson MDR Hospital in addition to non adhering to therapy as an out patient at a number of clinics. When I met him, he was not on treatment. He was then readmitted to Jose Pearson and stayed there for four months. He now takes his treatment at the local clinic. He does not have HIV. He has been in and out of prison (for theft and house break ins) and is unemployed, but studied for some time to be a preacher.

Lionel lives with his wife Ntombekhaya and her little child in a rented one room corrugated iron shack. His wife worked at a stall in town making R 100 per week, but lost this income when the trader decided to close the stall. As Ntombekhaya's mother gets the child grant (the child used to live with her) they had no income at all for some of the time Lionel was sick. Lionel was allocated a temporary disability grant only after he was discharged from Jose Pearson MDR Hospital. They have two other children who live with Ntombekhaya's mother at the coast in Kenton on Sea 50 km from Grahamstown. Lionel also has two children in Mossel Bay whom he has never seen as he has no money to support them or visit them.

Lionel has limited social capital. His mother died when he was young. His father abused Lionel physically throughout his childhood and although he lives in Grahamstown, Lionel has not had any contact with him for years and says that he no longer considers his father family. Lionel's sister lives and works in Johannesburg and has broken all ties with her family.

Eric: Eric was 33 years old when I met him and then lived in Grahamstown with his 4-year old son Luvo, his wife Zoliswa and her sister Aya. They shared a borrowed four roomed mud house. He was a patient at Temba, and is now cured from tuberculosis. He later moved to Bathurst with his wife and son and worked in a bar earning R 500 per month. They rented an RDP house there. Zoliswa's second sister, Fundiswa, came to live with them for a while in Bathurst. Fundiswa is HIV positive, but has not disclosed. After a few months in Bathurst the family moved to a game farm 30 km outside of Grahamstown where both Eric and Zoliswa were offered employment. Eric is also HIV positive, but feels healthy as he is on ARVs. Zoliswa and Luvo do not have HIV. Eric has been on ARVs since March 2005 which is also when he started his TB treatment. He was cured of TB six months later.

Among the key informants in this study, Eric is best off financially. However, his social capital is relatively weak and only Zoliswa knows that he is HIV positive. As he has not told his employer that he has HIV and is living outside of town and relies on hitch hiking to get to monthly clinic appointments, he has experienced some problems in terms of adherence. Eric’s mother has passed away. Although his father, who is re married, lives in Grahamstown they have little contact as the new wife does not like Eric or anything that has to do with Eric’s father’s past. They only came to visit him twice in the 6 months he was at Temba.

Mziwethemba: Mziwethemba is 32 years old and started his retreatment in January 2005. He completed his first TB treatment in 2000-2001, but it is not known whether he was cured or not. He says that he does not have HIV, but it is rare to experience recurrent TB with strong immune systems. He worked on a farm outside Grahamstown and earned R 495 per month. His sisters, girlfriend and son still live there, but Mziwethemba moved to his grandparents in Grahamstown so that he could have DOT at the clinic. His grandparents both have old age pensions. Mziwethemba does not want to go back to the farm as it does not have running water and electricity. Mziwethemba’s parents have both passed away, and he has some contact with his sister and girlfriend. Mziwethemba was only interviewed five times as he proved to be unreliable.

Nomangesi: Nomangesi is 28 years old and started her TB treatment in May 2005. She also has HIV, but is not on ARVs as she is too intimidated to ask clinic personnel to be assessed. She lived with her mother in Alexandria (80 km from Grahamstown) before moving to live with her 30-year older half sister and her children and grandchildren (totalling 12) in a six roomed house in Grahamstown in 2005. Late that year, she moved back to her mother and I lost contact with her. Her older sister was worried as Nomangesi’s mother has some psychological problems and drinks a lot of alcohol. Nomangesi’s sister has an old age pension, and there are other members in the family who have pensions. None are employed on a regular basis. They open their house up as a B&B during the National Arts Festival to make some extra money and do relatively well financially. The family living in the household is very supportive of one another and was of Nomangesi while she was living there although they never went as far as to go with her to the clinic.

1.3.3 Methods of research.

The main methods of research used were participant observation and semi-structured interviews. Patients were interviewed in the clinic facility or hospital, in their homes and in public places. Participant observation was conducted at meetings and gatherings, in the clinic environment, while walking around in the community with health workers, in informants' homes and while using other methods of research. Participant observation proved to be an essential research method and it was confirmed that "most social experience lies beyond words" (Hastrup & Hervik, 1994: 8).

A questionnaire was compiled and distributed to all the Community Health Workers at the time (39) in seven clinics and at the TB hospital in Grahamstown. Respondents could choose either an English or Xhosa version of the questionnaire and could also choose to answer in either of the two languages. There were 30 questions in total, some multiple choice and some open ended. Questions and answers were translated by two independent translators so as to achieve a high accuracy of data. 37 out of the 39 volunteers answered and returned the questionnaire. The results of the questionnaire can be found in chapter four. Because the survey relied on pre-set questions, answers had the potential to be inadequate on certain points.

Focus group discussion is a good research tool "justified by the relative lack of literature on the subject area" (Kironde & Klaasen, 2002: 108). As I was also part of a larger SANPAD sponsored project,[7] focus groups were conducted with the following groups:
Traditional Healers
TB patients at Temba
Community Health Workers
Middle aged women

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[7] I was a participant in and obtained financial support from a SANPAD (South Africa-Netherlands Research Programme on Alternatives in Development) Project titled: *"TB Stigma and Quality of Life in the Eastern Cape"* through the Institute of Social and Economic Research, Rhodes University. Data referred to as being from focus groups are from this project.

Middle aged men and women
Older people
Youth in school
Youth out of school

During the course of research I also piloted a research measure/tool called ACSA (Anamnestic Comparative Self Assessment) to be used in health related research (see appendix 2). As part of my research internship at the Institute of Social and Economic Research at Rhodes University I assisted in developing the measure and accommodating questionnaire and tested this on 20 tuberculosis patients at Temba together with a research assistant who worked as an interpreter. Although some sort of editing takes place when communication is translated, it is hoped that the final product is representative of the views of the subjects of research. Where this information is used, it is referenced as ‘ACSA pre test.’

Linking the individual experiences of informants with a broad level of analysis including global factors that play themselves out on a local and individual level is a central method in this study. It is, as Kleinman *et al.* note, impossible to separate the individual from a social level of analysis, health from social problems and representation from experience (1997: x).

The gap between representation and responsibility is a moral dilemma. Representation is complicated by the fact that “it is a matter not only of lies told *by* anthropologists, however, but also of lies told *to* anthropologists” (Metcalf, 2002: 1). When recording text, one continuously has to question the information given and cross check this with other sources. A method of triangulation was used where participant observation was used to validate data from interviews and vice versa. Informants’ accounts were also compared with one another, and this proved to be specifically useful when comparing providers’ and patients’ conflicting accounts. This happened often as both patients and providers, as we all do, attempt to control the impressions given (Goffman, 1969: 221). Repeating questions to informants at different times as well as asking the same questions of different people was done as a way of cross checking information.

1.3.4 Ethics and confidentiality.

Ethical approval was obtained from the Ethics Committee at Rhodes University. Permission to conduct research in the municipal clinics was obtained from Makana sub-district whereas the Provincial Department of Health permitted me to conduct research at Temba TB hospital. Prior to the initial interviews with patients, I explained the aims of the study and the nature of their expected involvement as potential informants. I assured them that their information was confidential, that their anonymity would be maintained and that they at any point in time could withdraw from the study. All names in this thesis have been changed.

Van Willigen points out that confidentiality and voluntary informed consent are the main components of ethical research practice (1986: 52). This is particularly important when researching in institutionalised settings, such as hospitals and clinics. Accordingly, this research adheres to the ideas of ethical research practice. However, one component of this specific research which has raised ethical questions is the issue of power and poverty.

Anthropologists need to ask themselves under what circumstances questions are asked. Although it was clear from the start that I was doing research, I observed that over time informants changed the way they perceived me. I became a friend and a helper with access to resources in terms of people, knowledge or money. I became part of their therapy managing group, a concept which will be briefly discussed in the next chapter and looked into more extensively in chapter six. Thus, when I asked questions, people answered them as part of their illness management strategy; e.g. as what they perceived as a necessity in order to get well. Information was given to me for use in managing their illness and not purely as information to a researcher for the sole purpose of research. On the other hand, they had given their consent and knew that I was a researcher and would use information for purposes of this research.

Van Willigen asks: “How and under what circumstances does consent have to be obtained again?” (*ibid.*: 45). This is an issue of concern and is related to the question of why people choose to give us information. Throughout the course of research I repeatedly stated my aims, time schedule and raised issues of consent. All informants were aware of the nature of my research and that their information would be used for this purpose.

This may simply be just what *it is like* to conduct research among sick people in poor communities. Patients in such situations will make use of any opportunity to improve their limited options to health, and anyone who shows sympathetic interest in their suffering and relative powerlessness is regarded as a valued resource. Nancy Scheper-Hughes, for example, played an important role in people's management of illness and health during her research among impoverished people in Brazil (1992). In a situation of poverty it is difficult, and maybe even unethical, *not* to apply knowledge and resources through anthropological research. Driven by a moral conviction one feels compelled to help to alleviate their suffering in any way possible, however limited that help may be.

However, for all a researcher's good intention to help the patient achieve satisfactory healing outcomes, one has to be aware that they may be contributing to the power play over meaning construction, power and access to resources. This dilemma has been raised in the past with reference to the field of clinically applied anthropology and has been critiqued by critical medical anthropologists who argue that such anthropologists are complicit in the hegemonic control of patients and their bodies through enforcing western medicine. Through endorsing the biomedical paradigm they also fail to address the fundamental causes of ill-health, that of social-economic inequality and structural violence.

1.3.5 The anthropologist as negotiator or advocate?

Medical anthropologists are known to work as "cultural consultants" and mediate between and offer advice to patients and health care personnel (Pelto & Pelto, 1978: 233). This is a form of brokerage and is also a research technique used. Briefly, a cultural broker is a person who serves as a link between two different cultural systems relating community oriented individuals who lack connections and resources with individuals as parts of larger systems (Wolf, 1965: 1076, in van Willigen, 1986: 128). When used in a clinical setting this brokerage becomes known as clinically applied anthropology. My 'applied' role throughout this research has been mainly that of the broker, in most cases more on behalf of the sick and disempowered than on behalf of health care personnel.

Another important question and aim, although not a research question as such, which I have asked every day throughout the course of research and while sitting in front of the computer is: “Are my actions helping the sick people or not?” It is an ethical question too, although not strictly in the sense of research methods. For me, when the research took on a life on its own, it has been the most important question in this study.

1.3.6 Applied anthropology as method.

A basic definition of applied anthropology can simply be “anthropology put to use” (van Willigen, 1986: 7). This “use” is regarded as beneficial to subjects of research, but also to the researcher. Here, participation in therapy management has allowed me into otherwise closed spheres and resulted in much useful data. Thus, applied anthropology is a useful research technique as well as, I would argue, ‘the right thing to do’ in this context. My direct involvement in the subjects’/patients’ therapy management was more as a result of a conscious decision on the research subjects’ part than on mine. Issues of power and access to resources of health cannot be separated from this decision.

Van Willigen writes that products of applied anthropology can be seen as threefold: information, policy and action. These are related as “information is obtained through research, information is used to formulate policy, and policy guides action” (*ibid.*: 8, 10). I have chosen a more short-term ‘person oriented’ approach to applied anthropology where ‘anthropology put to use’ is put to use in individuals’ lives directly rather than in only recommending policy changes to the system. I acknowledge the limitations in this approach. Throughout, I have tried to find a balance between assisting people and making sure they do not become dependant on my assistance. However in the long-term I hope that the findings of the research will have an influence on policy decisions for the future.

In the past, little recognition has been made as to the potential role that anthropologists may play as cultural and social brokers in the field of clinically applied anthropology in South Africa. I hope that through this applied research awareness will be raised of the potential role of the medical anthropologist in South Africa, a hitherto neglected area of therapy management.

1.3.7 Suffering as experience and representation.

Working in a field where human suffering is prevalent, even common, raises a number of issues difficult to rationalise or represent, and at the same time do justice to, in an academic piece of writing. My research has to a large extent been an emotional journey, often together with the research ‘subjects’. I am hoping to do justice to these realities of suffering, the relations of emotions, and not rationalise them away, while at the same time remain analytical.

It must be noted at this point that doing long-term in depth participant observation among people suffering from a debilitating and life-threatening disease is not easily achievable since one must be careful not to increase theirs, their families’ or even health workers’ burdens. Many a time I found myself not asking questions I wished to ask, or left potentially ethnographically interesting situations, because I felt that it was inappropriate to ask or observe in sensitive circumstances.

Throughout the course of research I was continuously faced with new ethical issues, some which took me by surprise. As my fieldwork came to a close and I was preparing to distance myself gradually from the informants I had become close to, they started contacting me, refusing to let our relationship be terminated. This method of ‘reverse snowballing’ manifested itself through phone calls over weekends and public holidays, day or night, asking me to come and visit – and lend money. I was asked to assist with employment contracts, to become an ARV treatment supporter, or to attend a meeting with the extended family. Ironically, as I tried to distance myself, the relationships grew stronger. This in a sense serves as ‘proof’ of the effectiveness of my general methodological and analytical approach to the data collected; namely that it is poor and marginalised people, with weak social networks, who get sick and who find it difficult to get well, and as such medical anthropologists are regarded as valuable resources. Hence, I became an important person in their therapy managing groups. But the dilemma remains as how to deal with these issues, both in terms of writing a thesis and in terms of ‘doing the right thing’ as a person interacting with other people through lived experiences.

It can possibly be argued that there is a difference between research ethics and moral responsibilities that we have to one another as human beings. If we are to ‘participate’ and ‘observe’ and only that, in terms of research ethics, then my research may not be ethical in terms of my own moral ethics. This was partly my own initiative, but was also requested, and in many cases expected of me.

It is perhaps true that “disempowered people everywhere will grasp at straws to gain some voice in the public discourse” (Metcalf, 2002: 15). I have certainly been asked to tell people’s stories in the public discourse, particularly in clinics, but most of the time people do not have an urge to be *heard* as much as they have an urge to *get well* and live a secure life with their families.

Life is not all about suffering, although, as is evident in the ethnography, people do spend much time and money on illness management. Issues of poverty, illness and powerlessness are highlighted, but I sincerely hope that I am doing justice to the lives of the people with whom I have conducted research, and that I have managed as far as possible to reflect what is true to them. People keep living and keep laughing, despite the poverty, pain and tears. Even the anthropologist may evoke humour. I once went to see Lionel at his home. I was quite grumpy when I got there, as I had had a long day and was tired. That day more than usual, I had been asked for money and help to organise identity documents and all sorts of other things. I was quite dismissive, so when Lionel asked me for R20.00, I quickly said “no” and immediately felt that I really could not handle all this begging and needing any more. As my visit ended, Lionel took me to the car, stuck a R20.00 note in my hand and said: “Here, take this. I want you to buy yourself a cool drink.” As it turned out, Lionel had just got his disability grant and felt that he now wanted to help the ‘poor’ student who was concerned about her future employment opportunities. It was also his way of reciprocating and making our relationship equal. That very act empowered him. Sometimes I had money and could help him, and sometimes he had money and could help me.

I am under no illusion and do not argue that the ethnography presented in the following pages are representative of all cases, or there is necessarily truth behind everything that was told to me. I am attempting to represent people, the stories they told me, and how they experience their lives as truthfully as possible, but the risk of misrepresentation always exists. To produce general anthropological knowledge from individual experiences in the field is a tricky business (Hastrup & Hervik, 1994: 1). To produce general anthropological knowledge from individual experiences of *suffering* is an even trickier business.

1.4 Chapter outline.

The next chapter is mainly theoretical and presents the anthropological perspectives to studying health and illness that are relevant to this thesis. Particular focus is given to Critical Medical Anthropology (CMA) as this is a theoretical framework which is suitable in the study of tuberculosis, and of individuals' experiences of tuberculosis, in South Africa. Tuberculosis is presented as a disease which is social in nature, thriving in environments of poverty and inequality. This thesis argues for a combination of both critical and clinical medical anthropology seeing disease both as social and biological. The interactions between biological and social (and to some extent biological and biological) are explored, resulting in an increased burden of illness in what Singer and Clair term a syndemic (2003).

Paul Farmer's term structural violence is explained in more detail and applied to a perspective where poverty and inequality are explored as risks to contracting tuberculosis. Farmer also argues for a human rights and social justice perspective on health (1996; 1997a; 1997b; 1999; 2000; 2005). In this thesis it is argued that at almost every level, people's experiences of illness can only be explored through an investigation of structures in the political economy of health.

Richard Wilkinson's inspiring analysis of the role not only of poverty, but of relative inequalities as creating and sustaining classes of sick people, is presented and it is argued that 'the sick' in South Africa is sustained as a group through a process of structural inequalities which, ironically, are reproduced through the actions of 'the sick' (Wilkinson, 1992; 1996; 1998; 2005). Tuberculosis in Grahamstown is presented as an interplay between human agency, and limitations to this agency.

The third chapter looks at DOTS, the global strategy to combat tuberculosis, both as ideology, policy and as practice in Grahamstown. It is noted that DOTS is a form of hegemonic control of surveillance. It is argued that curing tuberculosis in individuals is a necessary but insufficient strategy to combat the disease, as simply curing people of TB is not dealing with the basic structural inequalities that result in high rates of tuberculosis in the area of focus.

Interactions between the various levels of the health system are investigated at the local level. It is argued that the focus on programmes as a means of implementing health care is limiting in the current context of syndemic interactions. An integrated and less reductionist approach to health and health care is needed, incorporating national and global politics which are not directly related to health, but which have major implications on government's and individuals' ability to make healthy choices.

Interactions between clinic staff and patients are explored in a context of insufficient financial and human resources. However, it is argued that limitations in TB care at the local level cannot be blamed solely on low work morale.

Related to this, the fourth chapter looks at the role of the voluntary Community Health Workers (CHWs) as part of the implementation of DOTS at local level and as an integral part of the national ideology of Primary Health Care. Relationships and perceptions of the role of the CHWs among patients and professional health personnel are explored. The sustainability of a national TB care system based on voluntary participation is questioned.

The fifth chapter discusses the usefulness of certain anthropological concepts. Arthur Kleinman's notion of explanatory models (EMs) (1980) is presented and a detailed ethnography concerning people's perceptions about causes, symptoms and treatments of tuberculosis is explored. Kleinman's distinction between illness and disease is presented and it is shown that the illness component of sickness is more important to disease management than the biological disease itself.

The application of John Janzen's concept of therapy managing groups (1978; 1987) is presented in the sixth chapter and it is argued that support networks are extremely important in terms of dealing with tuberculosis and seeking care for tuberculosis as well as HIV. It is argued that although beliefs about diseases' aetiology do influence illness experiences and health seeking, structural issues related to poverty and powerlessness, and also stigma, are more important than health beliefs in influencing health seeking behaviour and adherence to treatment. Stigma is seen as having an impact on people's experiences of being sick, and on the illness itself, as well as their health seeking behaviour and is stronger among people with weaker support structures.

The seventh chapter shows how the introduction of temporary disability grants (DGs) for people with tuberculosis or AIDS introduces to the sick what Nattrass terms "perverse incentives" (2005). This is yet another manifestation of the impact of structural inequality on not only individuals' risk of contracting these diseases, but also on their ability to get well. It is shown that although the introduction of the DG for people with tuberculosis is a way of alleviating poverty, this reproduces the same system from which it is meant to alleviate poor people. However, it is also shown that people exercise agency in this seemingly disempowered context. Ideologies of compliance are looked into and it is shown that social support is more important in influencing adherence than 'patient deviance'.

The thesis concludes by advocating for a human rights and social justice based approach to health. As shown throughout the thesis, tuberculosis is a disease of poverty – a symptom of a deeper social ill. In fact, tuberculosis can be used as an indication of how far democratised South Africa has come in alleviating poverty (Benatar & Coovadia, 1991: 1). Unfortunately, with increasing HIV prevalence, the rate of co-infection is escalating. Although AIDS, as tuberculosis, is a social disease, the increasing rates of these diseases are also a result of a failure of commitment at all levels of the health system. As evident throughout the ethnography, a dedication towards seeing health as a right and encompassing the realisation of this right into a wider social justice based approach is necessary in order to combat tuberculosis in South Africa.

Chapter 2.

Theoretical approaches to medical anthropology in impoverished communities.

> The enjoyment of the highest attainable standards of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions.
>
> WHO constitution of 1946

2.1 Introduction.

Individual experiences of tuberculosis are related to wider national and global forces. This chapter discusses various approaches to studying and applying medical anthropology, and specifically examines the value of critical medical anthropology (CMA) as an approach to understand the connections between the micro and macro levels in the epidemiology and aetiology of tuberculosis. The importance of including macro level forces in anthropological micro level analysis is emphasised. The role of the anthropologist in the clinical environment is explored and it is argued that a combination of applied *clinical* and *critical* medical anthropology, rather than an opposition between these, is the most appropriate and useful approach. An anthropologist does not necessarily have to subscribe purely to the theories of critical medical anthropology in order to be a critical medical anthropologist (Heggenhougen, 2000: 1171); she/he can also be critical *within* the clinical environment even when applying more ethnomedical methodologies.

The chapter also argues for a human rights perspective on health. Practical and theoretical perspectives on structural violence and social suffering are presented. While poverty is a central theme, both in terms of the empirical findings and in terms of analysis it is also argued that not only are poor people more likely to get sick than rich people, but *relative inequalities* within and between societies (global or local) create, or sustain, a class of sick and poor people. Thus, poverty and inequality are central to the way diseases such as TB are transmitted and managed at structural and individual levels.

While it is argued for the necessity of including “invisible” structures of inequality in our anthropological analysis, the usefulness of a combination between social justice and traditional ethnomedical approaches is essential to make sense of who gets sick, why they get sick, and how they seek healing. People who are victims of structural violence may not directly perceive the workings of that violence in their daily struggles to avoid or overcome poverty, disease and illness. They experience and make sense of it from the context of their own unique social and cultural localities. Arthur Kleinman’s explanatory model (1980) and John Janzen’s therapy managing groups (1978; 1987) provide useful tools for this localised cultural and social analysis, and as they predate much of the critical medical anthropology approach they will be discussed first in the next section of this chapter.

2.2 The notion of the explanatory model.

The explanatory model (EM) was introduced by Arthur Kleinman in his influential book *Patients and healers in a context of culture* published in 1980. Although the model later has met with some criticism, from amongst others Kleinman himself (1995), it is nevertheless a useful tool when used in combination with other approaches. According to Kleinman, the explanatory model of any particular illness consists of (1) symptoms and signs by which the illness is recognised, (2) presumed causes of the illness, (3) recommended therapies, (4) the illness pathophysiology and finally (5) prognosis (1980: 105-07). These themes are central in the patient histories given in chapters five and six.

Kleinman has explained the purpose of the model as trying to find out “the ways in which an illness episode is interpreted and understood by patients, healers…and other social members of their local social world” (Kleinman & Seeman, 2000: 236). Once illness is explored in one particular environment, the aim is to make cross-cultural comparisons “to seek generalizations about these fundamental human experiences” (Kleinman, 1980: 8 & 111). Explanatory models are flexible as they change throughout the process of healing as new information becomes available. Imbalances in power can result as practitioners do not change their EM as easily as patients do.

An integral part of the model is the distinction between illness and disease. Kleinman explains disease as the “malfunctioning of biological and/or psychological problems” whereas illness refers to “the psychological experience and meaning of perceived disease” (Kleinman, 1980: 72). Illness is social and psychological whereas disease is biological. In later times, Kleinman himself has criticised both the model and the distinction made between illness and disease as being too static. He is more uncomfortable with models now than he was in the late ’70s and early ’80s (1995). Even so, the distinction is still used in this thesis to show that tuberculosis is not only a disease, but it is also an illness with wide-ranging implications. Patricia Kelly uses Arthur Kleinman’s distinction between illness and disease in assessing stigma among American TB patients (1999). Experiences of stigma fall under the illness category. As a result, illness and disease exist “as constructs in particular configurations of social reality” (*ibid*.: 73).

Ethnomedicine is primarily concerned with illness. Nichter has defined the ethnomedical approach, of both Kleinman’s and Janzen’s (see below) work, as the “study of how well-being and suffering are experienced bodily as well as socially, the multivocality of somatic communication, and process of healing as they are contextualized and directed towards the person, household, community and state, land and cosmos” (Nichter, 1992: x, cited in Rubel & Hass, 1996: 116). One of the weaknesses of the ethnomedical approach is that it tends to focus the study on concepts and the curing of folk illnesses, while overlooking killer diseases such as tuberculosis and malaria.

Although Kleinman does note that patients and healers act within a given health care system, he, and the cultural interpretive model he introduced, have been criticised for focusing on patient/practitioner relationships and exaggerating patient agency without seeing these as actors in a wider context of power and particularly their unequal access to this power (see Pappas, 1990; Singer, 1995). Pappas argues that for Kleinman, “institutions appear as if they were little more than backdrops” to actions in the clinic environment and that individual action is not related to social change or institutional relations (*ibid*.: 199 & 202). Kleinman limited his studies to the clinic environment. The focus in this thesis is not only the clinic, but also individuals, and patients specifically, as members of households and as actors in a wider network, such as therapy managing groups, which are presented below. These groups and their explanatory models of illness are shaped by and acted out within the larger context of inequality, or, to use Paul Farmer’s preferred term, structural violence.

2.3 Therapy managing groups.

It was found that one particularly useful concept when examining decision-making concerning health seeking behaviour is John Janzen’s (1978: 4) notion of the therapy managing group (TMG). The TMG is a network of close kin, friends and/or associates who manage, through moral support, information sifting and patient/healer brokerage, the therapy of the patient’s illness (*ibid*.: 4). The patient is at the centre of this network of people such as family members, members of households or co-workers who are also affected by the patient’s illness. It has proven useful to extend this notion to include health workers who have a very direct impact upon the patient’s experience of being sick and attempts at getting well. All these participants are of course guided by their own explanatory models. Whereas tuberculosis is often seen as a disease by the professional health worker, it is experienced as an illness by those who are sick and their therapy management groups.

Janzen’s model is useful to examine medical pluralism where people diagnose illness, select and evaluate therapies by combining therapies from different medical systems (1978: xviii). In this thesis, where it was found that traditional healers were seldom used for curing tuberculosis, the concept is more widely used as a tool to understand the dynamics of social networks in illness management.

Although the therapy managing group as a concept derives from John Janzen, healing as a social process has been well known to anthropologists working in Africa for a long time. The classic example is the Ndembu where Victor Turner shows that their therapeutic efforts are embedded in social relationships (1967). Illness and health, in other words, must be seen as social.

These various ethnomedical approaches or models that focused on the local and cultural have received increasing critique from medical anthropologists who are becoming increasingly aware of the political-economic embeddedness of disease and suffering. This has led to the formulation of the so called field of Critical Medical Anthropology discussed below.

2.4 Critical medical anthropology.

Medical anthropology as a sub-discipline has its origin in applied anthropology with anthropologists working as health care consultants in colonies and newly independent countries post Second World War (Leslie, 2001: 430). As a result, medical anthropology, regardless of theoretical approach, can be seen as an applied discipline. Our input as anthropologists in health care is continuously needed and we do play a role in the shaping and reshaping of approaches to disease and medical practice. After all, doctors, in Merrill Singer's words, "practice medicine, not social change" (2004: 14).

Critical medical anthropology (CMA) as a theoretical orientation in medical anthropology appeared in the early 1980s. Lynn Morgan argues that there are three distinct paradigms within the broader umbrella of CMA. One has a strong orthodox Marxist focus relating health care and status as direct results of exploitation of wage labour and the socio-economic formation of capitalism. The second approach Morgan terms "cultural critique" and is comparable with the Marxist perspective, but in a "lite" version without a strong Marxist terminology. Its main critique is focussed on the Western medical establishment itself. The third and final approach Morgan identifies is the "dependency theory approach", based on Wallerstein's world system theory, and relating development and underdevelopment as impacting on disease (Morgan, 1998: 107-108). It could be argued that Paul Farmer's structural violence approach is a fourth theoretical paradigm within the CMA orientation.

Hans Baer defines the political economy of health as "a critical endeavour which attempts to understand health-related issues within the context of the class and imperialist relations inherent in the capitalist world-system" (1982: 1). Baer argues that the political economy of health is played out through health care priorities at a structural level as well as at individual levels where illness is experienced. The importance of the global economy and relationships within it is essential in any analysis of a local health system and patients' personal experiences of illness. As the case studies in this thesis will show, patients' experiences of illness are strongly influenced by a larger global context, expressed in national, regional and local systems and processes.

In the last two decades the political economy of health has been expressed less in terms of the orthodox Marxist approach, but with a sustained focus on the political interplay between global and local, macro and micro processes and human agency, and limitations to this agency, within this context. These include the dependency or world systems approach (see Morgan, 1998), and Paul Farmer's structural violence approach (see 1996; 1997a; 1997b; 1999; 2005). Merrill Singer's definition of critical medical anthropology encompasses a broader perspective, including ethnomedical perspectives. He defines CMA as:

> a theoretical and practical effort to understand and respond to issues and problems of health, illness and treatment in terms of the *interaction* between the macro level of political economy, the national level of political and class structure, the institutional level of the health care system, the community level of popular and folk beliefs and actions, the micro level of illness experience, behaviour, and meaning, human physiology, and environmental factors (Singer, 1995: 81).

Paul Farmer has been extensively influenced by the CMA approach and his use of the application of structural violence and social suffering is worthy of more detailed analysis. Paul Farmer and other critical medical anthropologists have also emphasised the importance of inequality, poverty and risk. These are also presented in the following sections under the broader category of CMA.

2.5 Structural violence.

It is difficult to pin down exactly how Paul Farmer defines structural violence. He uses the term in a broad sense, including "a host of offences against human dignity: extreme and relative poverty, social inequality ranging from racism to gender inequality, and the more spectacular forms of violence that are uncontestedly human rights abuses…" (Farmer, 2004: 309). These are historically and economically rooted and necessitate a "historically deep and geographically broad analysis" (*ibid.*: 309). The application of the concept of structural violence in anthropology necessarily draws on both biology and history (*ibid.*: 308). A useful definition of structural violence which is probably akin to Farmer's use of the term is as follows: "Physical and/or psychological harm (including repression, environmental destruction, poverty, hunger, illness, and premature death) caused by exploitative and unjust social, political, and economic systems" (Haviland *et al.*, 2005: 725).

As identified in the above definition social inequalities are a central component of Farmer's approach. In fact, the notion of structural violence may be defined more accurately as an approach rather than as a theory. It is driven by the commitment to "ethnographically embedding evidence within the historically given social and economic structures that shape life so dramatically on the edge of life and death" (Farmer, 2004: 312).

The term "structural violence" was first used by Johan Galtung (1969, in Farmer, 2005) who saw it as "sinful" and results when structural power[8] leads to social inequality and resulting poverty for certain components of the social system. These inequalities are often based on race and gender discrimination (Farmer, 2005: 307). In short, Farmer continues, "the concept of structural violence is intended to inform the study of the social machinery of oppression" (*ibid.*: 315). Oppression as a result of these structures is seen as being a construct of history and "nobody's fault" yet it is a fact that people's agency is constrained as a result of these structures

The idea of oppression being "nobody's fault" can be related to Pierre Bourdieu's notion of symbolic power where those subjected to symbolic power do not themselves realise that they are subjected to this power (1996). It is structural and invisible, hence perceived as "natural". As a result, this invisible symbolic power inhibits agency and makes challenges to the power difficult to formulate and act out.

2.6 The demography of social suffering.

> Events of massive, public suffering defy quantitative analysis…Do numbers really reveal the agony, the interruption, the questions that these victims put to the meaning and nature of our individual lives and life as a whole?
>
> Rebecca Chopp, 1986, cited in Farmer, 2005: 42

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[8] Structural power can be defined as: "Power that organizes and orchestrates the systemic interaction within and among societies, directing economic and political forces on the one hand and ideological forces that shape public ideas, values, and beliefs on the other" (Wolf, 1999: 5, cited in Haviland *et al.*, 2005: 722).

Social suffering as an approach to the study of disease can be applied to this study. Social suffering results from "what political, economic and institutional power does to people" (Kleinman *et al.,* 1997: ix & xxiv) and how these powers respond to these challenges. Social suffering includes concepts and conditions which are usually covered by separate fields such as welfare, health, and religious, moral and legal issues. Suffering is "profoundly social" and adds to the burden of disease in the group or individual and can be experienced as added stress, guilt of being ill and loneliness (*ibid.*). Hence, social suffering can be seen in relation to syndemic interactions (see section 2.12 for more on the concept of syndemic).

It is important, as Kleinman and Kleinman point out, not to essentialise, naturalise or sentimentalise suffering (1996: 1). Thus, presenting and analysing other people's suffering is a large, and complex, responsibility for the anthropologist. The experience of suffering is not effectively communicated through graphs or statistics. Paul Farmer also warns against "the exoticisation" of suffering (2005: 40). Experiences of suffering are best expressed in stories told by the sufferers themselves. This is best done through a detailed ethnography.

The sheer weight of suffering makes it difficult even to grasp or understand the actual experiences of people's suffering (Farmer, 1997a: 262 & 272-3). Nancy Scheper-Hughes even suggests a "demography without numbers", referring to a theoretically driven demography. In simple terms, this demography is "simply descriptive" (1996: 891). Here, individuals and their histories are presented both as a detailed ethnographic account as well as an analyses within a wider multileveled context.

In this thesis a limited amount of statistics and numbers are given as a means of contextualising personal experiences, but it is also emphasised that the numbers on their own carry little meaning. When looking at the number of people being moved in order to make place for the giant dams in the Narmada Valley, India, Arundathi Roy uses the term "fascist maths" when numbers of people suffering are presented (Roy, 1999). Although this is a different context, the term can be useful when thinking about tuberculosis. In 2002, 8.8 million new cases of TB were detected, of which 3.9 million were smear positive (WHO, 2004: 4). These are huge numbers and their real meaning regarding the impact on people's lives can only be understood, but hopefully not accepted, once they are given an ethnographic context. I can only hope that I am presenting the experiences of a few of those people who I have worked among in a truthful manner without simplifying or exoticising their experiences.

2.7 The role of inequality and definition of poverty.

> To feel depressed, cheated, bitter, desperate, vulnerable, frightened, angry, worried about debts or housing insecurity; to feel devalued, useless, helpless, uncared for, hopeless, isolated, anxious and a failure: these feelings can dominate people's whole experiences of life, colouring their experience of everything else. It is the chronic stress arising from feelings like these which does the damage.
>
> Richard Wilkinson, 1996: 215

The uneven distribution of risks to bad health and rights to good health can be explored in terms of multilayered inequalities. Prevention politics and methods need to take a more social and structural view of health – a disease by disease approach is unlikely to be successful (Wilkinson, 1996: 71). In his insightful books investigating health and inequalities, Richard Wilkinson argues that it is not only *poverty* itself which results in people being prone to illness, but *relative income inequalities* that create conditions among the poor where certain diseases are common. The quality of social relations is worse in more unequal societies. Not only do unequal societies have more illnesses than more equal societies, but they also have more accidents and more homicides in addition to higher rates of depression, anxiety, stress and loss of self-control in addition to poor social networks (1996: 5; 2005).

In South Africa, escalating violence is an important result of gross inequalities. These processes are all connected. According to Wilkinson, "there is a significant tendency for mortality to be lower in countries with a more egalitarian distribution of income exist" (1992: 165). Thus, the larger the gap between the rich and the poor in a society, the more likely it is that the poor in this society will be sick. Inequality can be measured through the use of the World Bank measurement called Gini coefficient where a value of 0 indicates perfect income equality and 1 indicates perfect income *in*equality. According to the United Nations Development Programme, the Gini coefficient in South Africa rose from 0.596 in 1995 to 0.635 in 2001 (UNDP, 2003: 5). In sub-Saharan Africa as a region, the Gini coefficient is above 0.7. In South Africa, the richest 10% of the population have 44% of the country's income and consumption (UNDP, 2006). There is, Wilkinson argues, better social fabric in more egalitarian societies, and this has a significant impact on health among the population (1996: 85).

If poverty is redefined as "social exclusion", as Wilkinson argues, poverty and inequality are the most powerful determinants of health in a society (2005: 124). Social exclusion is a result of symbolic violence exercised through structures of oppression. "It is not that medical care is ineffective," Wilkinson continues, "but rather that its effectiveness is a minor influence compared to the socioeconomic factors which establish the initial burden of disease" (*ibid*.: 59).

Social relations in South Africa are based on gross inequalities of access to employment, education, wealth and health to mention a few. The health status of people living in conditions of overcrowding is worse than among those not living in overcrowded households (Stats SA, 2004: vii). It is not surprising that there is also a clear link between nutrition and health. A survey of South African households found that in households where no one went hungry in the year prior to the survey they had better health status than households where one or more people were hungry. The survey also found that 29.7% of households headed by Africans had at least one member who went hungry in the year prior to the survey, whereas the rate was only 2.9% in households headed by a white person (Stats SA, 2004: x). In terms of transmission of tuberculosis, both poor nutrition and overcrowding are essential risk indicators and in South Africa this still tends to be racially based. Marshall Sahlins linked poverty and inequality before it became fashionable to do so:

> Poverty is not a certain small amount of goods, nor is it just a relation between means and ends; above all it is a relation between people. Poverty is a social status…It has grown with civilization…as an invidious distinction between classes…
>
> 1974: 37, cited in Wilkinson, 2005: 67

The relations expressed by Sahlins and the list of feelings in the Wilkinson quotation at the beginning of this section will appear repeatedly in the stories of people in this thesis, not because I am attempting to make them fit into my agenda, but because that is what these stories of health and sickness really are about. People get sick, and remain sick, due to relations of multi-levelled inequality.

2.8 Poverty and inequality as risk.

> We must explore not only the life experiences of those sick with tuberculosis, but also the larger societal contexts in which they become infected, fall ill, and meet with a series of therapeutic misadventures leading to complications, ongoing transmissions to others and, often enough, death.
>
> Paul Farmer, 2000: 183

Much of the literature points to poverty as a risk factor for diseases such as TB, HIV and malnutrition (see Singer *et al.*, 1992; Kleinman *et al.*, 1997; Nguyen & Peschard, 2003; Farmer, 2000 & 2005). Ten years ago, even the World Health Organisation recognised that poverty is a major risk factor for tuberculosis and that in order to fight TB poverty had to be addressed in the control of tuberculosis. Poverty is, the WHO points out, “the world’s greatest killer” and unequal access to wealth as well as health care is a matter of life or death (1995). It is sad to note that this report was released 11 years ago, and although the WHO alone cannot be blamed for lack of action, it is clear that the poverty situation in the world has in fact worsened in these 11 years. What is needed now is nothing less than a “major shift in our way of thinking about the future” (Benatar, 1998: 297).

2 'I became sick because of my poverty.' 'Well, I became poor because of my sickness.' The two-way relationship between poverty and ill-health affects billions.

Illustration 2.1: Cartoon of relationship poverty/sickness (Global Health Watch, 2005: 17).

Farmer argues that the poor are *systematically* put at risk and, while pointing out that rich people have medical care as a "birthright", poor people have the "right" not to go to school, not to have access to safe drinking water and electricity as well as limited access to health care (2000: 197 & 200). Bring labelled as "at risk" can put individuals and groups further at risk as policy makers and health care officials can then "write off a people as 'naturally' predisposed to particular types of problems and therefore not worth the investment of particular kinds of resources" (Lock & Nichter, 2002: 11). Some people are more at risk than others to diseases such as tuberculosis. Those people most at risk of diseases are also those who in practice have less right to sufficient medical care.

In the developing world 75% of TB cases occur in the most economically productive age group (15-45 years) (Blanc & Uplekar, 2003: 95). Thus, not only is TB a result of poverty, but it also creates and exacerbates the situation of poverty among the already poor. Whitehead *et al.* term this cycle the "the medical poverty trap" (2001). If poverty and inequality are the real cause of diseases such as tuberculosis and HIV, then biomedicine can alleviate the symptoms, but not eradicate the disease itself. In order to do that, we must solve the issues of structural poverty and inequality.

The poor can be seen as what the WHO describes as a "socially vulnerable group". Vulnerable groups are often characterised by certain factors such as ethnicity, gender, geographical location, living conditions, education and social exclusion. These groups often take longer in reaching a TB cure than do their counterparts (WHO, 2005c: 12 & 23), that is, if they reach a cure at all. Risks are structured and we are not all equally prone to these risks and exposures.

2.9 Critiques of critical medical anthropology.

CMA has been criticised for being solely a theoretical approach in medical anthropology, unable to apply itself beyond the academic sphere and impossible to apply to a clinical perspective (Chrisman & Johnson, 1996: 93). Clinical anthropologists, on the other hand, are often criticised for being uncritical of biomedicine (Sargent & Johnson, 1996: xiv). In addition, clinical and interpretive anthropologists, such as Arthur Kleinman, have been criticised for not taking larger issues of power and domination into account when exploring patient/practitioner relationships (Baer *et al.*, 1997: 25).

Thomas Johnson criticises CMA for not being sufficiently self-critical and for not realising that their perspective on reality, just like the biomedical reality they criticise, is just as much a cultural construction (1995: 108). It is essential for all anthropologists, whether they are working in an academic or clinical environment, to realise that they too see the world through "cultural" glasses. This realisation must be an integral part of our analysis. However, I will still argue that CMA plays a critical role in developing and applying anthropology.

Scheper-Hughes and Lock criticise political economic studies in anthropology as tending to "depersonalise the subject matter and the content of medical anthropology by focusing on the analysis of social systems and things, and…neglecting the particular, the existential, the subjective content of illness, suffering and healing as lived events and experiences" (1987: 137 cited in Singer, 1990: 184). Commenting on Farmer's "structural violence" approach in his "An anthropology of structural violence" paper published in *Current Anthropology* in 2001, Scheper-Hughes together with Bourgois, warns against broad-brush concepts, arguing that they hinder ethnographic critique. They continue, saying that "…critical anthropologists still need to disentangle the causes, meanings, experiences, and consequences of structural violence and show how it operates in real lives – including how victims become victimizers and how that hides local understandings of structural power relations …" (2004: 318). Pierre Bourgois and Nancy Scheper-Hughes argue that Farmer's notion of structural violence is too much of a "black box" as it is inadequately elaborated, although they concede it is a crucial concept in understanding the experiences of people suffering under these structures. They warn against a too deterministic analysis and emphasise the need for more ethnographic detail. To quote at length:

> We need to specify empirically and to theorize more broadly the way everyday life is shaped by the historical processes and contemporary politics of global political economy as well as by local discourse and culture. To be useful ethnography must be attuned to the local without predetermination (Comment to Farmer, 2004: 318).

However, in his paper "The consumption of the poor: tuberculosis in the 21st century" (2000) Farmer makes extensive use of ethnography at a micro level and provides the reader with excellent "thick description" (Geertz, 1973) while at the same time locating the ethnography within the broader structural framework.

At a more general level, Lynn Morgan criticises CMA for being an outdated approach, relying too much on out of date approaches such as dependency theory. She adds that there is too little social dynamism in CMA (1998: 106 & 118). I would agree to an extent that some forms of CMA, particularly the one Morgan terms orthodox Marxist, do use terminology which is too rigid, but Morgan herself is using a limited perspective by arguing that CMA as a whole is lacking social dynamism. There is flexibility, openness and also variety within critical medical anthropology.

In following Farmer’s approach this thesis aims at providing both ethnographic ‘thick description’ and making sense of this using broad macro theories and approaches. Individual experiences of suffering and illness are located within a wider framework of global structures, relationships and political economy. The anthropologist has a responsibility to present their cases of the informants/sufferers in a truthful manner, as far as that is possible. However, it is born in mind that ethnographic ‘truths’ are inherently partial and incomplete (Clifford & Marcus, 1986: 7).

We also need to look at experiences of suffering and how these have the potential to challenge the medical hegemony (Scheper-Hughes & Lock, 1996: 32). To realise this potential, these experiences of suffering must be explored and expressed in a manner which contextualises the experiences in a structural framework that are characterised by inequalities in power and access to this power. However, it is extremely risky for anthropologists to undermine the important contribution of biomedical TB treatment in helping those currently afflicted by the disease. For this reason I still see a place for anthropologists in the field of clinically applied medicine in assisting with identifying and addressing the reasons why those afflicted default on their medications. In order to facilitate this process the application of Kleinman’s use of explanatory models of illness, and Janzen’s concept of therapy managing groups provide useful tools for understanding what determines patients’ decision-making and their adherence or resistance to clinical interventions.

2.10 Tuberculosis as a social disease.

The fundamental aim of medical anthropology, Singer argues, using Ronald Frankenberg’s term, is to “to make social of disease” (cited in Singer, 2004: 21). Tuberculosis is, as Randall Packard has clearly shown in his study of the history of tuberculosis in South Africa, a “classic social disease” as it thrives among people and environments experiencing overcrowding, malnutrition, physical stress and immunosuppressant infections – all associated with poverty (1990: xix).Thus care must be taken not to look at technology as the only remedy for social ills (Farmer, 2000: 185).

As early as in 1904 New York City's public health officer, Hermann Briggs, "made social" the problem of tuberculosis by singling out "[h]omeless, friendless, dependent, dissipated and vicious consumptives…likely to be most dangerous to the community" (Biggs, 1904, cited in Lerner, 1997: 1424). Thus, the realisation that social factors play a fundamental role in the spread of tuberculosis is not new. However, efforts to control, and even eliminate the disease are almost solely based on biomedical solutions.

Illustration 2.2: Public health poster used in New York in the 1930s.[9]

For critical medical anthropologists, disease is a social and biological production. An understanding of both processes, and a historical perspective, are needed to understand social diseases. Biomedicine traditionally sees disease as a thing in itself, as an objective factor observed on an individual basis, and not as a cultural construction. Accordingly, there is little need to contextualise disease (Singer, 2004: 9). As John Janzen notes, "all topics and issues come together in the body, a site of experience, control, resistance, articulation, and identity" (2002: 44).

2.11 The technology of tuberculosis treatment: Biomedicine as ideology.

Biomedicine is not free from ideological or cultural beliefs. The power of biomedicine is manifested in the clinic environment, and is expressed both as ideology and action (Singer, 2004: 13). Stambolovic points out that "scientific medicine is an institution" and the larger the gap between the expert definition and actual patient experience, the larger

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[9] http://www.nlm.nih.gov/exhibition/visualculture/tuberculosis.html (accessed 03.12.06)

the feeling of alienation and powerlessness on behalf of the patient (1996: 301-2). Thus, the biomedical system itself is entrenched within a structure of inequality.

Howard Waitzkin introduces the terms of micro and macro level interactions in relation to medical discourse and patient interaction. Medical encounters tend to consist of micro level individual interactions. Macro level structural processes influencing these micro interactions as well as the cause of the disease itself are seldom taken into account. Thus, Waitzkin continues, not only do the social issues themselves not receive attention, but the ideological messages conveyed through the medical encounter tend to support the existing social order, although mostly unintended (Waitzkin, 1989).

Rather than including social issues in the doctor-patient encounter, technical statements are used to direct the patient's description of signs and symptoms as well as the course of illness. As a result, it is these signs and symptoms that are given attention, not the wider structural context from which they result. However, Waitzkin emphasises, this is not due to inadequacies on the part of the doctor, rather "this *lack* is a basic part of what medicine *is* in our society" (*ibid*.: 232).

Arthur Kleinman has been criticised for not giving the dynamics of power sufficient attention in his studies of clinic interactions. Although Kleinman notes that patients and healers act within a given health care system, he, and the cultural interpretative model he introduced, have been criticised for focusing on patient/practitioner relationships without seeing them as actors in a wider context of power and particularly unequal access to this power (see Pappas 1990; Singer, 1990; 1995).

It is necessary, both for the anthropologist and for the health professional, to acknowledge that knowledge, including biomedical knowledge, should be regarded as a cultural construct and not a truth *per se* (Pelto & Pelto, 1997: 147). It is our task, as Singer argues, not only to understand medicine, but also to challenge and change it (1990: 185). It is not the case, as is often argued within the biomedical paradigm, that anthropology makes for "interesting stories" whereas epidemiologists and biomedical practitioners present the "real stuff" (Heggenhougen, 2000: 1171).

Nancy Scheper-Hughes, in explaining an interpretive and post modern approach, argues that “the body, illness, disease and death are seen as simultaneously biological and social” (1996: 891). The multileveled social and economic processes identified throughout this thesis are played out in the bodies of the sick. Thus, social processes cannot be separated from bodily processes.

Biomedicine has value and a therapeutic mandate which anthropology does not have (Chrisman & Johnson, 1996: 92). In fact, Margaret Lock and Nancy Scheper-Hughes argue that one of the biggest challenges for medical anthropology is “to come to terms with biomedicine, to acknowledge its efficacy when appropriate while retaining a constructively critical stand” (1996: 44). As evident throughout this thesis, people need to have access to and to adhere to biomedical therapy in order to be cured from tuberculosis. However, biomedical interventions alone are insufficient in curing people of their ills.

The blind faith in biomedicine’s power is obvious in narrow statements such as: “Tuberculosis is one of the straightforward diseases we have to deal with as medical practitioners” (Enarson, 2000: 57). Tuberculosis is a disease likely to occur in certain social contexts. To understand and combat the disease it needs to be critically unpacked. Paul Farmer acknowledges that biomedicine is “vulnerable to be deformed by ideology” (2005: 235). If biomedicine is an ideology, the link is even more direct (see Singer, 2004: 13). However, it is important to note that this biomedical ideology is practised by individuals, each with a different take on its role and, perhaps more importantly, how it is practised in the clinic environment.

Throughout the course of my research I have been trying to come to terms with the realisation that in order to cure TB, TB patients *must* complete their biomedical treatment, and I have been encouraging them to do exactly that, while I at the same time have been faced with my own inability to both diagnose TB both in terms of tests and examinations (and I have often been asked by patients to do both) as well as prescribe the life saving drugs.

2.12 “2+2= more than 4”: The concept of a syndemic.

Merrill Singer and Scott Clair have introduced the term “syndemic” to describe and explain the “synergistic interaction between two or more coexistent diseases and resultant excess burden of disease” (2003: 423). Whereas biomedicine often sees each disease as a separate entity, clinically identifiable, the term syndemic enables us to see the “big picture”, consisting of interacting biological and social factors. In a syndemic, although it is emphasised that *actual* biological interaction between the diseases occurs, the term points to “the determinant importance of *social conditions* in the health of individuals and populations” (Singer & Clair, 2003: 428). Ultimately, social conditions may be more important than the nature of pathogens in the infected bodies (*ibid*.). Biomedicine, as structured today, cannot cure the underlying social causes of syndemic processes, they have to be dealt with outside of the clinical environment.

The synergistic interaction between multiple diseases increases the total burden of disease. As has recently been discovered in South Africa, a new extreme drug-resistant strain of TB, XDR TB,[10] has emerged in HIV positive patients. All XDR patients were initially identified as HIV positive.[11] The first press reports in September 2006 commented that 52 of 53 infected patients died within weeks of becoming infected (McKie, 2006). XDR patients are reported to die very rapidly, usually within 25 days of infection (Makhubu, 2006: 1). By the end of November 2006 over 300 TB patients in South Africa had tested positive for XDR. Ten of these reside in the Eastern Cape (Thom, 2006: 5). As part of a syndemic, XDR TB will have disastrous and fatal effects on people and health care in South Africa and even poses a threat to world health. At the time of the emergence of XDR TB in South Africa there was no therapy available in the country. The extreme drug-resistant strain has spread to all provinces in the country, being prevalent in almost 10% in all tested MDR TB cases (Makhubu, 2006: 1). As will become evident as this thesis progresses these two diseases entities, TB and HIV, both thrive in similar conditions and share similar socially predisposing factors.

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[10] XDR is defined as a TB strain which is resistant to the first line drugs rifampicin and isoniazid as well as three or more of the six second line of TB drugs, one of which is fluoroquinolone http://www.doh.gov.za/docs/reports/2006/xdr-tb/index.html (accessed 03.10.06).

[11] http://www.doh.gov.za/docs.pr/2006/pr0822a.html (accessed 03.10.06).

Co-infection with HIV and TB does not present the patient with symptoms of these two diseases only. As Singer and Clair point out, and which is also the experiences of informants in this study, the combination of poverty, discrimination and suffering results in stress for the patient which again leads to early disease progression for the HI virus in the patient (*ibid.*: 430). In addition, it is reported that an HIV positive adult with no symptoms needs 10% more food energy than a HIV negative person (Boseley, 2005: 8). This, however, is a situation where there is likely to be less food available due to the likelihood of loss of employment for the infected. Through syndemic interactions, co-infected people generally look, and are, sicker than people only infected with TB. Again, we see the complexity and multifaceted nature of syndemic processes. There is an urgent need to address social factors in addition to biomedical factors in order to combat diseases. Diseases as a result of syndemic interactions cannot be cured by biomedicine only.

In medical circles there is often a perception that people usually do not have to deal with more than two illnesses or poverty related crises at the time (Kleinman *et al.*, 1997: xi). *All* the case studies I have done so far indicate that this is in fact *not* the case. Not only are TB and HIV “twins”, as a nurse at Temba remarked, but both diseases thrive in situations of poverty as well as escalating the suffering by turning employed individuals into unemployable people. The diseases do not affect individuals only, but households and the wider community.

In Grahamstown, the increased emergence of synergistic interactions must be explored in a context of disempowerment, poverty and inequality. Among the HIV positive patients in Grahamstown taking ARVs through the government programme, more than 50% of the patients the doctors see are co-infected with tuberculosis. In South Africa 66% of all TB cases are co-infected with HIV (MacFarlane, 2005: 1).[12]

2.12.1 The HIV/TB syndemic and stigma.

The relationship between TB and HIV necessitates the consideration of stigma, since HIV is a disease associated with high stigma, whereas among the black population in the

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[12] Recent research has found that there may be a syndemic relationship also between HIV and leprosy (McNeil Jr., 2006: 5).

past TB was not particularly stigmatised due to its common occurrence among this section of the population. One needs to consider how this syndemic has altered the stigma attached to TB. The most straight forward definition of stigma in terms of impact on patients is probably that of a social response resulting in "additional suffering beyond the symptoms" (Weiss, 2001: 19). Although this is a useful definition, it does however leave out relations of power on a structural level. Goffman, defined stigma as "an attribute that is significantly discrediting" serving to reduce the person possessing these attributes (1963, cited in Parker & Aggleton, 2003: 14). A stigmatised infectious disease such as tuberculosis can also be seen simply as a disease which "inspires fear in others due to the risk of infection" (Jaramillo, 1998: 139).

Studies of illness related stigma often explore stigma as something that happens between people in a community, leaving out larger contexts of power and powerlessness. The term stigma, Link and Phelan argue, can be applied when "elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (2001: 367). Stigma is a complex social process and must be seen neither as static nor as occurring only between individuals in a local community. Stigma is relational occurring through relations of difference, where stigma results in a reproduction of these relations of difference. However, the concept of stigma cannot be seen *only* as simple binary oppositions between "normal" and "abnormal" or "desired" and "undesired".

It is essential, as this study clearly shows, to look at stigma not only as occurring between individuals as members of a local community, but also to understand stigmatising processes as occurring on a larger scale, also based on difference, allowing stigmatising to take place. In addition to allowing stigma to unfold, the situation of unequal relationships of power also sustain, or even increase these same power differences as stigmatised and marginalised people are less likely than others to challenge these structurally based differences (*ibid.*). Stigma is not exclusively played out in a limited relation to micro level "difference", but more so in relation to structural inequalities, also based on difference, stigma is played out in a broader political economy of exclusion.

In their study of stigma and access to ARVs among HIV positive children in Brazil, Abadia-Barrero and Castro use a framework of structural violence and argue that "structural violence in the forms of poverty, racism, and inequalities in social status, gender and age" fuel the experiences of stigma (2006: 1219). These discriminatory processes, they continue, also have a negative impact on the *right* to health care (*ibid*.).

Link and Phelan criticise research on stigma as only focusing on any one particular circumstance at a time (2001: 381). The limitation of this one-sided approach is relevant in this study where HIV/AIDS and TB are linked, not only in terms of medical symptoms and biological processes, but also in terms of stigma and discrimination. Social diseases such as tuberculosis show that we need to not only include other *diseases* in our analysis, but also other societal factors such as relations of global and local inequalities, rights to health care, violence, media, social networks, employment relations and attitudes and priorities within the health care system. As a result, we need to move away from a narrow psychological approach to the study of stigma.

Whereas my initial intention was to discuss TB related stigma in a dedicated chapter, the analysis of fieldwork data proved that the nature of the experience of stigma is integral both to people's explanatory models and therapy managing groups. As a result, issues of stigma are specifically incorporated in these two chapters.

2.13 Multiple afflictions in impoverished households.

All the people either living with or cured of or who have died from tuberculosis that I have spoken to in this study, come from a context of poverty. This is not a coincidence. Biomedically, the external physical determinants of risk of infection are the amount of droplets coughed into the air combined with rate of ventilation (Farmer, 2005: 181). As is clear throughout the ethnography, afflictions rarely occur independently. Entire households are affected and experiencing increasing syndemic social and economic interactions as a result.

When Eric's mother was in a car accident on her way to an Easter Church function in Port Elizabeth, I had to lend Eric R250 so that he could go and see her in hospital. Receiving a relatively good salary, Eric makes R 1500 a month, so a high proportion of his salary went to management of his mother’s health. In addition, Eric spent money on management of his HIV infection, resulting in spending perhaps 25% of his total salary on therapy management without even being able to invest anything in prevention of illnesses or accidents or medical aid. He has to take one full day off a month, just to fetch his ARVs.

At one ARV Committee meeting a nurse from V. Shumane clinic presented the following three cases, all with CD4 counts below 200:

1. A woman in her 40s has a husband who died of tuberculosis due to his advanced stage of AIDS. The woman does not have TB now, but has previously been on treatment and is cured. Her CD4 count is very low.
2. A 5-year old boy is cured of his tuberculosis. He completed his treatment in December 2004, when he was three years old. His mother has HIV, but her CD4 count is still high and above the critical limit of 200. The father of the child is unemployed and does not live with them.
3. A 7-year old boy who lives with his granny as his mother died of AIDS related infections. They do not know where the father of the child is.

All of these cases highlight not only the link between HIV and TB in the individual, but also show that these diseases do not affect only individuals, but groups of people living in a structurally limiting context. As a result or maybe as a cause of these illnesses, social relationships are disrupted. Household incomes are not available in these particular examples, but experience shows that they are likely to be very low. The failure of biomedicine to see sick people as groups of people entrapped by a wider context of inequality which results in further sickness and marginalisation is evident throughout this thesis. Seeing sick people as part of a global context of inequality is a challenge practitioners of biomedicine need to meet in order to deal with diseases such at tuberculosis.

2.14 Risks, poverty and inequalities in South Africa.

South Africa can be seen as a middle income country in terms of per capita income. However, this income is not evenly distributed among the population. The Eastern Cape is one of the poorest provinces in the country. 14.4% of the country’s total population live in the Eastern Cape, whereas only about 8% of the GDP is generated here. The per capita income in the Province was R 6774 in 2000, whereas the national average in the same year was R 12 411 (SSA, 2003, in Provide Project, 2005: 7).

The province has the highest poverty rate in the country. The levels of poverty and inequality are unacceptably high. Using the European Union's definition of poverty, namely living on less than the national average, it is clear that the average in the Eastern Cape is to be poor. The province has a high level of both poverty and relative inequality. Using Wilkinson's theory of the relationship between poverty, inequality and sickness (1996; 2005), this may serve as part of the explanation as to why the level of illness is high in the province too.

Poverty can be measured in terms of employment and access to an income. In South Africa, the unemployment rate is between 26.7% and 41%, depending on how narrow a definition one chooses to use (Boyle, 2006). Regardless of definition, the figures are not only unacceptably high, they are an indicator of how badly equipped people are to deal financially with increasing health related costs to life.

In Cacadu, the District which Grahamstown falls under, the strict unemployment rate in 2000 was 30% whereas the expanded unemployment rate was almost 40%. The figures are likely to be higher now (SSA, 2003, in Provide Project, 2005). The big difference between the two can be explained as "structural hopelessness" as it may reflect the fact that people have simply given up searching for jobs. This is reflected in the expanded definition of unemployment. None of the unemployed people in this study, and I must have spoken to about 50, had actively looked for employment in the 28-month period during which the research was conducted. As participants in this study have low levels of education, their prospective employment opportunities are in sectors needing manual labour such as the building industry or at the local brick making factory in Grahamstown. The nature of these jobs is strenuous, further limiting opportunities of finding employment for people with or cured of tuberculosis, which are in most cases still physically weakened.

Even amongst those lucky enough to be employed, levels of poverty are high. According to the report *Migration and Domestic Workers: Worlds of Work, Health and Mobility in Johannesburg* published by the Southern African Migration Project and Wits Palliative Care, more than 20% of South African domestic workers earn less than the minimum wage with a fifth earning less than R 500 pr month. The report also states that the domestic workers' lifestyles, largely due to their sacrifice of personal relationships as a result of migration, put them at high risk of contracting that HI virus (Groenewald, 2005). As we can see from this, poverty exists on different levels and is fundamentally structural and extremely difficult to escape from, even with full-time employment.

Household or personal income predicts mortality risk, "with each additional dollar of income conferring a slightly smaller decrease in the mortality risk" (Blakely & Wilson, 2006: 2024). In Cape Town the relative risk of developing tuberculosis for deprived and non-deprived people is 53% to 2% (Yach & Harrison, 1995, in Stephens, 1999: 473). To the extent that the Cape Town figures can be used of an example of differences in South Africa as a whole, we can see that the inequalities between the rich and poor in terms of risk of developing tuberculosis are immense. South Africa is sub-Sahara's wealthiest country, but at the same time it is the country where the HI virus has spread faster than in any other country in the region. As a result, the TB rate is sky rocketing. The primary reason for this is the persistent social inequality in the country (Farmer, 2005: 45). This inequality has fundamental structural causes related to both the health system and the wider and historically grounded political economy.

Lionel describes the manner in which he experiences poverty as being "hungry for money". Meanings of poverty and inequality at individual and community levels are expressed through the ethnography of illness management and experiences presented in this thesis. A low material living standard does have psychological factors, resulting in increased stress for the have not's as it is *relative* poverty, and not exclusively absolute poverty, which increases stress levels (Wilkinson & Pickett, 2006: 1775). As this research shows; inequalities in health result from environmental, social, cultural and financial factors as well as genetic and biological factors. As a result, in order to combat health related problems, such as tuberculosis, we need solutions inclusive of all these levels.

When I mentioned issues of poverty and inequality and their connection to tuberculosis, to receivers of health care, I was met with a mixture of surprise and resignation. I also found that people attempted to analyse their own personal experiences and connect them to wider factors in their environment, but never beyond what they could see and experience directly. I realised that it was expected of me, and that it became my responsibility, to give people a space, even if it was only in our conversations, for them to explore their pasts, presents and futures in order to regain some sort of control over their lives. Sometimes I was requested to make these connections public in sharing them with the health care providers, nurses in particular, by whom many patients felt silenced. Empowerment of patients both to participate in the analysis of their lives as well as shape the analysis themselves is an essential task for the medical anthropologist. Although recent developments in medical anthropology analyse patient experiences in a global context, patients themselves seldom participate in this level of analysis. We have a responsibility to allow "local actors [to] comment on and engage with global processes" (Nguyen & Peschard, 2003: 463). However, people did not comment on the invisible structures of inequality. They have more than enough to deal with in focusing on how they are going to survive. Hence, the structural violence which has a major impact on people's lives and agency are, in Bourdieu's term, symbolic.

Anthropological approaches and models such as Kleinman's explanatory model and Janzen's therapy managing group are valuable in exploring illness management. However, when looking at a social disease such as tuberculosis, as well as exploring syndemic interactions between TB and HIV, it is argued that they are best used in combination with more macro related approaches such as critical medical anthropology. Throughout the thesis the usefulness of Paul Farmer's approach of structural violence to issues of health and risks to sickness, as well as suffering, and Richard Wilkinson's analysis of the relationship between inequalities and health in analysis of tuberculosis in Grahamstown is shown.

Chapter 3.

Clinic interactions in a global world.

Is curing tuberculosis in individuals sufficient a strategy for the overall control of tuberculosis in a population?

Pronyk & Porter, 1999: 109

…that is also medicine, if people treat you nicely.

Yvonne, tuberculosis patient at Middle Terrace Clinic

3.1 Introduction.

This chapter first explores global, national and local strategies for the management of tuberculosis and how these impact on the delivery of health care at the clinic level. As this thesis is arguing from a structural violence perspective a brief review of how health policy at the various levels is influenced and shaped by global processes needs to be considered, particularly as it relates to TB epidemiology and management. An important concern relates to the problems in accessing affordable drugs in the context of World Trade Organisation constraints.

As Directly Observed Treatment – Short-course (DOTS) is the main component of the World Health Organisation strategy to stop TB, this chapter examines how it is applied in South Africa at the various levels. It is argued that although this standardised strategy enjoys a certain amount of success, additional intervention strategies are needed in impoverished communities with high co-infection rates and the increasing incidence of drug resistant strains of tuberculosis. With the recent appearance of XDR TB, the need for an integrative approach to TB care is more apparent than ever.

It is further argued that biomedical interventions, based on a paradigm that perceives each disease as a separate entity occurring in the body, are alone insufficient in dealing with multiple social diseases such as TB and HIV. With the advent of democracy in South Africa a new constitution was introduced guaranteeing all South Africans the right of access to health care services, social security, and to life. As shown throughout this thesis, we have a long way to go before these rights are realised in South Africa.

The chapter then focuses in on the structure and function of the clinic system in Grahamstown which is the main site of TB care and DOTS delivery. Patient/therapy management group interactions with practitioners in the clinical environment are also examined. It is shown that these interactions occur in a context of escalating sickness in the communities and an increasing workload for staff in clinics and hospitals, limiting action at all levels.

3.2 From Global to Local – The application of the WHO Stop TB Strategy.

The World Health Organisation (WHO) was established nearly 60 years ago in April 1948 and is the United Nations agency for health. WHO's objective is the attainment of the highest possible level of health by all peoples. In the WHO constitution, health is inclusively defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".[13] This is mainly to be achieved through global programmes, such as DOTS, the global strategy to stop TB, designed by WHO experts and implemented to various degrees in member states. The World Health Assembly is the main decision-making body for WHO, meeting in Geneva in May each year. The World Health Assembly is attended by delegations from all 193 Member States. Its main function is to determine the policies of the WHO and propose and approve specific programme budgets.[14] Although the WHO plays a crucial role in global TB control as it does in managing and controlling other diseases, it is not responsible for funding or organising national health budgets. The WHO performs an advisory role to national governments when needed.[15]

The Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) is an independent public-private partnership, of which the WHO is a part, established in 2002 to work towards increasing funding to fight these three diseases in countries with the greatest need and to contribute to poverty reduction as part of the Millennium Development

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[13] http://www.who.int/about/en (accessed 27.11.06).

[14] http://www.who.int/governance/en (accessed 27.11.06).

[15] J.M. Rwangaboba, pers. comm., 12.12.05.

Goals. The Fund will support efforts in prevention, treatment, care and support of the infected and directly affected that complement existing programmes and/or activities.[16]

In 2000 the Stop TB Partnership was established to realise the goal of eliminating TB. It comprises a network of international governmental and nongovernmental organisations, of which the WHO is the most important, and countries, donors from the public and private sectors and individuals that are committed to work together to achieve this goal.[17]

In 2006 the WHO/Stop TB partnership launched their Global plan to stop TB 2006–2015. The main aims of the plan are briefly summed up below:

1. DOTS expansion (see section 3.2.2 below).
2. Addressing TB/HIV and drug resistant strains of TB through increased focus on high risk groups such as prisoners and collaborative TB/HIV activities.
3. Contributing to a general strengthening of health systems.
4. Engaging both public and private care providers.
5. Empowering people with TB and communities with high rates of the disease through social mobilisation and public participation in TB care.
6. Enabling and promoting research to develop new drugs, vaccines and diagnostics (WHO, 2006b: 36).

According to the WHO, full funding of this plan (USD56 billion) will lead to 14 million lives saved and curing 50 million people of tuberculosis. Importantly, the plan also aims to reach one of the Millennium Development Goals which is to halt the incidence of TB, and begin to reverse it, by 2015 (*ibid*.: 16). The plan is also a step on the way to the WHO goal of eliminating TB by 2050 (*ibid*.: 23).

The global plan states that "the association between poverty and tuberculosis is well established" (*ibid*.: 45). The plan suggests the poverty in TB control can be addressed through six steps. These steps include assessment of the health system, cultural and socio-economic barriers to care and the combating of these barriers in addition to a specific focus on vulnerable groups such as HIV positive, prisoners and refugee

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[16] http://www.paho.org/English/HCP/gfatm.htm (accessed 27.11.06).

[17] http://www.stoptb.org/stop_tb_initiative/ (accessed 29.11.06).

communities (*ibid.:* 47). The targets and strategies expressed in the global plan are ambitious. Nonetheless, the plan states that although the standardised DOTS strategy leads to better access to health care for the poor, DOTS is in most cases proportionally more expensive for the poor than for non poor (*ibid*.: 46).

3.2.1 DOTS – The centrepiece of the WHO Strategy

Briefly, the main components of the DOTS strategy as outlined in the Global Plan to Stop TB 2006-2015 are:

1) Government commitment to a national TB programme.
2) Case detection through passive case finding.
3) DOTS for all smear positive pulmonary TB cases.
4) Uninterrupted supply of essential anti TB drugs, and a system of programme monitoring and evaluation (WHO, 2006b).

The World Health Organisation is working on an extended strategy called DOTS Plus in which treatment of multi-drug resistant strains of TB and TB in HIV positive people are dealt with specifically (see WHO, 2006b: 35-42). The next chapter presents how the DOTS strategy is being executed in South Africa. Through the ethnography, it is shown that there are certain challenges in terms of how the South African government has chosen to execute DOTS. The purpose of DOTS is self–evident and involves the direct observation of a patient swallowing his/her medication by another designated person on a daily basis. The aim is to increase adherence and avoid drug resistance.

Although DOTS is commonly seen as increasing the cure rate of tuberculosis (see Dudley *et al.*, 2003; Kironde & Neil, 2004; Wright *et al.*, 2004), surveillance of the patient swallowing the pills can be seen as both alienating and authoritarian and it has been recommended that the use of DOTS should be reconsidered (Zwarenstein *et al*., 1998: 1343). While this thesis does not question DOTS as the foundation of the national TB programme in South Africa, it is argued that the DOTS strategy needs to be extended in areas with high rates of co-infection and drug resistant strains of tuberculosis, both of which escalate costs of medication and increase rates of expensive hospitalisation.

The cost of curing a patient of tuberculosis through hospitalisation is three times higher than through community based DOTS (Wilkinson & Squire, 1997: 1395). There are also significant social and economic consequences of hospitalisation for the patient through loss of income and alienation from the community. In addition, hospitals are becoming increasingly dangerous for immuno-compromised patients due to antibiotic resistant organisms, giving patients nosocomial infections.

DOTS is a standardised strategy with few considerations as to varying local conditions and demands. Structural and poverty related issues are not considered. Porter *et al.* (2002) point out that TB control needs to change from a global desire to find a “gold standard” for TB care to also directly address the relationship between global inequalities and the spread of tuberculosis. The authors argue that this top-down standardised approach to TB control must be challenged (2002). It is problematic that DOTS as mapped out by the WHO is seen as *the only way* to deal with tuberculosis at global, national and local levels. As mentioned, this limits the ability to deal with syndemic interactions as are increasingly experienced in South Africa.

The DOTS strategy is patient focused and does not take into account the important role of social support in influencing patient adherence to therapy and cure rates in general (Lienhardt & Ogden, 2004: 835). The important role of social capital in therapy management is explored in chapter 6.

Although indigent patients in South Africa have free access to TB treatment, there are major costs involved for the sick to reach cure. Rights of the sick differ according to social and financial standing, rooted in historical structures of ethnic, social and financial inequality. The poor and, more often than not, African, section of the population is, as they have been since the arrival of Europeans at the Cape, seen as needing assistance in looking after themselves. Hence, they are victims of increased control in the health care system. In reality, due to their marginalised situation in society, they need more, rather than less, flexibility in managing their sickness. The ethnography throughout this thesis shows how people are marginalised in their employment situation and in many cases either lose their jobs as a result of illness or give up their jobs themselves as their employment conditions do not allow for the flexibility needed in order for the sick to visit the clinic every day to adhere to treatment.

Despite endorsing the DOTS strategy (see DOH, 2000) the government has failed to clearly articulate a policy on the use of volunteers under the DOTS programme. This is explored in more detail in the next chapter.

3.2.2 Access to affordable and effective medication.

Uninterrupted supply of essential TB medication is one of the main components of the DOTS strategy. Supply of medication to clinics and hospitals in Grahamstown is generally good, although there have been cases where patients have come to DOT in the clinics and one or more of the essential drugs have run out. At the time of writing, three months after the XDR outbreak was recognised by the Department of Health, third line drugs are still not available to the public.

Virtually no new TB drugs have been developed in the last 30 years (Nofemele, 2006: 1). Despite 2 million TB related deaths every year, in the last 28 years prior to 2000 only one new anti-TB drug came on the market (WHO, 2000). Out of the 1393 new medicines registered in the US and Europe between 1975-1999, only 16 were for “tropical diseases” afflicting people in developing countries. Rather, transnational pharmaceuticals focus their research on expensive “lifestyle” medicines aimed at the developed world. Pharmaceuticals are profit driven rather than public health driven (Global Health Watch, 2005: 102).

According to a survey of pharmaceutical companies conducted by WHO, one of the main reasons for this lack of interest in development of TB drugs is the high investment needed combined with a lack of perceived economic gain. The pharmaceutical companies also reported that as a cure for TB already exists, they were not interested in further drug development, particularly as TB is as good as extinct in developing countries where governments would have been able to afford new technology (WHO, 2000:1-3). Notwithstanding this, in their Global Plan to fight TB 2006-2015, the WHO spells out that if the plan is fully funded, they aim to achieve the first new TB drug in 40 years by 2010 and achieve a new TB vaccine by 2015 (2006: 18).

Perhaps surprisingly, the WHO report suggests that in order to create an enabling environment for the development of new TB drugs

> …the WHO should be pressuring governments to place value on financing tuberculosis drugs, where possible, and strongly encouraging them *to protect and enforce international patent laws* (WHO, 2000: 3, my emphasis).

In this case, the WHO is siding with the transnational pharmaceuticals, emphasising the importance of patent rights in protecting inventions and investments as a means of encouraging further inventions and investments in the development of new drugs. Intellectual Property Rights are an integral part of the agreement on Trade Related Intellectual Property Rights (TRIPS), part of the World Trade Organisation agreement in 1994. Through their powerful lobby the pharmaceuticals have managed to have patent laws, and the discriminatory monopoly of knowledge, included as an agreement in an organisation preaching free and so-called indiscriminate trade.

Rather than protecting powerful financial interests as the WHO suggests, Global Health Watch recommends the pharmaceutical research should be financed through publicly supported research centres committed to public health and social considerations rather than profit making through commercial trade (2005: 112). The tuberculosis medications used in South Africa are listed in appendix 1.

3.2.3 National Government Commitment to TB eradication.

The South African strategy is limited in scope and does not recognise tuberculosis as a social disease demanding a holistic and inclusive approach encompassing interventions outside of the clinical environment. From 1997 through to 2000 the real government spending (taking inflation into account) on health care in South Africa rose by less than 1% annually (Harsch, 2001: 16). The national health budget for 2005/06 was R9.8 billion, an increase of 11% from the previous year's budget. For the 2006/07 financial year the budget was increased to just over R11 billion.[18] In the context of the increasing

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[18] Minister of Health Manto Tsabalala-Msimang's 2005 and 2006 budget speeches. http://www.health-e.org.za/resources/budget_health.php & http://www.pmg.org.za/briefings/priefings.php?id=283 (accessed 04.10.06). If annual inflation is taken into account, the annual increases in the health budget are minimal.

burden of HIV and opportunistic infections such as tuberculosis these budget allocations are at best insufficient.

Despite their efforts to rectify many of the past inequities of the previous apartheid health system there are still challenges with regards to management of health care at provincial level. During most of the time of this research the Eastern Cape Health Member of the Executive Committee (MEC) failed to address health related challenges in the province and was fired from his position in April 2006. In 2002 he faced over a thousand charges of corruption and took nine months paid leave in his period of MEC to deal with these.[19] The Eastern Cape Department of Health is also facing problems of massive under spending. In 2001, R328.4 million allocated from the National Department of Health was not spent and had to be sent back (Thom, 2002a; 2002b). Although this is a result of the lack of commitment towards service delivery to the poor (*ibid*.), under spending is caused by lack of capacity to absorb funds at all levels in the province.

3.2.4 Dealing with the syndemic.

> *We are not a TB hospital anymore, we are an AIDS hospital.*
>
> Matron at Temba TB Hospital

Approximately 30% of HIV positive people undergoing TB treatment in sub-Saharan Africa die within 12 months of starting their treatment. About 25% of those who do survive treatment die during the following 12 months (Murray *et al.*, in Harries *et al.*, 2003: 120). In simple terms, the official WHO strategy to the syndemic is: “Two diseases, one patient”. As is evident throughout this thesis, TB control can only be achieved through HIV control. In Grahamstown, the number of patients on re-treatment is increasing. This is generally not due to non adherence demanding increasing control of the patient, but to cured people with compromised immune systems who are re-infected with tuberculosis. Dealing with the underlying causes of high rates of tuberculosis, a preventive and inclusive approach focusing on rights to health is needed.

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[19] http://www.health-e.org.za/news/easy_print.php?uid=200331412 (accessed 04.10.06).

The national tuberculosis programme is explored in some detail in the next chapter. Suffice here to note that there is a fundamental lack of willingness and capacity in the Department of Health to address syndemic interactions. Even as recently as March 2006 our minister of health, Manto Tsabalala-Msimang, failed to mention HIV in her annual World TB Day speech.[20] However, the minister does agree that it is problematic that a curable disease such as TB is "stealing the lives of men, women and children" when "all it takes is six months of taking the treatment correctly on a daily basis".[21] How she explains these unnecessary deaths of a curable disease without realising the importance of addressing HIV remains unclear.

3.2.5 Case Detection.

In Grahamstown, passive case finding based on sputum testing seems to be working well, but with escalating rates of drug resistant tuberculosis (which cannot be detected through smear, but only through sputum culture and drug sensitivity tests or DST) and co-infection resulting in higher rates of smear negative pulmonary TB cases (Médecins Sans Frontiéres (MSF)), 2005), this is proving to be inadequate. A more forceful approach to case finding, using different diagnostic measures, is necessary. In addition, in a meeting concerning XDR, the WHO recently recommended that DST must be accelerated in resource-poor settings (2006c: 9).

There is a disproportionate increase in smear negative pulmonary tuberculosis in people with HIV infection (Harries *et al*., 2003: 116). According to Médecins Sans Frontiéres (MSF), only 20-60% of HIV positive pulmonary TB patients are smear positive (MSF, 2005).[22] The co-infection rate in South Africa is 50-60%.[23] This is the case also among TB patients in Grahamstown. The number of cases going untreated is increasing. Because the DOTS approach is target driven, detection of smear negative cases not targeted tend to go unnoticed. It is necessary to redefine and broaden the DOTS strategy in countries with a high HIV prevalence to diagnose and treat TB in HIV positive people.

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[20] http://www.doh.gov.za/docs/sp/sp0324a-f.html (accessed 24.04.06).

[21] http:// www.doh.gov.za/docs/sp/sp0324-f.html (accessed 24.04.06).

[22] Unpublished report, no page number available.

[23] Dr Kate Hodges, pers. comm., 10.02.2006.

3.3 The structure and function of TB care in Grahamstown.

The Eastern Cape provincial Department of Health receives its funding from the national Department of Health, as do the other provincial departments in the country. The province then enters into a "service agreement" with the district municipalities, funding them according to census. However, the census in Cacadu may be as much as 25% under enumerated.[24] The Eastern Cape is divided into ten district municipalities, one of which is Cacadu. Cacadu is split into sub-districts, or Local Service Areas (LSAs) which again are made up of municipalities. Grahamstown is the centre of both Makana municipality and Makana sub-district/LSA, which also includes towns such as Alicedale, Alexandria, Port Alfred and Bathurst (see map in appendix 3).

The provincial Department of Health in the Eastern Cape has a TB directorate. This particular directorate does not devolve authority onto district structures so the Makana LSA therefore falls directly under the provincial TB directorate. Plans are however in the pipeline to create a TB directorate/department at district level.

The Department of Health in the Makana LSA is organised on a programme basis, just as other levels of the national health hierarchy and international organisations such as the World Health Organisation are. Apart from the TB programme, there is an ARV programme, a nutrition programme, a programme for non infectious diseases, one for chronic diseases, one for mental health, and a health promotion programme. There are twice monthly programme meetings where programme managers report on their activities. There is little actual cooperation across the programmes. After drawn out formalities, programme managers report on workshops and meetings they have attended in addition to a few interventions at clinic level such as the establishment of the first MDR support group in the country – a great pride of the local TB manager. There is an urgent need for more outcome based reporting – and action.

Clinic staff recognise that many TB patients are also HIV positive. However, few clinics systematically offer HIV testing for TB patients. Although this occasionally does happen,

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[24] M. Whisson, pers. comm., 15.11.06.

it is much on an *ad hoc* basis depending on individual nurses' initiative. The nurses themselves are struggling to cope with a rapidly escalating work load.

Tuberculosis patients often receive care from non governmental organisations (NGOs) working with HIV/AIDS. The Raphael Centre in Grahamstown works with people living with HIV. They employ ten people and cater for 20 patients at a time, teaching them life skills over a seven week period. Many of these have or have had tuberculosis in the past. The centre is located in a previously white residential area of town, enabling those who feel stigmatised in their communities to seek care without having to be afraid of being recognised. Women are the primary users of the services.

The Grahamstown Hospice has 37 people employed in Grahamstown and Port Alfred and caters for approximately 200 patients at any one time. They mainly do "end stage" care, but also hand out food parcels and assist people with their grant applications and wills. Although they receive some government funding, they survive mainly on private donations. The Hospice previously focused their care on chronic diseases and cancer specifically, but now AIDS patients make up 75% of their clientele. Most of these either have or have previously had tuberculosis.

The South African National Tuberculosis Association (SANTA) was responsible for the training of DOTS volunteers until 2004 when the provincial Department of Health took over and later sub-contracted this to an East London based organisation called the Small Project Foundation (SPF). Due to lack of provincial government funding and commitment, the provincial SANTA office in Grahamstown had to close down in 2005. SANTA's role in TB care is looked into further in chapter 4, sections 4.2.1 and 4.2.2.

The role of traditional healers in TB care is explored in limited detail in chapters 5 and 6.

3.3.1 Clinic organisation in Grahamstown.

There are six government clinics in Grahamstown. Apart from Town Clinic in the town centre, these clinics are located in areas inhabited by a marginalised section of the population. Four clinics, namely V.Shumane (previously called Tantyi), Raglan Road, Joza and Extension 7 have an extremely impoverished clientele and each have a big case load with 50-100 TB patients at all times.[25] Approximately 20% of these are re-treatment cases. Middle Terrace, located in the previous coloured area of Grahamstown, has approximately 40 cases, as has Day Hospital which is run by Province and works closely with Cacadu LSA. Day Hospital is responsible for patients in the rural areas surrounding Grahamstown. It also has a dental clinic. Town Clinic has from 0-10 TB patients. Extension 7, the clinic covering the area of most informal settlement, has the biggest MDR case load.

At all the clinics TB patients walk past the line of other clinic users and form a separate queue to go into a separate room. This is to ensure that their visit will be quick. They do not need to see a nurse as they are already diagnosed. This separation in the clinics does create some sort of stigmatisation as people in the "slow lane", as the normal line is called, often assume that those in the "fast lane" have HIV, a highly stigmatised disease. This "information" is often spread in the communities. Clinic personnel have been quick to recognise this, and at some clinics inform the slow lane about the organisation and about HIV and TB on a regular basis. With the increasing burden of illness confidentiality in the clinic is a luxury.

Below are two clinic diagrams illustrating the manner in which DOTS is organised in clinic spaces.

3.3.2 Raglan Road Clinic

TB patients go directly to the waiting room on the left. They are given their medication over the counter between the waiting room and TB office. When the few TB patients who have not been DOTed by 9 o'clock move to the other room, this room is used for ante natal and infant health care – another indication of the constraints of clinic care.

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[25] See map in appendix 3. Government clinics are circled in blue. Eight clinics are circled as one of them is a satellite clinic of Joza which is not open every day. Day Hospital is also circled as it is used as a clinic in the same manner as the municipal clinics even though it is run by the provincial Department of Health. Hence, there are eight circles but only seven government clinics (one provincial and six municipal).

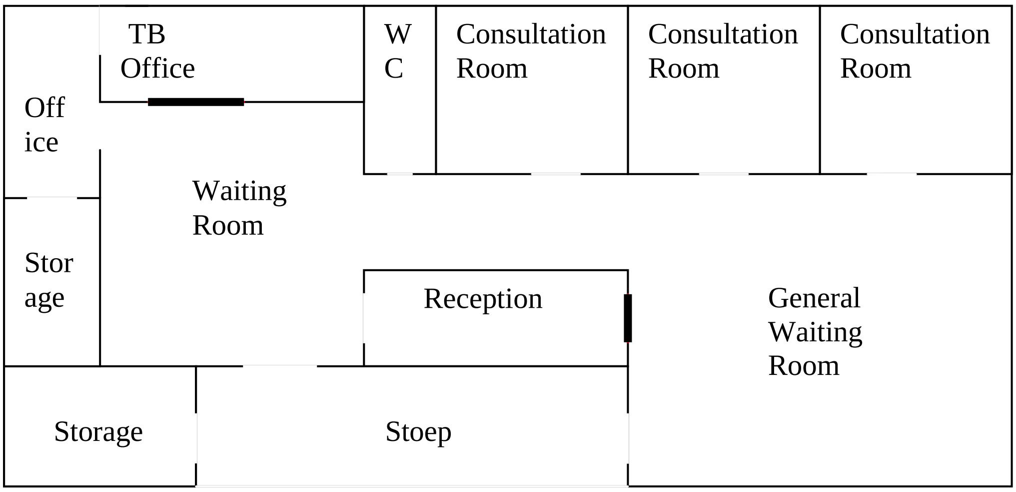

Diagram 3.1:

The main building at Raglan Road Clinic. Bold lines represent counters where patient/practitioner interactions take place.

General clinic visitors know that tuberculosis patients receive care in a specific area of the clinic. From the stoep, also used as a general waiting room, they can see into the room where patients are DOTed.

3.3.3 V.Shumane Clinic.

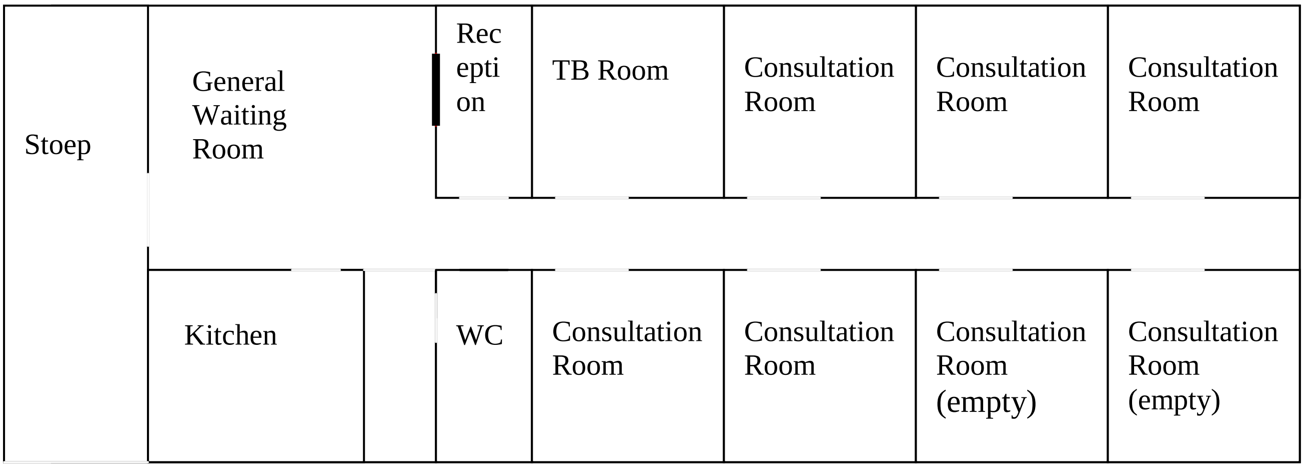

Diagram 3.2:

V.Shumane Clinic. The bold line represents the counter where patient/practitioner interactions take place.

There is no waiting room specifically allocated to TB patients at V.Shumane. Instead, patients wait for their turn in the actual room allocated to tuberculosis patients. This is also the case at Joza and Extension 7 clinics. Apart from the absence of a counter separating patients from practitioners, this is similar to the organisation at Raglan Road Clinic. In order to get to the TB room, patients have to walk through the general waiting room at the clinic. Again, TB patients are visible to those waiting in the slow line.

At all the clinics, volunteers DOT patients. They do this from when the clinic opens at 07h30 until approximately 10h00, by which stage most clinic patients have taken their tuberculosis therapy. The volunteers then go out on home visits to DOT patients in the community. On Fridays they try to visit those who did not adhere to therapy in the previous week.

Whereas patients bring their own bottle of water to swallow their pills at Joza Clinic, they use cups and water provided by the clinic at the other clinics. After use, patients rinse them briefly in water and put them to dry, ready to be used by other TB patients. When patients are DOTed at Raglan Road, they use the same cup which they dip into a bucket of water as there is no tap immediately available. It may be that tuberculosis bacilli can be transmitted through use of unwashed cups (Vecchiato, 1997: 192), but according to one Grahamstown doctor the chances of reinfection are “slim”, although it cannot be ruled out altogether.

Patients generally prefer to be DOTed in the clinic rather than at home. It is well-recognised that if neighbours see a Community Health Worker at someone’s home, it is assumed that this person has HIV. In areas with endemic unemployment people spend much time gossiping in their homes and yards. Gossiping is an important factor leading to inclusion/exclusion in the community. As discussed, it is also not unproblematic to visit the clinic daily. Once patients are too sick to go to the clinic, they are either transferred to Temba or DOTed in their homes. Regardless of the type of direct observation used, the patient is at risk of societal stigmatising attitudes.

3.3.4 Patient/practitioner interactions.

Practitioners are commonly known to exhibit attitudes of moral superiority. According to one doctor, conflicts are increasing in patient/practitioner relationships because patients now have information from radio and TV and can dispute the authority and knowledge expressed by practitioners. He comments that: “There is a shift in authority, as people now dare to challenge nurses’ authority. Community Health Workers [volunteers] have a more caring attitude than nurses.” Although this research found that some volunteers are uncompromising in their interaction with patients, they are mostly found to be understanding, helpful and caring. Relationships between nurses and patients are more often problematic than between volunteers and patients.

Yvonne, who was DOTed in her home by a supportive Community Health Worker from Middle Terrace Clinic, says that the nurses are impatient and get easily angry with people. “Patience”, she says, “is the most important thing for a nurse to know, and when they get angry with you at the clinic, then you don’t feel like coming again.”

Below are two examples of patient/practitioner interactions at Temba Hospital highlighting conflicting approaches to the meaning of care and patient rights.

Ronnie: Ronnie was given eight pills every morning, but had not been told by clinic staff what they were for. Visiting him, I asked him how his health was as the doctor had examined him earlier that morning. Ronnie answered that: “She examined me, but she didn’t tell me anything. Why do doctors never tell you anything?”

The following morning Ronnie asked me to look through his file to find out what these eight pills were for and for how long he was going to take them. When I asked the nurse to see the file, she did not object to me wanting to access confidential information (as I had expected she would do). Rather she asked: “Why does he want to know when he finishes his treatment? Why does he need to know? What does he want to do? I will call him in here tomorrow and then he can ask his own questions.”

I asked Ronnie why he does not simply have a look at the file himself: “No, sisi, then they will give me some tablets so that I will fall asleep and never wake up again! They don’t like people asking questions and making trouble for them.” Ronnie felt no ownership over his own medical history, a representation of his life while he was in hospital. All decisions concerning his life were made, by someone other than himself, on the basis of that file.

The end of this conflict came a few days later. As the nurses were doing the rounds with medication, Ronnie turned to me and, like a naughty school boy, whispered: “When they turn around and leave the file at my bed - have a quick look at it!” I did and found that apart from tuberculosis medication, Ronnie was given a sedative every morning, probably as he was experiencing some extreme worry due to his medical and social condition. The manner in which Ronnie was treated clearly goes against the patients’ charter for tuberculosis care outlined below.

Moses: Superior and arrogant attitudes are common among clinic staff and nurses in particular. Numerous times I have witnessed nurses degrading both patients and their family. Once Moses had extreme back pains and his mother was massaging his back to ease this pain. Doctors at Settlers Hospital had given him a prescription for morphine, but the nurse at Temba Hospital did not want to give it to him, even after Moses, his mother and I had explained the situation and the nurse herself had seen Moses’s face of agony. She shouted at us: “Do you know what morphine is!? It is a drug, so it is not good for him.” She left Moses with his pain and only gave him the prescribed medication hours later, after having made the point that it was her, and not us, deciding if and when a patient gets medication.

Despite what the doctor above observed, it is found that it is difficult for patients and their families to challenge nurses’ ways of thinking about patient autonomy and the role of therapy managing groups in healing. Schneider and Gilson point out that “authoritarian systems of management are dominant across the health system. ‘Inspection’ is the norm rather than ‘capacity building’” (2001: 11, cited in van Rensburg, 2004: 365). Patients and their therapy managing groups are structurally disadvantaged and seen by nurses as being ignorant, not knowing what is best for the sick. Patients and their families are aware of this, but rather than openly challenging health workers, distance themselves saying, as Moses's mother did, "there is no use anyway, they [the nurses] don't care" as a way of protecting themselves.

As already mentioned, the empowerment of people with tuberculosis and enhancing community participation in TB care is a central aim of the global plan to stop TB 2006-2015. In addition, the global plan's aims express the need for a patient charter for TB care (WHO, 2006b: 36). In fact, such a charter outlining the rights and responsibilities of people with tuberculosis has recently been put together by the National Tuberculosis Centre at the University of California and is available at the WHO web site. This charter includes rights concerning access to information of available treatments as well as personal medical records, patient confidentiality and rights to free and equitable care. As a means of dealing with the relationship between poverty and adherence, the right to nutritional security or food supplements are emphasised. Patients' obligations are outlined as including sharing of information with health workers, completing treatment and contributing to community health.[26]

3.3.5 Increasing workloads in the clinics.

However, bad practitioner attitudes do not explain the high rates and unequal distribution of tuberculosis in Grahamstown, nor can frustration among practitioners be blamed on them alone. Health workers are not only demoralising, they are also demoralised (Walt, 1999: 81). At Middle Terrace Clinic, which has a smaller workload than most other clinics, the nurses each see up to 60 patients every day, almost twice of what is recommended by the Department of Health. They have been offered stress counselling, but need more staff. One nurse commented: "It won't help talking about it. You are not appreciated until you are not there anymore. It just makes you more stressed. I am up to my ears in stress."

Dr B sees 16 patients per hour on his weekly clinic round.[27] The four minute consultations include the use of an interpreter and a small icebreaker comment, particularly with children. The doctor briefly flicks through the patient's file and asks a

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[26] http://www.who.int/tb/publications/2006/istc_charter.pdf (accessed 29.11.06).

[27] Dr B works part time for the municipality, seeing patients in the clinics. He is also the general practitioner for municipal employers and runs his own private practice. M.Whisson, pers. comm., 27.11.06.

few questions such as “how long have you been smoking for?” or “have you been tested for HIV?” or “do you feel better now?” before he listens to the patient’s chest. He then briefly explains the diagnosis and fills in the disability grant form if necessary (see chapter 6). Patients rarely ask questions, and look timid as they enter the consultation room.

Walt argues that “possibly the most important actors in the tuberculosis story are those at the local level – the patients, their families, and the health professionals with whom they come into contact” (1999: 79). Although Walt does not take structural political and economic complexities into account, it is a fact that there is a serious shortage of health workers in most of sub-Saharan Africa, impairing the provision of health care and treatment of HIV, malaria and tuberculosis. Africa has 24% of the world’s burden of disease, but only 3% of the world’s health care workers and 1% of the global health expenditure (WHO 2006 annual report, in Benjamin, 2006). Migration of skilled health workers from developing to developed countries is also a major challenge facing health care. Each year between 1998 and 2004 approximately 1500 South African nurses applied for registration in the UK alone (Nullis-Kapp, 2005: 85). In 1997, South Africa lost R67.8 billion in human capital investment in the health sector (Chanda, 2002: 160).

In South Africa, almost two thirds of all doctors work in the private sector serving 9 million people whereas the remaining third serve 25 million people (Harsch, 2001: 18). Annual per capita expenditure is six times larger per patient in the private sector compared to the public sector (Marais, 2006: 21). These disparities clearly impact on TB control on the continent, and again we can see that this challenge cannot be solved through medications. The message from Global Health Watch (2005: 117) is clear:

> Not only are the health care systems of developing countries under-resourced and over-burdened, but they face having their most precious assets poached and drained away by the pull of rich country health care systems.

Grahamstown clinics have been promised more nurses to deal with the increasing burden of sickness. In 2006 each municipal clinic was promised one additional full time nurse to be paid by the provincial Department of Health. At the same time however, the provincial Department of Health increased the responsibilities of the clinics to include chronic and psychiatric patients.[28]At Temba Hospital, which is the responsibility of the provincial Department of Health, they went as far as advertising for the three nursing posts promised by the Department of Health. After they had conducted interviews and decided whom to appoint, the Department of Health withdrew the approval for the posts and no one was appointed.

Nurses' efforts have shifted and rather than curing people of their ills, they do their best to keep people alive for as long as possible while the sick slowly get weaker. Their training did not prepare them for this and they are experiencing chronic exhaustion with no end in sight.

As is the case for patients, nurses' rights are also infringed upon. There are numerous stories of nurses who have asked authorities for their long overdue annual leave, only to be told to wait until next year. Not only does this create high levels of stress and increased absenteeism among nurses, but the quality of patient care is compromised as a result.

The failure of the government to speed up the delivery of ARVs is another major issue. There is a backlog of people with CD4 counts below 200 needing antiretrovirals in the sub-district, but nurses simply don't have time to prepare and present them for treatment to staff at Masonwabe ARV Clinic at Settlers Hospital. At the weekly ARV review meetings the social worker at the programme used to present a detailed social report of each patient, but this is no longer possible due to the increased need for ARVs among people living with HIV. Consequently, the social aspect of sickness is neglected and poverty related issues such as household income, need for nutritional supplements and social grants, are not given sufficient attention. As a result of ignoring social aspects of sickness and healing, the fundamental causes of disease and ways of healing are not adequately addressed.

Lack of resources in the health sector has a major impact on the lives of the sick and their ability to get well. Practitioners are forced to make *public health decisions* based on

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[28] M.Whisson, pers.comm., 21.11.06.

available resources, rather than *clinical decisions*, based on medical need, due to limited resources. Often necessary tests are not taken as they are expensive, draining the system further. Lack of resources robs patients of their rights to care.

Administrative staff in the LSA are often not working in conjunction with clinical staff, nor are they sympathetic to the problems they face. The crises in TB care specifically and the health system generally is complex:

> …low work morale, lacking work ethos and failing productivity have detrimental effects on patients, staff and entire organisations alike; in the health sector these detrimentally affect courtesy, accountability, ethical conduct, responsiveness and caring health workers (van Rensburg, 2004: 367).

3.4 The role of global institutions.

Throughout this thesis the ethnography shows that the WHO slogan "Health for all" remains an illusion in Grahamstown. The WHO is crucial in combating tuberculosis and other infectious diseases. However, political constraints put the organisation outside of important arenas where decisions are being made, determining the outcome of efforts to control the disease (Gandy & Zumla, 2003: 11). Rights to health are related to education, to trade, to employment and to security.

Global institutions such as the World Trade Organisation (WTO), the World Bank (WB) and the International Monetary Fund (IMF) influence health and health care even though this is not their focus as such. Decisions made in these institutions are first and foremost based on short-term financially profitable solutions. The number of votes a member nation of the IMF is allocated is related to how much money that particular country has invested in the Fund.[29] As a result, rich nations are more likely to benefit from decisions made by the Fund than poorer nations.

With the escalating power of these institutions, their influence on national policies increases concurrently. It is becoming progressively more difficult for South Africa to withstand global pressures. No more than one year after the ANC was voted into power in South Africa they were pressured by the IMF and WB to limit regulations on foreign

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[29] International civil society organisations term the voting allocation "one dollar-one vote".

business and increase rates of privatisation. In the following year the Reconstruction and Development Programme (RDP) was dropped in favour of the new macroeconomic framework Growth, Employment and Redistribution Programme (GEAR) embracing a "competitive, fast-growing economy" (Harsch, 2001: 13). Reductions in state expenditures are central to the philosophy of these organisations.

Global Health Watch argues that economic globalisation worsens global health (2005: 10). However, the negative impact these institutions have on health does not mean that they should be excluded from the arena. These powerful institutions are here to stay. Rather, organisations such as WHO, UNICEF and other UN agencies working with health related issues should attempt to influence these institutions to also prioritise health in trade related negotiations (*ibid*.: 355). Reforms in the global financial system are needed in order to improve global health. For African countries to be able to get themselves out of the poverty trap they must be allowed to implement economically favourable and protective policies which in the current global market are not approved of, but which is the way in which most European countries stabilised their economy in the post war years.[30]

Social and financial inequalities in South Africa are increasing. Not only do these inequalities lead to social exclusion making economic upliftment progressively more difficult for the marginalised, but support for redistributive social policies is generally decreasing (Deaton, 2001; Gough, 2001, in Global Health Watch, 2005: 19). This is highly problematic in South Africa where such programmes are in dire need. Public confidence in the government's capacity to perform its duties is diminishing. In fact, in October 2006 South African media reported that the minister of health herself was admitted to the private wing of a Johannesburg hospital.[31] This is a clear indication that public health in South Africa is suffering, lacking both financial and human resources in order to provide the sick with appropriate care.

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[30] When Norway discovered oil in the North Sea, for example, they imported "know-how", but did not contract any companies which were not focused on transferring this "know-how" to Norwegians thus ensuring that the wealth remained in the country to benefit all inhabitants. This positive discrimination is illegal today and countries attempting to exercise this can be sued by companies as not upholding the rule of "free trade" (see the TRIMS – Trade-Related Investment Measures - section of the WTO agreement).

[31] http://www.zahealth.blogspot.com (accessed 26.10.06).

3.5 Conclusions.

Porter and co-workers point out that “although tuberculosis is associated with poverty there are few signs of health care providers working with other sectors like agriculture, defence, education or town planning” (1999: 268). Social diseases challenge the almost exclusive focus on disease management – and cure rather than prevention – at clinic level and demand an approach focusing on socio-economic aspects of sickness. Although management and prevention of illness must be given clinical focus (Kleinman, 1980: 382), this is insufficient in managing tuberculosis. Health care providers feel, and are, relatively disempowered in relation to the politics of the provision of health care. As is evident in this thesis, an integrative, holistic and structural approach is necessary to challenge and combat the high tuberculosis prevalence in South Africa. This requires political commitment at international, national and local levels. If not, the crisis among overworked and under appreciated staff will increase beyond its current situation of despair.

Disease control programmes need to be sensitive to “existing structural relationships and social dynamics, particularly among those most marginalised groups in a society” (Pronyk & Porter, 1999: 100). While this is true, it is perhaps more important to *challenge* these structural relationships of inequality if we wish to combat social diseases such as tuberculosis.

Chapter 4.

"They work for peanuts": Experiences of voluntary Community Health Workers working with tuberculosis treatment delivery.

4.1 Introduction.

This chapter presents the ideology of Primary Health Care and community participation in the newly democratised South Africa. TB care delivery and community DOTS (Directly Observed Therapy-Short course) through the use of voluntary Community Health Workers (CHWs) is presented. The nature of volunteerism and the motivations of the volunteers in Grahamstown are explored. It is argued that a government practice based on the use of volunteers is an unsustainable approach to TB care in a context of growing rates of tuberculosis, co-infections and drug-resistant strains.

In Grahamstown patients can be DOTed by clinic staff or volunteers at the nearest clinic, or by a voluntary CHW in their own or the volunteers' homes. Often, patients start off in the clinic and, if they are proved to be reliable patients, continue to take their treatment in their homes, where they are visited by a CHW once a day, which brings medication and observes the treatment being taken. Although the volunteers also have responsibilities in the clinic concerning nutrition, HIV/AIDS care and counselling, and do home visits for chronically sick patients, their role as DOTS supporters is the focus of this chapter.

This chapter is less 'anthropological' than the following chapter as much of the information used stems from a questionnaire conducted with the volunteers in mid-2005. However, volunteers' interactions with patients are also observed to great detail.

4.2 The ideology of Primary Health Care and Community Health Workers.

The term "Community Health Worker" has been used since the 1980s, after a decade long discussion in the WHO and UNICEF about health care. Prior to that, "primary health workers" or "village health workers" were used (Walt *et al.*, 1990: 17 & 21). At the WHO Alma-Ata Conference in 1978 "Health for All by the Year 2000" was adopted as the global slogan and it was to be achieved by means of a comprehensive Primary Health Care approach. The use of CHWs was seen as an integral part of achieving this.

The training of community members to participate in health care was part of a broader development ideology aimed at empowering communities. The CHWs were to provide health education and assist in the treatment of diseases (*ibid*.: 20 & 26). Most CHW programmes ignored the structural distribution of power and wealth (*ibid*.: 26). As shown throughout this thesis, this is still the case. In apartheid South Africa, talk of community empowerment conflicted directly with the ideology of the oppressive state.

The WHO recommends that "NTPs [National TB Programmes] should consider harnessing community contribution to TB care where there is the need to increase access to effective TB care" (WHO, 2001: 4). Thus, TB care is an integral part of Primary Health Care Programmes. Details of community participation in the provision of the DOTS service is left to the discretion of the national departments of health. Voluntarism is not emphasised by the WHO.

The core aim of the WHO strategy using the comprehensive PHC approach was that health care would become easily available, accessible, affordable and acceptable. The CHWs role was to facilitate this. In present day South Africa, community involvement in health care, and specifically in HIV/AIDS and TB care, is part of Primary Health Care (PHC) where Community Health Workers play a central role in health care delivery. However, the role of volunteers as community workers is not specified in the national policy. With respect to TB care in South Africa, Westaway and Wolmarans argue that: "Providing a service that is available, affordable and accessible does not automatically lead to acceptability" (1993: 543). Acceptability is, they continue, intricately linked with patient compliance with the TB treatment (*ibid*.: 546).

Van Rensburg *et al.* point out that community involvement and participation is being implemented in South Africa today as a mechanism to counteract apartheid oppression. The authors argue that "through community involvement and participation, this new era in health care has contributed to the acceptability, accessibility and quality of health care" (2004: 163). However, there is no formal evidence in policy that voluntary health workers are formally recognised as part of this strategy. Indeed, their involvement seems to stem from forces outside of government structures rather than from government programmes or policy makers.

The National Health Act of 2003 states that one of the general functions of the national Department of Health is to "promote community participation in the planning, provision and evaluation of health services" (21; 2: h). Hence, although community participation is acknowledged, the voluntary nature of this, which is a fundamental component of DOTS in South Africa, is not given recognition. Furthermore, in the section on TB in the Government's Strategic Priorities for 2004-2009 DOTS is not even mentioned, never mind community participation or the voluntary nature of it (DoH, 2004: 9 & 10). In the general section on Primary Health Care, the National Department of Health (*ibid*.: 8) verbalises challenges of

> finalising the funding of municipal health services, providing full funding for primary health care based on the cost of providing a package of PHC services; eliminating fragmented services provided by provinces and municipalities; strengthening quality of care at PHC level; and strengthening community participation in the governance of PHC services.

Admittedly, although this could possibly include providing formal paid employment of DOTS volunteers, there is no guarantee from the National Department of Health to do this. Likewise, the National TB Control Programme emphasises that "treatment supporters are best recruited as part of a community based system…treatment supporters should work closely with local health authorities" (DoH, 2000: 10). The government has not acknowledged volunteers' role in health care delivery, nor is it taking responsibility for their training or continued involvement. This is a significant omission, if that is what it is, because, as this chapter shows in some detail, the volunteers play an invaluable role both in the care of TB patients and the administration of TB drugs.

4.2.1 What is a volunteer CHW?

There are almost as many different definitions of a CHW as there are national PHC programmes of which they are a part. Without going into great detail, it is emphasised that the role and definitions of the CHWs have changed over time, according to national programmes and the role of government ideology in nation states. Whereas CHWs in some countries are remunerated, others work on a purely voluntary basis (see Dudley *et al*., 2003; El Ansari & Phillips, 2001; Kironde & Klaasen, 2002; Ross Hill *et al*., 2002).

The term “community” is in itself problematic. What is a community? What does it mean to be a member of a community? Can one be a member of many communities at the same time? How does membership change over time? Does a community have clear boundaries? Are communities separate, static and unchangeable entities? A definition which is used both by UNAIDS and WHO is rather vague: “A group of people who have something in common and will act together in their common interest.” The definition states that: “many people belong to a number of different communities – examples include the place where they live, the people they work with, or their religious group” (UNAIDS, 1997, cited in WHO, 2001: 6). In this context it is useful to look at “the community” as a geographic area in which patients and volunteers live and which consists of a geographically bounded area falling under various clinics’ areas of responsibility. Theoretically, volunteers are to be chosen by the members of the community in which they live and provide care. In practice this is particularly difficult in urban areas where there is little unity in kinship, local history or leadership.

In selecting volunteers health authorities emphasise that the volunteers have to live in the same area as the one which the clinic covers. Practically, this makes follow ups and home visits much easier. It may also decrease the level of stigma and increase the level of empathy. This is an extract from my field diary illustrating the close connection, and the need for this, between volunteers and patients both in terms of geographical space and experiences of illness.

> *Jackie’s brother died of an AIDS related illness four years ago. This motivated her to become a volunteer. She also has an uncle who was on TB treatment and later defaulted (he lived in the same area, but in a different street). Three houses down from where Jackie lives, lives a mother with her 18-month old boy, Willow, on TB treatment. Willow’s aunt, who is also on TB treatment, lives next door. (She has a son a few streets away who was on TB treatment, but did not adhere to therapy, saying it was his “own business”.) Another four houses down the road, in a shack behind somebody’s RDP house, lives Megan (4) who is on TB treatment. She lives with her mother, stepfather and 5-month old baby brother. Both Megan’s parents have HIV, but she has not been tested. Her body is so small it almost disappears. When I stroke her back, my fingers almost go through her. She is lost in her too big clothes. Jackie sees the patients every day. If they are not at home, she tries again later on the same day.*

Not only does this example show that one of the motives to become a CHW is through sympathetic shared suffering but that CHWs are likely to know many fellow sufferers in their area. TB is transmitted in close networks in geographical by small and underprivileged areas. This is a context of action which must be taken into consideration when people’s health seeking behaviour and interaction with health authorities are investigated.

Up until 2004, the South African National Tuberculosis Association (SANTA), as well as different other independent organisations such as St Johns Ambulance in Grahamstown, was training voluntary Health Care Workers to work in the DOTS programme. SANTA’s objectives are relatively holistic and include concern about all matters related to care of the patient and his or her contacts or dependants. In addition, SANTA supports anti-tuberculosis work and the spread of information aimed at preventing and curing the disease (Ginwala & Collins, 1991: 275).

SANTA in the Northern Cape has specific criteria used in selecting “the ideal volunteer”. The characteristics include: literacy, fixed home address, living nearby patients, ability to respect confidentiality and a willingness to serve the community (Kironde & Neil, 2004: 506). Although SANTA in the Eastern Cape does not have set criteria, these qualities were looked for in their volunteers.

In her study of health care in the rural areas of the Transkei and Ciskei (while they were still “independent” homelands in South Africa), Julia Segar (1992) refers to voluntary CHWs as “Voluntary Health Workers” (VHW). Kironde and Kahirimbanyi (2002) term the voluntary CHWs involved in TB care in the Northern Cape “lay volunteers”. It has previously been stated that Community Health Workers can either be paid or work on a voluntary basis as a part of Primary Health Care Programmes. Thus, the voluntary health workers focused on in this study could rightly be termed Community Health Workers. Voluntary health workers may be an appropriate term, but I choose not to use it as it is not used in the local context. Although the CHWs in this article do not have extensive formal training, I find the term “lay volunteers” problematic as it discredits them their extensive experience as health care providers.

Here, I choose to vary the terms used as that seems to be the norm among people working in the system. The volunteers can be called exactly that: volunteers. I am nonetheless aware of the complexities connected to this. The volunteers themselves as well as nurses and organisational staff in the sub district call them volunteers or Community Health Workers. Locally, they have also been termed DOTS volunteers, but, as they do perform other functions than simply DOTing patients, I find “volunteers” or “CHWs” wider, but at the same time a more accurate term to use. Darvill & Munday (1984) define voluntary activity as “unpaid work, which is done for, or through some sort of group or organization to one or more persons to whom the volunteer is not related” (in Merrell, 2000a: 32). The fact that all the volunteers receive a stipend from the government and therefore are not volunteers in a pure sense indicates that CHW may be a more accurate term than volunteer.

4.2.2 The volunteers in Grahamstown.

There are about 4000 DOTS volunteers in the Eastern Cape. These have been trained by the South African National Tuberculosis Association in the province, SANTAEC. However, due to lack of government funding, the SANTAEC office was closed down in July 2005. Not only did the closure leave ten staff unemployed, but it also left no one responsible for the training of more volunteers. With an increasing burden of disease and workload for nurses in the clinics, it is recognised by all involved in health care in the Makana sub-district that more volunteers or paid staff are needed.

The Provincial Health Department in Bhisho decides by whom and with how much financial resources the volunteers are to be trained. In early 2005 it was decided that organisations would have to tender for resources to train volunteers. An East London based non governmental organisation, the Small Project Foundation (SPF) won the tender and is now responsible for payment of the volunteers. However, the training is the responsibility of the sub-district/LSA and is in the process of being updated and standardised. This process is expected to take a year or more and all volunteers have to go through a 69-day course organised by Cacadu in order to be formally recognised and allowed to work as volunteers through the clinics. Their stipend will be increased from R 600 to R 1000 per month after they have completed training. By mid-2006, there was no show of commitment at LSA level to conduct training of new volunteers.[32]

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[32] Grahamstown Hospice also has people working for them and receiving the R 600 stipend, but the Hospice consider these employed as they have a contract, structured time and use Hospice facilities and equipment. In addition to this, they have unpaid volunteers.

Although the voluntary CHWs are formally responsible for tuberculosis and DOTS, they also perform other duties such as weighing babies and taking blood pressure as well as being part of patients' support network and serving soup to TB patients DOTing in the clinic. Their responsibilities vary slightly between the various clinics depending on how many patients are DOTing in the community and in the clinic, the case load at clinic level and the nature of the relationships between nurses and CHWs.

The volunteers have a commitment to patients and to the convenience of the patients. This is also felt by patients who contact them after hours. Thandi, a CHW at V.Shumane Clinic, told me that "they also come in the evenings if they are sick and even highjack me on the way to Church on Sundays." They are, in other words, valuable not solely as providers of health care, but in *the manner in which this is done*. Paid nurses do not even have time to see patients as people and not merely as patients. Volunteers in the health sector bring "their own unique qualities including personal and life experiences which enhance the nature of the service provided" (Merrell, 2000b: 101).

Many volunteers are aware of this. However, whereas they see their job as valuable and necessary, and the nurses depend on them to do this job, many do not see their skills as something nurses *don't* have. One volunteer said that "We don't really have [biomedical] skills that they [the nurses] don't have…then again, we are quite good in the community." The undervaluing of their skills can be understood in the context of the biomedical paradigm where increasing skills and status is followed with a greater distance from the patient.

4.2.3 The demographics of the volunteers.

Age and level of education among the volunteers are similar. The majority are under 40 years. 17 volunteers are between 20 and 30 years of age, 15 are between 31 and 40 years old. Only five are between 41 and 50 years old. All volunteers have finished standard 5 (Primary Education). 31 of these left school between standard 6 and 10 (Secondary Education), whereas five have some sort of tertiary education.

Level of education	No of volunteers
Some primary education	1
Some secondary education	31
Some tertiary education	5
TOTAL	37

Table 3.1:

Volunteers' level of education.

These findings are similar to Kironde & Kahirimbanyi's findings of education level among DOTS volunteers in the Northern Cape (2002: 21). The volunteers are generally in the most productive age of their lives where they should be either establishing or be at the top of their careers. However, for them this is far from the case.

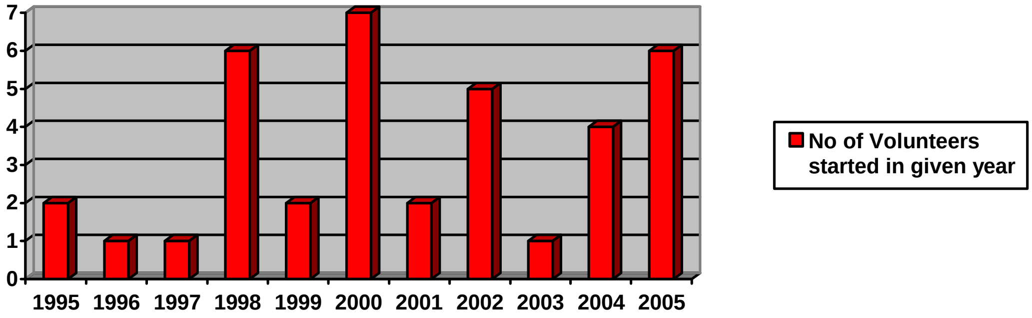

Table 3.2:

Year in which the volunteers started volunteering in the clinics.

As we can see from this, 19 volunteers (51%) started before or in the year 2000 and have been volunteering for between five and ten years. This is significant, as it includes more than half of the volunteers working now and amounts to extensive experience. The average time a volunteer has worked at the clinic is five years. The range is 11 to one year. According to the memory of the volunteers, few have left while they have been there. The turn over is low. Thus, the volunteers are committed to long-term service despite their disappointment of not being adequately remunerated.

4.2.4 Volunteering as gendered work.

The fact that volunteers are predominantly women must be considered. Traditionally, a woman's role has been that of care giver – to her husband, her children and her parents. Thus, it is not surprising that there are significantly more women than men volunteering in the health sector. Of all the municipal clinics in Grahamstown, there is only one male nurse.

In Grahamstown 29 (78%) out of the 33 volunteers working through the clinics are women. All five of the volunteers at the local TB hospital are women. This number corresponds with the number SANTAEC operates with. The reason given by one employee at SANTAEC is that "they care more about the people. Women are the only ones willing to help out with this problem of TB – they make the world go around."

However, reasons given by the volunteers as to why this may be the case differed. One reason given was that more women than men are sick. However, evidence shows that slightly more men than women in Grahamstown have TB. In Kironde and Kahirimbanyi's study from the Northern Cape, 93% of the DOTS supporters are female whereas only 41% of the patients are (2002: 21). Thus, although the volunteers feel that more women than men are sick, this may not be a true reflection of reality.

Other reasons the volunteers gave for the unequal distribution of gender in their voluntary work were linked to the gendered roles in the household, where men are said to think that looking after sick people is "women's work" or a waste of time as there is no payment. These are reasons why men are seen, or see themselves, as "too good" or unsuited to do voluntary work and look after sick people. It was argued that women are more active and work harder than men and that they are more caring than men. Women also saw themselves as powerful as they had the skill to look after people as well as seeing themselves as righteous, gaining "at the end of the day". One volunteer said that: "It's care, love, dedication and respect that you get from females and something to stand up for – what you are doing."

As we can see from this, the volunteers see their commitment and motivations as highly gendered. The following sections will look at the motivations of the volunteers in more detail.

4.3 Working relationships.

New volunteers often knew someone already working as a volunteer. Also, the friendships established through volunteering together are important for the volunteers. This was also found in a study of volunteers in England (see Merrell, 2000c: 467). Community Health Workers share experiences and support one another in difficult times. Some do home visits together. The friendships, many have expressed, will continue even if they stop volunteering together.

Studies by Hoad (1991) and Field *et al.* (1997) found that significant tensions were found between volunteers and paid staff, nurses in particular, when volunteers participated in direct patient care (see Merrell and Williams, 1999: 490). Contrary to this, I found that, in Grahamstown, where the volunteers participate in direct patient care, this does not seem to result in tensions between them and the nurses in the clinic, but seems to be beneficial for all involved. It is known by all what their responsibilities are.

There is a relationship of mutual support among nurses and volunteers at the clinics. There is no record of nurses seeing volunteers as a threat to their authority, or volunteers feeling that their importance is downplayed or not appreciated by the nurses. Although this is appreciated by the volunteers, they have on the other hand articulated that they feel that they do lack support and understanding from the health authorities in the sub-district and from the provincial government.

It may be useful to look at Merrell and Williams's concept of "synergy" in this context. Synergy means "working together" and is derived from the Greek term "sunergos" (*ibid*., 490). A synergistic pattern "brings phenomena together, interrelating them, creating an often unexpected, new and greater whole from the disparately, seemingly conflicting parts" (Katz: 1984: 202, cited in Merrell & Williams, 1999: 490). In Grahamstown paid workers and volunteers working together has resulted in mutually beneficial experiences and outcomes concerning patient care and personal relationships between the volunteers and nurses. Tensions are minimal and are not seen to have any significant impact on personal relationships nor on patient care.

4.3.1 A culture of volunteerism as a motivating factor.

One of the employees at SANTAEC claimed that there is a “culture of volunteerism in South Africa”. By this he meant that voluntary, or unpaid, work is common in communities. There are no statistics available on this, simply because “volunteerism” is such a broad term and may include making coffee in Church, organising school functions for children, DOTing your neighbour, etc.

About a quarter (9/37) of the volunteers themselves know family members or friends who have volunteered. 30 of the volunteers themselves had done no voluntary work before. Of the ones who had done voluntary work, only one had been volunteering in the health sector. The remaining six had volunteered in the police force, school governing council, the ANC and for the municipality.

Almost half of the volunteers (16 out of 35)[33] come from households where one or more members have been dependent on help from Community Health Workers. Of these 16, a total of 14 said that this influenced their decision to become volunteers themselves. Although these volunteers do not come from a context of volunteerism, it is clear that the role of volunteers have influenced them to become volunteers. This can be seen as a culture of volunteerism.

It is the volunteers themselves, through their contribution to health care in the community, who reproduce the system of community health care based on volunteerism and a culture of willingness to work as volunteers in the health care system. Bearing this in mind, it is essential to make the volunteers feel that their efforts are appreciated. If not, this may have serious implications for the sustainability of the system. However, motivations of the volunteers do not simply boil down to previous experiences with community health care workers or other voluntary work, but include a variety of other factors.

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[33] Two respondents did not answer this question.

Literature on voluntary Community Health Workers has not looked into volunteers' lack of alternatives to voluntary work. Where history of employment *is* linked to motivations, literature has either focused on previous work experience of the volunteers (see Merrell, 2000a) or the exploitation/lack of remuneration of volunteers (see Merrell 2000a; Kironde & Kahirimbanyi 2002; Kironde & Neil 2004; Taggart *et al.*, 2000). No focus has been given to the fact that the volunteers have *no alternatives* if they wish to work. In Grahamstown, many volunteer because there simply is no other work. In an area where the unemployment is endemic, the volunteers are expressing a paradox between hope and despondency and a social commentary on the failure of the state to provide employment now and in the future.

In the survey, volunteers were asked how they see their working future in the next ten years. Significantly, a total of 26 (70%) did *not* answer the question. Seven answered that they see their future as "bright" and/or "successful". Only two respondents saw themselves as having a job. Thus, it seems that many of the volunteers simply have no hope of ever receiving employment in the next ten years.

4.3.2 "I like to work with people, to help them." Altruism as motivation.

On the surface, altruism seems to be the most important reason for people doing voluntary work. As motivations for the DOTS volunteers Kironde and Klaasen studied, altruism was one of the most frequently given motivations. However, the authors go on to say that the volunteers thought that funds would be released for them and that "hope for eventual remuneration was found to be the strongest factor motivating youth to join the programme". When this did not happen, the novelty of participating wore off (2002: 104 & 106). Thus, there are motives other than altruism at work. This is also noted by Merrell who writes that altruistic reasons may be over-reported as they are "…viewed more favourably by society than egoistical motives, such as furthering one's career or gaining skills" (2000a: 34).

The volunteers studied by Angela Taggart *et al.* said that they had "time to give to a personal project" and wanted to "help in their community" (Taggart *et al.*, 2000: 4). As the volunteers have time available, they feel that it is better to be doing something for the community than to sit at home “and do nothing”. How, it can be asked, is it possible for people to volunteer if they have no regular income?

There are benefits to volunteering. All TB patients who DOT at the clinic get soup and bread before they take their treatment, as it is not supposed to be taken on an empty stomach. The volunteers often join the patients. I also observed one volunteer using this bread for her daughter’s lunch box at school, so the volunteers do find incentives for themselves, even if these are minimal.

None of the volunteers in Grahamstown live alone. 20 (54%) of the volunteers have children and live with them. For each child below 14 years of age the mother receives a child grant of R180 a month. About half of the women live alone with their children and half live with other members of their family such as siblings, aunts, uncles or parents. Most of these have a parent with an old age pension or a disability grant (R 780 per month) and/or a sibling with a job. Mary, a volunteer, explains her situation: “I support my baby [two year old boy] with the grant. My brother works as well; we live with him and my sister. The child’s father also pays R 200 a month. They [her family] know that there are no jobs in Grahamstown.” The importance of social grants for patients is explored in chapter 7.

Combining grants and employment within households comprising of extended families allows for one member of the household to volunteer and possibly receive a stipend or a paid job in the future. They all come from relatively stable households with supportive networks which are not based on the nuclear family. In addition, the volunteers with children contribute the child grant to the monthly income of the household. Only two of the 38 volunteers are married. At Middle Terrace, one woman had to stop volunteering in 2001 when she got married. Her new husband did not allow her to volunteer anymore as she now had “responsibilities” to him and her new family.

The main motivations given for voluntary work in this study, were working with and helping people and members of the community (a total of 18 or 49%), educating them and helping them access clinic care or social benefits such as disability grants (6). *All* respondents mentioned altruistic motives in explaining their participation in voluntary work.

Previous illness of family members was frequently given as a reason for becoming a volunteer (7). A majority of the illnesses were TB related. It is ironic that volunteers, also coming from relatively marginalised families with experience of tuberculosis are the ones providing TB care. One volunteer said that “I do more than the other volunteers at the clinic because my brother died of AIDS and I was the one to fetch medicines for him. So I am doing this for him.” She felt that her altruism made her a better volunteer than the others. People who have family members who have had TB can understand and identify with the amount of care that is needed in order to cure the patient. It is a common saying that “it is the poor who help the poor”.[34]

Other reasons given by the volunteers were the fact that there are no paid jobs in town (3), that they have skills and have undergone training to look after people (3) and “it is because our government slogan says ‘wake up and do something’ (*vukuzenzele*). To be able to help people is a great gift.” Altruistic motivations are not necessarily in contradiction with more egoistic motives.

4.3.3 Nothing but a clever career move?

Motives such as helping in the community and solving problems of illness which were given as reasons for the volunteers’ involvement in the health sector may not be as simple as pure altruism. 31 out of 35 volunteers are considering a future career in the health sector. A breakdown of their plans and dreams of a future is given below in Table 3.3.

Volunteering is seen as important work experience particularly for those aspiring to enter the health profession. The volunteers feel that they get “a foot in the door” at the clinics, so that if employment should come up, they are considered for the position. Volunteering is a way of participating in health care, which is what they enjoy doing and where they dream of a future. Thus, volunteering is a way of living out a dream to the extent

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[34] M. Whisson, pers.comm., 10.11.06.

possible, while at the same time hoping for better conditions in terms of payment and sustainability.

Career	No of volunteers
Nurse	18
HIV/AIDS Counselling	10
Social Worker	1
Doctor	1
Not sure	1
TOTAL	31 (out of 37)

Table 3.3:
Career plans of volunteers who wish to work in the Health Sector.

In order to qualify for nursing school, biology as a matriculation[35] subject is needed. However, one does not need Matric to become an assistant nurse. Bearing their level of education in mind, only a minority would be able to qualify for nursing school. For this minority though, this would be a good option as nursing students receive a monthly allowance of R 2000 during their training – this being almost four times the stipend the volunteers are supposed to get today.

The volunteers do have status and recognition in the community which would not be afforded them if they were seen as unemployed. They are seen, not only as helpful to people in terms of health care, but also as mediators who are influential in a sense that they can help people in accessing care. According to one volunteer, people in the community “like us”. She continued, saying that “I am proud of what I am doing.” Many volunteers proudly told me that patients come to their houses in the evenings and weekends to ask for help and advice. They gain status through their relationship with the clinics. This form of recognition is much appreciated and enjoyed.

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[35] This is the South African High School Diploma.

4.3.4 The importance of acknowledgement from the community.

The volunteers know that they are doing an important job, and feel that they are not appreciated by the health administration in the sub-district. Thus, their reasons for why they think they are doing an important job are mainly linked to responses from the community. More than a third (14 out of 37) of the respondents said that helping the community remain healthy was most important to them in their job. Another third (13 out of 37) expressed that they understood their importance through reactions from the communities in which they worked. They mentioned that “clients come and say thank you” and “the community is pleased with me” or “I can see them [the patients] getting better”.

Seeing patients’ health improving is an incentive to continue their voluntary work. The aspect of their work they liked the least was “when patients don’t take their pills” or “the stress of seeing people’s problems when I can’t solve them, such as serious illness or death”. Thus, the volunteers’ loyalties lie with the people of their community and the appreciation they receive from them encourage many of the volunteers to continue their work. However, as we know, one other motivating factor is hopes of future employment – this can only be realised if voluntary community health workers are formally recognised and included in the National TB Control Programme.

4.3.5 Monetary incentives as motivation and sustainability of care.

“Community TB Care in Africa” is a WHO coordinated project where community contribution in TB control is evaluated at district level in a number of African countries. In their report from 2001 it was recommended that in order to prevent “drop out” of TB treatment supporters (volunteers) they must “continue to receive whatever is the perceived benefit in a specific setting” (WHO, 2001: 4). This recommendation leaves it up to national governments to decide what, or how much, is the appropriate benefit for TB volunteers. However, the WHO does also recommend that National Ministries of Health “need to ensure *adequate* [my emphasis] financing, on account of the new costs involved in harnessing community contribution to TB care, while recognising that it is a cost-effective approach” (*ibid*.: 5). The definition of “adequate” still needs to be agreed upon. In this study, perceptions of what is “adequate” differ between the volunteers and those responsible for providing them with incentives. This is a major obstacle in creating a sense of responsibility and commitment among the volunteers.

With an ideology of PHC, including goals such as equity of service delivery, the use of community health workers “increase[s] the coverage and equity of service delivery at low cost compared with alternative modes of service organisation” (Walker & Jan, 2005: 225). However, a desire for remuneration can be seen as a major obstacle to community participation as attrition rates among volunteers tend to be high after the initial years of novelty wears off (Kironde & Kahirimbanyi, 2002: 22).

In Cacadu district volunteers have been promised a stipend of R600 per month. This is to be paid in lump sums of R3600 twice a year. Although this money is paid, it often comes with months of delay, making it difficult for the Community Health Workers to plan and invest in their lives. Some see this delay as non-payment. The Small Project Foundation (SPF) intends to pay remuneration on a monthly basis after the volunteers have handed in time sheets.

Many volunteers mention that they get a stipend, explained in the questionnaire as “R600 stipend per month”, “I get money after a year” and “Not enough money. Because *sisebenza itransport ukuhamba* [we have to use transport to get to work], worse on rainy days”. It is important to note that this is *not a salary*, there is no contractual agreement and there is no guarantee as to how long the payment of this stipend will continue. The future of community participation in and organisation of TB control is uncertain.

Money is an issue of great concern to all Community Health Workers. They feel disappointed with the government and feel that their work is not sufficiently appreciated. They work hard and do tasks professional nurses or social workers are assigned to, but do not have time to do. Mary explains: “We are doing a job in the communities. And at the clinic also. People talk to us…Now, we are doing the nurses work…which is very hard. The nurses can’t go out to the community. They are doing half of the work; we are doing the other half.”

Most volunteers thought that R 1000-1500 per month would be a suitable payment for their 4-5 hour working day. Some thought that the R600 they are supposed to get at present is sufficient. This is an important point because if the government could keep its promises and pay the volunteers R 600-1000 per month on time, and not on an unpredictable six monthly basis, most volunteers would be satisfied and able to invest in their and their dependants lives. With the implementation and completion of the 69-day course, the volunteers may increase their job satisfaction and relationships between the different levels of the system may be improved.

Joy Merrell uses the concept of ambiguity in her study of volunteers in well woman clinics in England. She argues that ambiguity, seen as tensions experienced by the volunteers, comes from trying to integrate “values of volunteering” with demands of “specified levels of activity and quality” in the National Health Service (2000b: 94). The tensions, Merrell continues, comes from the need to know where the boundaries of their role lay (*ibid*.: 96). As in the case of the clinics in Grahamstown, the volunteers in Merrell’s study did not have a clear job description. This ambiguous tension was also felt by the volunteers in this study who expressed that they increasingly take on new responsibilities such as record keeping of TB patients, administration of ARV drugs and other tasks previously done by professional nurses. They find it increasingly difficult to limit their position and responsibilities which define them as volunteers. This tension of boundaries increased volunteers’ feeling of being unappreciated and may in the long term reduce them simply to unpaid professionals.

4.4 …but are they being exploited?

With a health system, and TB care and control in particular, so utterly dependent on the work the volunteers are doing, keeping the volunteers satisfied is a matter of life and death. El Ansari and Phillips argue that satisfaction among the volunteers “plays a crucial role in understanding commitment” among them (2001: 353). In their study of DOTS volunteers in the Northern Cape, Kironde and Neil found that, as previously noted, many volunteered “in the hope of eventual remuneration, which evidently affected sustainability” (2004: 507). In the same study, 90% of the DOTS volunteers expressed a need for further recognition of their work (*ibid*.: 108). A central problem with volunteer programmes is that it cannot be expected that people work full-time and “because of the voluntary nature of the work it is difficult to control the quality and amount of work done" (Walt *et al.*, 1990: 81). This is also the case in Grahamstown.

The use of volunteers is a way of reducing spending while effectively achieving treatment targets, in a health sector which is already pressured while facing new and expensive challenges, such as the HIV/AIDS pandemic and now the new XDR TB. At the same time, volunteerism increases community participation and social solidarity within the community (Taggart *et al.*, 2000: 2). Use of community health workers can also give patients a degree of autonomy which is difficult to achieve in clinic based care (Walker & Jan, 2005: 222). The use of community health workers "does involve the use of limited social recourses" (*ibid*.: 221). Does this use of "limited social resources" imply a degree of exploitation of the volunteers?

In Makana LSA, the idea of using voluntary health workers, rather than employed health workers, is a way to deal with unemployment through activating and educating people while at the same time not having to spend the resources or show the commitment they would otherwise have to if they were to formally employ and pay the volunteers salaries instead of irregular stipends.

However, with SPF taking over the responsibility for the volunteers, they have to sign a contract. This contract makes them legally liable for any equipment they are using. Not only is this dubious as they are required to use this equipment in order to perform their duties as volunteers, but it was also explained to them by the SPF representative as "what is meant here is that you are given a kit and you mustn't let it lie around. If you do, then what must the department do, no?" This clearly does not explain "legally liable" in sufficient detail.

The contract also stipulates working hours from 08h00 till 12h00 five days a week and a maximum of five sick days per month. The volunteers must inform the LSA if their employment situation changes, even if they find paid employment after 12h00 or on a week end basis as, according to the SPF, "it would not be fair if you were both volunteers and working. Then someone else should get a chance". The line between being a volunteer and being employed is blurred.

Intellectually, the use of volunteering can be seen as exploitative (Merrell, 2000a: 32; Merrell & Williams, 1999: 494). However, literature of the experiences and motivations of volunteers has shown that this is not the case. In their study of volunteers in a home-based visiting project for mothers in Sydney, Australia, Taggart *et al.* found that the volunteers did not feel exploited as they felt that they gained from the visits (2000: 4). Joy Merrell found that the volunteers in her study “gain from their participation in the clinics as well as giving their time and effort” (2000a: 31). However, as Merrell continues, for their participation to be sustainable, the relationship between the giving and the taking needs to be one of balanced reciprocity based on trust. If this balance is achieved, volunteering need not be exploitative, but can be empowering to women (*ibid*.). Thandi explains*:* “I become wiser, more experienced, and educated to care. Being a volunteer helps me a lot.” Nomfundo also emphasises skills she has learnt through volunteering: “…dressing [of wounds], weighing of children, giving people TB treatment. I learn everything.” However, if trust in the relationship of balanced reciprocity is broken, the system of volunteers may no longer be sustainable. In Grahamstown volunteers are becoming increasingly impatient and angry, losing trust in and respect for the health authorities in the district.

Sharing of skills can be a positive experience as it can be seen as “a means of breaking down traditional divisions of labour and as an empowerment process in that technical knowledge and skills are shared” (Merrell, 2000b: 98). However, it can also be seen as exploitative as the level of recognition and acknowledgement, financial or not, does not seem to increase at the same rate as the skills level among the volunteers does.

Exploitation can be emotional, based on a perceived lack of appreciation. Volunteers in Grahamstown feel that their work is not appreciated. However, at the same time, they do feel that they gain personally from volunteering.

4.5 The future of volunteerism for the sustainability of South African TB care.

The volunteers were not promised any payment initially, but this is important to them now, and is likely to influence their length of commitment to TB care. The question is: Is the government responsible for fulfilling the volunteers’ changing demands when this was not part of the initial agreement? No, they are not. But, and this is a very important but, if the Eastern Cape, and South Africa as a whole, intend to have a sustainable Primary Health Care system capable of managing diseases such as HIV and TB, in addition to the escalating rate of XDR TB, then this cannot, and I would argue, should not, be done on a voluntary basis.

Although about half of the volunteers answered that they would work as volunteers for 10 to 30 years, “until I get a pension” or “my whole life”, the remaining half said that they would only work as volunteers for one to three years or “until I get a job”. The use of volunteers is unsustainable. In addition, when answering the question concerning what they don’t like about volunteering, the feeling of being unappreciated was frequently mentioned through statements such as “broken and unfaithful promises from the government” and “being unappreciated both by staff and patients”. This feeling may result in the volunteers not staying in the system for another 30 years after all. Introducing guidelines for the Community Health Workers and their responsibilities may lead to a feeling of empowerment among the volunteers.

This uncertainty is also reflected in nurses’ and patients’ perceptions of the sustainability, or lack thereof, of the manner in which Community Health Workers are remunerated. Nurses fear that the volunteers will leave if they get no payment. In addition, according to one volunteer, “patients worry that we will go. They ask us why we are not paid because we help them a lot.”

It is a danger that as soon as the volunteers’ tasks become “a job”, they start looking for ways to get out of the community and into the clinics as professional health workers. As will be shown throughout this thesis, some Community Health Workers have already distanced themselves from the community on a moral basis. However, the question is: is this problematic? If the volunteers have proved themselves as being committed health care workers, then why should their skills and experiences not be recognised and facilitated? This very commitment may make them better nurses than those who have chosen nursing purely as a career.

Volunteers “should be seen as complimentary to the formal services and not as cheap substitutes” (Walker & Jan, 2005: 226. See also Merrell, 2000a: 38; 2000b: 94). There is a “shadow price” on the use of “free” labour. “[I]t has an economic cost because it is a resource that has alternative, valuable uses” (Walker & Jan, 2005: 224).

One way of creating a sustainable system would be to *recognise* the experience and knowledge the volunteers have. More than half of the volunteers in Grahamstown have more than five years of experience. This can eventually be built on through a formal training process which would *allow them to be employed* as CHWs, or clinic assistants and educators. The cost will not be significantly higher than the cost of having the volunteers today and is, due to increased health worker commitment, likely to be cheaper for the health sector in the longer term. Necessary capacity building within the health sector will be provided.

It is possible that creating a formal title and training for the volunteers’ responsibilities will have a beneficial effect on the nature of the work. However, there is also a danger involved in that “people will become volunteers for the money” as people in the Makana sub-district have argued. It is likely that a formalisation will change the nature of the work for the better. The challenge will be to make the rewards less appealing to people who are after a salaried job while at the same time being appealing to committed and compassionate individuals who wish to contribute to TB care in South Africa.

As formally recognised, the volunteers will be likely to have limited sick leave, set working hours and increased motivation and commitment to their work as they will feel that they are being seen, heard and acknowledged for what they do. They have skills, and they know it. As Nomfundo says: “We do have skills the nurses don’t have: [we can do] community work, we assess families’ needs, and refer them to social welfare… the nurses look at us as friends. We help them, they help us.” Volunteers often mentioned that they, unlike the nurses, have “people skills” and that they “know the community”, the people there, their history and their needs. In Australia, Taggart found that the volunteers were “seen [by patients] to be more accessible than the busy professionals” (Taggart *et al.*, 2000: 5). The volunteers have valuable skills much needed in the health sector which are not provided by anyone else.

4.6 Conclusion.

TB was declared a national priority in 1996 and DOTS was adopted by the National Department of Health (Sinanovic *et al.*, 2003: S57). However, despite this declaration, the Department of Health is failing to make provision for training of volunteers as well as, through formal and committed incentives, failing in its continued involvement in TB care at community level – involvement which is essential in the government's adoption of the DOTS strategy.

This chapter has explored the role of volunteer Community Health Workers in Grahamstown. Their motivations for becoming volunteers have been explored as a means of assessing the sustainability of a health care practice based on volunteerism. Volunteers add immense value to the formal health care system, but there is a growing frustration among them as to the lack of formal recognition of their work.

Although more research needs to be done, it is cautiously argued that the motivations of the volunteers alone are not enough to create a sustainable system of management of tuberculosis that will be able to deal with a rapidly increasing disease burden. The volunteers' strengths and limitations must be taken into account, and the cheapest and most realistic way of doing this may be to formalise their training and make them full worthy members of the South African Primary Health Care system. Community participation in health care is important in a newly democratised nation such as South Africa and must be recognised by the government. As soon as this is done, the next step may be to employ, or at least recognise the volunteers formally and grant them more reliable incentives.

Chapter 5.

Explanatory models of sickness.

5.1 Introduction.

In this chapter Kleinman's explanatory model (EM) is used to explore experiences, causes and symptoms of illness. While Kleinman's model is of some value, it is emphasised that its scope is limited as the framework has too narrow a focus on illness related behaviour, concentrating mainly on the micro level of experience. Instead, it is necessary to widen the scope by including broader structural issues of poverty and inequality in analysing ethnographic data.

A central feature of an explanatory model of a disease is the nature of symptoms and their perceived causes. How people perceive the cause of tuberculosis influences their experience of illness. This chapter presents, contextualises and makes sense of patients' and practitioners' perceived causes of tuberculosis using literature from most of the world's regions. People's health seeking behaviour and their treatment outcomes are influenced by their perception of causes and more importantly their *ability* to act on these perceptions. A person's explanatory model of their illness is also influenced by responses from the people they interact with and the structural context in which these interactions take place. In order to understand the role of explanatory models, we need to look outside the clinic environment and include the broader forces of structural violence as these have an impact on people's decisions and may even cause them to abandon their existing health beliefs.

Explanatory models of illness can determine whether stigma will be experienced. In this chapter TB related stigma is explored and it is shown that it is fruitless to investigate without also exploring AIDS related stigma. Stigma largely affects the structurally weak in a community (Rangan & Uplekar, 1999: 272), resulting in further stigmatisation, marginalisation and a weakening of social relations. Following Richard Wilkinson's approach to health presented in the second chapter of this thesis (see chapter 2, section 2.7), it is argued that worsening social relations leads to increased stress, increased rates of illness and violence, and increased illness. Stigma and discrimination are produced and reproduced in a context of existing structural inequalities.

5.1.1 The explanatory model.

According to Kleinman the explanatory model of any particular illness can be seen as consisting of a number of components worked through in this order: (1) symptoms and signs by which the illness is recognised, (2) presumed causes of the illness, (3) recommended therapies, (4) the illness pathophysiology and finally (5) prognosis (Kleinman, 1980: 105-07). Kleinman argues that the extent to which the patient's and therapists' explanatory models coincide and concur will determine the outcome of therapy. This chapter will focus on the first three aspects of the model. Health seeking and therapy management will be discussed in the next chapter.

Kleinman's ethnomedical model focuses on the local "inner workings of clinical care" (1980: 27) and is useful in explaining how people see their symptoms, causes and the required treatment of their illness. The model does not allow for consideration of the effects of institutionalised relations of power. This is a clear weakness of the model and the manner in which it is applied by Kleinman. In Grahamstown my research suggests that the structural causes and constraints of sickness are more important than the cultural beliefs.

Kleinman's distinction between the illness and disease aspects of sickness is useful. Kleinman sees illness as "the psychosocial experience and meaning of perceived disease" (1980: 72). Although this definition is applied to this study, it is also shown that the experience of tuberculosis is more influenced by socio-economic inequalities and poverty than it is by cultural or individual psychosocial factors. As Kleinman notes, concepts of illness and disease can only be understood within a context of meaning and social relationships (*ibid*.: 73). Understanding people's experiences of illness in Grahamstown does not only require a focus on culture, but also on the limitations caused by structural hardships.

The component of their explanatory models that was most clearly articulated by informants in this study was that of their illness aetiology, or the perceived causes of illness. It was also in the perceived causes of tuberculosis that structural violence was most clearly articulated.

5.2 Symptoms.

The first aspect of Kleinman's explanatory model is the symptoms and signs by which the illness is recognised. According to the WHO, TB can be a diagnostic condition of AIDS (WHO, 2005d). As a result, the health of people suffering with HIV/TB deteriorates rapidly and symptoms are experienced for a relatively short time prior to seeking treatment. With HIV being a highly stigmatised condition with similar general symptoms to tuberculosis, some people with TB think that they are experiencing the symptoms of HIV and delay or even avoid seeking treatment for their symptoms.

The symptoms of tuberculosis identified by the Department of Health and communicated in their posters and leaflets to be found in the clinics are night sweats, loss of appetite, loss of weight, coughing for more than two weeks and tiredness. These are non specific symptoms and could also be experienced by someone with simple flu or chronic bronchitis. In many cases staff take precautionary measures and advise people to get tested both for HIV and TB. This is reflected in a high number of negative sputum tests. Passive case finding is insufficient.

5.2.1 Patients' explanatory models: multiple general symptoms.

Moses had headaches and night sweats for three weeks and coughed up blood. "I just spit it out and put my foot on it to make it go away, now the nurses have told me that the TB is still there in the spit." This was in February 2005. He went to see a private doctor who sent Moses to Settlers Hospital where he tested positive for both TB and HIV, and was sent to Temba. About this period Moses says: "I was scared I was going to die. I was very sick. When they told me I had HIV, I felt nothing [physically], but when I got TB, I was sick."

Thando reported loss of weight, loss of appetite, coughing and general fatigue. He also said that he had "red nails" (presumably the skin under the nails). His condition deteriorated rapidly. He was bedridden and did not seek treatment until he lost consciousness and was taken to Settlers Hospital by ambulance. "I was confused in hospital, I couldn’t think straight. Everything was blank.” Thando did not seek treatment himself, but relied on family to do so on his behalf. He was soon transferred to Temba where he spent two months before completing his treatment as an outpatient at Joza Clinic. Thando was also HIV positive. Two months after Thando was cured he felt sick again with the same symptoms. This time his condition also deteriorated quickly. I had arranged to take him out for lunch to celebrate that he was cured as well to talk to him about ARVs, but when I went to fetch him only a week after the arrangement, he was sitting on his bed, grey in colour and extremely thin. Despite being so unwell he had not gone to the clinic to check if he may have succumbed to TB again, even though he was aware that he had been coughing for more than two weeks. As a result, he became sicker and was taken to Settlers Hospital in an ambulance where he was again diagnosed with tuberculosis.

These two cases show that patients’ knowledge of their symptoms does not necessarily result in them seeking help and a cure. There are other reasons affecting health seeking such as social support and economic factors to mention a few. This will be dealt with specifically in chapters 6 and 7.

5.2.2 Psychological symptoms.

Clinically, physical symptoms are easier to identify than psychological symptoms. However, for many, psychological symptoms gave them their first inkling that something was wrong. Eric felt that he wanted to be alone and that he had became impatient with his son, Luvo. These psychological changes were his first symptoms and show the serious and life changing nature of tuberculosis, particularly when combined with HIV. The increased worry and stress Eric experienced as a result of feeling that “something was not right” continued throughout his illness and even after reaching a TB cure. Management of HIV continued.

Lionel first experienced a combination of physical and psychological symptoms. He started feeling sick when he was in prison, but did not seek treatment there as it was not seen as “manly”. His first symptoms he describes as “a pain in my chest and in my heart”. He did not know what the pain in his heart was, but he thinks it was a result of being scared of dying away from home. Lionel only went to the clinic after he was released from prison. More than two years after starting treatment, he is still experiencing symptoms and side effects such as nausea of the drugs.[36]

5.3 TB aetiology as multi causal.

People generally give multiple, and sometimes conflicting, causes of tuberculosis. Some change their explanations over time. Explanatory models are not static, but change over time and according to context. In addition to relating infection with tuberculosis to other diseases such as HIV or pneumonia, it is a common perception that the manifestation of the symptoms may only become evident a long time after initial infection. In one case observed in the clinic, a man diagnosed with tuberculosis in 2006 explained that his present infection was due to employment in a cold room in a butchery in the early 1970s. Eric says that he probably contracted TB from his aunt who had TB in 1986 and was at Temba. Eric also mentioned other causes of his disease as will be presented later in this section.

Metcalf and co-workers found that among women in Ravensmead, Cape Town, cold weather (38%), smoking (31%), alcohol (21%) and poor nutrition (29%) were given as causes of the disease (Metcalf *et al.*, 1990). Although these causes look different and distinct on the surface, they do have one common denominator: poverty. Without going into the “truth factor” of these given causes, it is a well known fact that both smoking and excessive drinking are behaviours more common among poor people than among the wealthier section of a population (see Wilkinson, 2005). Poor nutrition is related to poverty. Cold weather as a suggested cause is also poverty related. In this study, a number of informants attributed their TB to poor housing conditions. This was especially felt in the winter months.

5.3.1 Curability and infectiousness.

The knowledge that tuberculosis is infectious and can be cured by the use of medicine from the clinic is common. This is also true among members of the communities who do not have tuberculosis (SANPAD focus groups). The knowledge of perceived

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[36] Side effects of first line tuberculosis drugs include jaundice, hepatitis, fever and rash, bleeding and renal failure, impaired visual acuity and deafness in addition to unsteadiness and ringing in ears http://www.doh.gov.za/iads/docs/tuberculosis.html (accessed 28.11.06).

infectiousness and curability of tuberculosis come together in the sense that people have clear ideas of how one gets TB and how one is cured. This is also the message from government, nurses and health workers, and as a result people have taken ownership of this information. However, there are cases where people do not know, or do not wish to know, that TB is curable. These are replies from CHWs in a clinic after I asked what people in the communities to think about TB.

> ***Thandi:*** *"Some people think that TB is not curable and that it is bad to have TB. But we tell them that TB can be helped."*
> ***Gloria:*** *"People stay away from people with TB even after they have started treatment. Often people don't know that it is curable."*
> ***Nosipho:*** *"Like in my area, there is a child, a girl who is six years old, who has TB and the neighbours tell her that she cannot come and play with her child because she is going to infect her child. But I told her that it is not like that. If you take your treatment TB is no longer contagious. Now the child can come and play at her house."*

All the people I asked, knew that tuberculosis is infectious and "is in the air" and can be transmitted through coughing. However, this does not mean that they do not hold stigmatising attitudes based on morality or think that TB can be spread in other ways too. The recent outbreak of XDR TB in South Africa may increase TB related stigma.

Uninfected people are distancing themselves from people infected with TB, even though they know that they are not infectious anymore or that it is safe to share utensils. Eric's father did not come to visit him at Temba, even when he knew that Eric was in danger of dying. After Eric was cured, he was given different utensils from the others at his father's home. This type of physical and social distancing is not particular to South Africa. A study from Texas, United States, found that almost all patients felt that friends and family avoided them after diagnosis became known (Kelly, 1999).

There is a fear of being infected, but also of being infectious. Thando isolated himself throughout his treatment even though he knew that he was not infectious. "I don't want to be responsible for someone who is healthy." Thando's reaction contradicts his knowledge. There are other reasons for his self isolation and distancing than lack of knowledge. Thando's family was unsupportive and refused to accept both his TB and HIV infections and isolated him. As a result Thando felt alone in his illness management. At an individual level, stigma consists of both internal and external processes. Whereas external stigma can be seen as actual experiences of discrimination, internal stigma is associated with an experience of shame and fear of being discriminated against (POLICY Project, 2003: 4). In reality, internal stigma is a result of external stigma either directly or indirectly experienced by the stigmatised person. Stigma is not a constant, but changes over time and according to the socio-economic context. Health workers are central players in informing the communities about tuberculosis and have the potential to play a major role as de-stigmatisers, but do not always succeed in doing this.

Illustration 5.1:American Lung Association poster, ca. 1935.[37]

5.3.2 Infected sputum as a cause.

Generally, people with TB know that sputum is the mode of infection. In the above mentioned study from Ravensmead, some people reported that TB germs could be transmitted through *standing* on TB infected sputum (Metcalf *et al.*, 1990: 409). Moses thinks this may be one of the reasons why he got sick. Spitting on the ground is nevertheless mentioned by a number of respondents. This has been linked to tuberculosis as affecting and being transmitted by youngsters, who are seen to have no manners by spitting on the ground. When Moses saw blood in his sputum, he thought it would go away if he spat it out and that it would not infect other people if he covered the sputum

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[37] http://www.nlm.nih.gov/exhibition/visualculture/infectious01.html (accessed 03.12.06)

with dust. After diagnosis and receiving information in the clinic, he now knows that his sputum was still infectious for a while outside of his body, particularly on hot days: “When it is hot, sputum becomes open and that’s how you get it [TB].” In her study from Botswana Liv Haram encountered a patient saying that “it will penetrate the sole of your foot and cause you to suffer from TB” (cited in Haram, 1991: 170). Moses says that cultural and moral differences, and not poverty, are the cause of the difference in tuberculosis prevalence among blacks and whites in Grahamstown: “The TB rate is different in the white areas because the people there have the knowledge[of how TB is transmitted and infection avoided], but black people don’t care.”

Nomhle, a patient at Temba, links the increasing rate of tuberculosis to bad manners among black people: “In the old days there was not as much TB as there is now. People used to cover their mouth when they coughed then, and nowadays people don’t hold their mouth when they cough.” Individual behaviour is blamed, rather than their disadvantaged status as a result of structural violence, even among those who themselves have TB.

5.3.3 Tuberculosis as happening to anyone.

Tuberculosis as something that “anyone can catch” is a mantra in the clinics, often mentioned in the same sentence as “drinking and smoking causes TB”. That these two perceived causes are *not* contradictory will be shown below. The notion of tuberculosis as something anyone can catch comes across in the following statement from a nurse talking at a local clinic World TB Day celebration: “Many think that TB is a disease of poverty. That is not true. TB is not only a disease of the poor. It can happen to anyone”. This was followed by nods of agreement among the general visitors at the clinic. The idea of tuberculosis as indiscriminately affecting people regardless of class or colour is seen as a way of combating stigma. This approach is enjoying relative success in the communities, but it limits people’s opportunities to question their situation in relation to wider structures of inequality. Although not pursued in this thesis, it may be that poverty related stigma is greater today than during apartheid when people felt they were suppressed together.

When I told Moses that I had read that it is mostly poor people who get tuberculosis, he exclaimed: “No! Did you really read that? Anyone can get it. It is in the air. It is not just here, it is everywhere." He uses the fact that TB is "in the air", making everyone vulnerable as we all need oxygen to live, as a means of explaining that it is not poverty related. However, some people are more likely to get sick than others, depending on living conditions, nutritional status, strength of the immune system and simply how much bacilli there is in the air. As both a cause and effect of this, there are more bacilli in the air in poor places than in wealthier areas. Patrick, a patient at Temba, appears to understand the fact that nutrition is an important component to get well and limited by poverty. He explains: "Everyone can get TB, because it is in the air. But, poor people get it easier as they don't have strong bodies because they can't afford proper food, so rich people don't really get TB as they are strong." This statement reflects his awareness of poverty causing immune suppression resulting in increased susceptibility to social diseases such as tuberculosis.

In the focus groups conducted with people who neither have tuberculosis nor work in the health sector, poverty and dirt in connection to tuberculosis came up more often than among those in contact with clinics. In one focus group a man said that tuberculosis was genetic because: "It goes with the family historical background". This was also mentioned by one of the community health workers. In reality, this is probably related to overcrowding and poverty. Some people are born into this situation while others are not.

5.3.4 Poverty as cause.

Health or disease,
the choice is yours.

Tuberculosis poster at Middle Terrace Clinic

The above statement indicates that getting sick is choice based and that the patient making the wrong choice can be rightfully blamed for own sickness. Causes limiting patient agency are not acknowledged.

Infectious diseases such as tuberculosis primarily occur among the poor. Emphasising this through education and information may result in further stigmatisation of people with tuberculosis. However it may also take some of the blame away from the poor if poverty is seen in a structural context and not as a matter of individual choice. One volunteer at Raglan Road noted that assuming the TB symptoms only occur among the poor may cause delay in people presenting with their TB symptoms at the clinic as they would feel stigmatised.

A survey conducted in Manila found that 86.2% of the people questioned linked tuberculosis with poor living conditions, whereas only 24.8% attributed TB to the spread of germs (Portero Navio *et al.,* 2002: 303). Although the percentage of people linking tuberculosis to poor living conditions in Grahamstown is probably far below that of Manila, this connection is nevertheless made. Lindelwa commented that black people are more likely to get TB than white people "because you know that our place is not right. We are so poor." She added that she and her children don't have warm clothes and that there is a draught under the door and windows. However, Nozithembiso's tuberculosis was also connected to her "love too much to eat the ice lollies and cool drinks" as well as not putting on warm enough clothes on cold days. Humoral causes of tuberculosis will be discussed in section 5.3.6 below.

Speculating on why I had not succumbed to TB as he knew that I frequented clinics and hospitals often and intermingled with infectious TB patients, Lionel mentioned dirt as a reason: "It can be poverty you know…prison is a dirty place. People are smoking, doing everything. And there are many places out here…it is not a clean environment." He commented on the same thing during his admission at Jose Pearson Hospital. "It is poverty that brings them [the patients] here. There is no money, no food, you get sick. It is double this [sickness/situation]. That is the situation that brought them here." When it comes to being sick with a potentially deadly disease he says: "Everybody is afraid to die whether they are poor or not".

If stigma is seen as a social response resulting in "additional suffering beyond the symptoms" (Weiss, 2001: 19) and it is clear to those *without* tuberculosis that those *with* tuberculosis are poor, this can cause further marginalisation and isolation of people with tuberculosis. On the other hand, "making social" of tuberculosis could possibly relieve infected people of blame and accusations of being bad or immoral.

As already noted, the epidemiology of tuberculosis is an epidemiology of inequality (Stephens, 1999: 471). In the 20 ACSA interviews with TB patients at Temba Hospital, *all* had histories of deprivation and inequality and multiple misfortunes based in structural violence. This is the story of 30-year old Zoleka:

> *In 2001, when I was doing my Matric, I was sick so I did not finish my exams and failed. I was staying with my grandmother and brother. In 2002 my grandmother started to get sick. She was attacked by a stroke. By the time she had the stroke it was only me and her and my child at home. I thought she was sleeping, but then my aunt came and found her. She died in 2003. My brother died in 2004. He was a breadwinner. He was attacked [with a knife] and operated in PE and died in April 2004. The attack was in September 2003. I was told in hospital that I was HIV positive. I thought it was a mistake, that they had made a mistake. I felt angry when they talked about it in the clinic. They told me to join a support group, but I only went some times and then I accepted it [the infection]. After a year I told my family. It [the worst time in my life] is still happening as I am alone. So I am worried as there is no one. In January my child moved to a relative. In February 2005 my mother died from TB. She was at Temba. I want to see my child growing up before I die.*

This tragic illustration of multiple misfortunes would normally raise suspicions of witchcraft directed at family. Zoleka’s story indicates the relationships between poverty, violence and sickness as Wilkinson has pointed out (1996; 2005). Zoleka has been unable to finish school due to poverty and illness, and so the cycle of poverty is likely to continue. There is a history of tuberculosis in her family and her brother, Zoleka told me later, was drinking excessively and became involved in a fight which later resulted in his death. Zoleka is unable to take care of her young child and feels that she has lost control of her life.

Although poverty is recognised as a cause of TB, particularly among those who do not have TB, the underlying structures causing poverty are seldom mentioned. Mirriam, a patient at Temba, mentioned in the focus groups that: “You can’t blame anyone. This is caused by stress and depression which results in your body parts becoming weak and that causes the whole body to be weak and so causes up TB. It is also caused by the way people behave, drinking a lot and smoking. Also by being poor and have no money.” The process Mirriam mentions is accurate, and visible, and it is not a result of mere coincidence.

We now live in a democracy and, as a result, people have to some extent stopped looking for structures of violence, or imagine that they have ceased to exist. However, the structures are still there, but they are increasingly invisible and accepted by people without them understanding their functions. We need to look beyond what is visible.

5.3.5 Traditional causes of tuberculosis.

Due to limited time and resources traditional aetiologies and the occurrence of patients divulging their views of tuberculosis are not explored in great detail in this thesis. Although some traditional causes are mentioned by patients and practitioners, it is unclear as to how prevalent these are and how they are related to biomedical aetiologies. Tuberculosis caused intentionally through witchcraft is not explored although it is commonly seen as causing sickness especially when multiple misfortunes in a kin group occurs as is the case of Zoleka (see section 5.3.4 above). Historically, it has been noted that tuberculosis can be caused by witchcraft (Macvicar, 1939; Jansen, 1973).

Although TB patients take biomedical therapy to combat the disease, they do not necessarily subscribe to the biomedical explanation of the disease. Traditionally, the cause of tuberculosis does not seem to be seen as contagious. Hence, as reported from Chiapas in Mexico (Menegoni, 1996: 392), TB related stigma may be considerably less than if it was thought to be infectious.

In the focus groups it was asked if tuberculosis was associated with the *impundulu* bird, a dangerous witch’s familiar, which has been recorded as an important figure in local belief systems on the cause of tuberculosis. Traditionally, the *impundulu* is believed to feed on its victim’s blood, slowly killing them (Hirst, 1990: 161). This was confirmed in the responses, although there was some disparity based on age. Some young people said that beliefs concerning the *impundulu* were old fashioned and they themselves did not believe in them anymore. There was consent that TB could not be caused by the *impundulu* kicking in the chest although the symptom of “vomiting blood” could be confused with TB. Traditional healers said that the blood vomit which was caused by the *impundulu* could be cured with the help of traditional medicine. On the other hand, traditional healers said that they could not cure blood vomit (sputum with blood) which was caused by tuberculosis. Among the Zulu further north in South Africa the *inyoni* bird (equivalent to *impundulu*) is more often associated with sudden strokes and the passing of black faeces.[38]

An unsolicited response given by some healers in the focus group was that tuberculosis could be caused by the river sickness caused by the river snake (*umlambo*). *Umlambo* is explained as having excess water in the body as a result of “weak blood” caused by insufficient nutrition. According to one healer, a person can develop a cough from *umlambo* in the kidney moving into the lungs. This is then diagnosed by the doctor as TB, but in fact it started off as *umlambo*. These beliefs do not seem to prevent people from seeking help at the clinic. In a pluralistic medical system dual therapy is not necessarily seen as a problem. A person can go to the clinic to get medicine for symptomatic relief and at the same time go to the traditional healer to deal with the wider social or spiritual causes of illness. In one instance, I observed an old man telling the doctor that he had gotten TB from being kicked in the chest by an *impundulu*, but that he still believed that he could only be cured through biomedicine. Diviners in Grahamstown have previously been recorded pointing out that “being kicked by an *impundulu*” is a metaphor for being infected with pulmonary tuberculosis. Through a SANTA programme in the 1970s, diviners were educated about TB and since then often refer suspected patients to biomedical practitioners (Hirst, 1990: 244). Blending of ideas is evident. Metaphorically, the *impundulu* could be regarded as the personification of structural violence. Hence, the use of Western medicine that deals with the pathologies arising out of a system of inequality and lack of concern is appropriate.

It is commonly perceived that weak or bad blood can be combated through general immune system boosting therapies, both traditional and biomedical, in addition to sufficient nutrition specifically meat and a diverse diet. Bad blood as resulting in tuberculosis is also reported from Botswana (Haram, 1991).

5.3.6 Causes of tuberculosis related to coldness – a humoral perspective.

In Pakistan, Liefooghe and co-workers found that a number of patients attributed their disease to physical factors such as having a cold bath – even after they had been

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[38] P. Bernard, pers. comm. 13.11.06.

hospitalised and educated about tuberculosis (1995: 1689). I discovered that this is also the case in Grahamstown, where beliefs on hot/cold precipitating factors are enforced by volunteers, nurses and doctors. Although they emphasise that smoking and drinking are common causes of tuberculosis, I have also observed CHWs and nurses warning patients against washing clothes in cold water and drinking cold, fizzy drinks.

In Grahamstown, the tendency to relate coldness to tuberculosis can be divided into two groups: 1) coldness as the outside temperature the body is exposed to and 2) coldness as food and drink which is taken into the body orally. Often, TB is seen as a result of other lung diseases which are caused by cold and change in temperature, such as the common cold, flu and pneumonia.

Yvonne, a 63-year old widow, is not sure how she got tuberculosis. She thinks that she might have got it last winter (2005) when she went to Alicedale, a nearby village, with her Church group. She remembers that when they arrived in Alicedale by bus it was colder there than in Grahamstown. What is evident in this story is that it is understood that there can be a time lag between the exposure to cold temperature and the evidence of symptoms of tuberculosis in the body. In Yvonne’s case this delay was one year. Bodily reactions to cold temperatures can be ‘stored’ in the body, and might only result in active tuberculosis later. I was unable to determine whether this is related to the fact that one can have latent TB infection for many years without developing active TB.

Margaret (64), who lives in the same street as Yvonne, was exposed to cold water while she was hand washing other people’s clothes, for which she earned R 500 per month. One private doctor told her that she had to stop washing clothes in cold water by hand as this had an adverse effect on her infection. As Margaret has no other way of washing clothes, she lost her income and became dependent on her old age pension and her son’s salary. She still felt fit for work and wished to work rather than receive a grant. Being exposed to extreme temperature fluctuations was mentioned by patients in Haiti where a domestic worker was quoted as saying that: “All that ironing, and then opening the refrigerator” (quoted in Farmer, 2005: 35). People working in low status occupations are often more susceptible to unhealthy conditions than those more educated and with more rights or knowledge of those rights.

TB is also seen as being caused by cold food and drink. Nozithembiso's aunt, Lindelwa, explains that Nozithembiso had contracted tuberculosis because she "loves too much to eat the ice lollies and cool drinks" as well as not putting on warm enough clothes on cold days. Nozithembiso agrees with her aunt's theory. At the clinic in Port Elizabeth, where they moved to from Grahamstown, their suspicions were confirmed by a nurse who told them that Nozithembiso should avoid cold fizzy drinks so as to not be re-infected with TB.

Hammond-Tooke relates dirt to heat in a system of pollution beliefs (1989: 50). He adds that the term *go fisa* means "to be hot" and can refer to fever (*ibid*.: 94). As pollution beliefs were not an integral aspect of this study, this has not been looked into sufficiently, but a link between dirt, heat and night sweats could be interesting to explore in the future.

5.3.7 Tuberculosis as a result of unhealthy working conditions.

A number of patients mention that some working environments are more dangerous than others in terms of tuberculosis. Both Ronnie and Eric mention the role of chemicals in paint entering the lungs while breathing as a risk factor. Ronnie worked as a painter, and emphasises that the indoor paint jobs are most dangerous due to insufficient ventilation: "You know…there are some strong chemicals in some paint. You work for money, because that time you care only for money. But it [the chemicals] affects you slowly." It was the urgent need for money which prohibited Ronnie from making healthy choices.

Eric adds a preventive factor in his experience with paint fumes. He says that he may have gotten TB because he once helped a lady paint her house on the outside. He claims that had he drunk milk before painting, his lungs would have had a protective layer preventing him from contracting tuberculosis. In the focus group with traditional healers, milk came up as both a general health boosting drink and, specifically, as being good for the lungs.

One other work-related cause of contracting tuberculosis expressed by informants is dust. A number of people who had worked in the local quarry and at a brick making factory, claim that tuberculosis can come from dust entering the lungs. It is unclear as to whether the dust and fumes are seen as being the actual cause of TB, or if they are seen as weakening the lungs and making a person more susceptible to contracting the disease from other sources, or of activating latent TB. Although not all of the examples given here were seen to directly cause TB, there was nevertheless a perception that these jobs are more dangerous than other jobs. The poor have the most dangerous working conditions, less protective equipment and employment options, poorer employment rights and health care, and this increases their vulnerability to tuberculosis.

5.3.8 Tuberculosis as a moral disease.

TB can be seen not only as a social, but also as a moral, disease. Perceived causes of tuberculosis are linked to perceived morality, or supposed lack thereof. Smoking and drinking are associated with poverty, lack of self control and avoidance of responsibilities to get out of this cycle. Individual agency is exaggerated.[39] This is related to behaviour commonly condemned by the Church. These attitudes are shared and promoted by health workers, many of whom possess positions of respect and responsibility in the local Church. This is reflected in their explanatory models which are not merely focused on how tuberculosis is to be treated as a physical entity, but also on how they understand "the problem of tuberculosis" to arise. Although smoking and drinking can, in indirect ways, make the body more susceptible to diseases, and tuberculosis is only one example, this explanation is not often conveyed from practitioner to patient. Rather, the message is simplified and takes on a moral character. Many CHWs believe that smoking, one of the most common causes mentioned in the clinic, directly causes tuberculosis.

When aetiologies are attributed to moral deviance the disease is stigmatised and serves to marginalise an already weakened section of a population. Even amongst those who do not attribute *their own* tuberculosis to smoking and drinking, they believe that, generally, it is possible to get TB from smoking and drinking.

Prior to Moses' own infection, he thought that only people smoking and drinking got TB, but now he knows that anyone can get it through infection by others: "You cannot get TB

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[39] Sexual behaviour takes on a similar moral character but is not given focus here as informants do not relate this to tuberculosis. Sexual behaviour occurring outside of marriage is related to HIV infection and is commonly regarded as immoral both by clinic practitioners and members of the community.

from yourself. You get it from other people." With his own infection, Moses has changed his perspective on the aetiology and morality of tuberculosis. He now has tuberculosis, but did not smoke or drink prior to infection. Explanatory models and stigmatising attitudes change over time and according to the situation of the person involved. Information in the clinics may also impact on this although it is not clear to what extent, as stigmatising attitudes are spread there too.

Even though the incidence rate of tuberculosis is higher among alcoholics than non drinkers, this does not in any way mean that TB is caused by drinking. In their focus group, traditional healers agreed that it is "today's liquor", and not the one they used to drink in the old days, which is to blame. In fact, traditional beer, *umqombothi*, is nutritious. Again, we have to look at socio-economic and structural factors that make it more likely for some rather than others to get alcohol related problems. As also noted by Wilkinson (1996; 2005), those who feel weakest in a society are more likely to drink more alcohol.

Clinic personnel and social workers in Grahamstown see smoking and drinking as morally and socially unacceptable behaviour. "The problem", one social worker commented, "is that alcohol and cigarettes are socially acceptable drugs." Smoking and excessive drinking are common in Grahamstown East, where there are high rates of tuberculosis. Mzwandile, a police constable, says that there is frequent excessive drinking in the township during the week ends. This results in trouble and fights, often with knives or other weapons (as was the case with Zoleka's brother, above). According to Mzwandile, most of the people drinking excessively are unemployed (as most of the TB patients are too): "For them life is stressful as they don't have a job and therefore they drink. And when they drink, they get into fights. And women who drink often walk alone in the dark to get home, and then they get raped and get HIV. If someone is raping, they will not use a condom, you know?"

Victims of tuberculosis have to shoulder the blame for their affliction because they are regarded as morally deviant; their burden is increased because of the stressful conditions they find themselves in: unemployment, family instabilities, poverty, hopelessness, inadequate and often insecure housing. All these factors increase stress in the individual, resulting in increased vulnerability to other pathogens and a tendency to create dependency on drugs and alcohol (Wilkinson, 2005: 12-13). With limited financial resources and increased dependency on alcohol, the nutritional status declines, making households even more susceptible to disease. Added to these are the problems of the crowded and badly ventilated *shebeens* (drinking taverns) that they frequent where tuberculosis pathogens thrive and multiply. A vicious cycle is created whereby illness increases stress and levels of poverty, leading to vulnerability to infections, dependency on alcohol and other drugs. In this sense then, alcohol can cause tuberculosis.

Importantly, however, this cycle of entrapment is not how it is presented in the clinics, or by the patients themselves. In the clinics management of tuberculosis is presented as simple moral and choice-based decisions and actions and not as a result of poverty and structural violence. Paul Farmer expresses the unfairness of this situation in the following statement: “There is nothing wrong with underlining personal agency, but there is something unfair about using personal responsibility as a basis for assigning blame while simultaneously denying those who are being blamed the opportunity to exert agency in their lives” (1999: 84).

Thembisa is a 44-year old HIV positive patient at Temba. Her boyfriend died in 1984 of a lung disease which may have been tuberculosis. He was working at a glue factory. Thembisa, crying, explains the misery in her life in the last few years leading up to her TB diagnosis:

> *My mother died in 1984. My father bought a house in 1994 and died in 1999. Then my brother came and chased us away. I had no shelter. I slept with men in shebeens who had no girlfriends. I had nothing, so men with no girlfriends were supporting me. That is where I got my disease [HIV] from. I felt that I had no future. I did not care what would happen to me. Clothes, food and shelter were most important to me. I hated everything. I felt that I was in the darkness, that I could not reach the better side. Then my younger brother looked for me everywhere and found me. He built me a shack in his yard. I can’t remember when it was, but three or four years after my father died. My brother, who works at a garage, now gives me food.*
>
> (ACSA pre test)

After Thembisa was chased away from her deceased father’s house, she did not have many opportunities to exert agency. In order to survive, she was forced to perform sexual favours. She would either sleep on cold *shebeen* floors or go home with men from the *shebeen* and spend a night at their service. Had Thembisa had other options in terms of employment or a supportive social structure to rely on, she would probably have chosen differently. However, with the life she lived due to poverty, it would almost have been a miracle had she *not* contracted HIV and TB.

Thembisa did not identify herself as a sex worker, but nevertheless engaged in an informal form of sex termed “survival sex”. Sex is used as a means to survive poverty and is classified with other forms of small scale informal money making and is relatively short-term (Preston-Whyte *et al.*, 2000: 166-167). Due to the informal nature of this form of sex work condoms are seldom used, putting women at risk of contracting HIV. For women refusing to perform sexual favours for money, drinks or unreliable relationships, rape and other violence is common (*ibid.*; see also Wojcicki, 2002).

5.3.9 Syndemic interactions as cause.

In a few words, Mirriam’s (52) story expresses the experience of a syndemic which the majority of TB patients in Grahamstown have to deal with.

> *In 2004 I started to get sick with high blood [pressure] and arthritis. I took treatment at Day Hospital for the high blood. Last year, in 2005, when I was taking the treatment for high blood, I was attacked by a bad cough. They [the nurses at the clinic] asked me if anyone at home had TB. I told them that my boyfriend had TB. Then they gave me a bottle to spit in and I found that I too had TB. When they told me about this TB I also asked them to take my blood, and they found that I was [HIV] positive…My boyfriend too is HIV positive.*
>
> (ACSA pre test)

Literature from Asia shows that there TB is a highly stigmatised disease (Atre, *et al.*, 2004, Auer *et al.*, 2000; Barnhoorn & Adriaanse, 1992; Rajeswari *et al.*, 2005). By contrast, Steen and Mazonde argue that tuberculosis does not carry a social stigma in present day Botswana, but fear that once tuberculosis becomes known as an AIDS related disease, TB related stigma may result (1999: 167-169).

HIV is a stigmatised condition. Health workers in Grahamstown have numerous stories of how people ask the health workers to park around the corner and walk to the client’s house so that neighbours do not see the car with the Department of Health or NGO logo. Prior to 1998, only those performing homecare for HIV patients would wear navy blue uniforms, now all the volunteers wear navy blue as a way to combat HIV related stigma for the individual patient. Some health workers have noticed that this has increased the stigma carried by TB patients as they are being labelled as HIV positive even in the cases where they are not. Health workers report that people delay health seeking for their tuberculosis due to the association with, and fear of having, HIV.

People who have TB experience stigmatising attitudes in their communities. Most people, particularly the younger generation, are aware of the syndemic. If a person infected with TB looks sick, it is often assumed that he/she has HIV. People with tuberculosis experience that *being* sick is not a problem in terms of attitudes, it is *looking* sick which changes attitudes. In particular, loss of weight is associated with HIV; both tuberculosis and HIV are wasting diseases. Patrick, who is co-infected, says: “I think they are the same, as when I have TB I also have a runny tummy, a temperature and I am losing weight.”

Patients who have to take their TB medication daily in the clinic are commonly regarded as being infected with HIV. This suspicion arose when people came to get their tuberculosis medicine and had to stand in a separate queue, and go to a special room. At Extension 7 Clinic people waiting in the general queue started gossiping that the people going “to that room” had HIV. As a result the health workers had to inform all the other patients in the clinic that “that room” was for people undergoing TB, not HIV treatment, suggesting that TB itself is not as stigmatised as HIV. However, with increasing awareness of the link between the two, increasing stigmatisation of TB may occur as a result. This was also found in the focus groups conducted through the SANPAD project.

5.4 TB and HIV terminology.

Together with the issue of cure, the difference between TB and HIV are most clearly expressed by informants in their terminology. In the United States, Rubel and Garro found that Mexican immigrants avoided using the word tuberculosis when discussing their illness due to the stigma attached to the disease (1992). This is contrary to my findings in Grahamstown where people had no problems calling tuberculosis by its name.

Whereas people who were co-infected would term tuberculosis by its real name, they would not use the term HIV. Although this influenced their disclosure of the condition there were cases where the HIV positive patient who had disclosed would still refer to his/her HIV as "this problem" or "this other problem of mine". In the focus group interviews with elderly people, HIV was also alluded to as "this thing that exists now", or "this existing disease", and the disease "with three words". This reluctance to verbalise the name of HIV as against that of TB signifies a difference between the two diseases in terms of stigma.

Although TB is curable and HIV can only be *managed* through treatment, access to effective medical treatment does serve to lessen stigma, but as evidence shows, add to it through increasing association in the clinic environment between people infected by one or both diseases. This again is linked to the knowledge of and belief in the efficacy of these medications. Whereas being infected with HIV is stigmatised because it is transmitted sexually and is deadly,[40] tuberculosis causes social avoidance as it "is in the air" and is transmitted from one person to another by just being in the same room or on the same vehicle.

Correct knowledge does not necessarily lead to correct action. Although Thando knows that TB is curable, he still delayed presenting at the clinic as he would then have had both to face and to tell others about his other, and in his case stigmatised, condition.

5.5 Marginalisation leads to illness leads to further marginalisation.

Richard Parker and Peter Aggleton suggest that both discrimination and stigmatisation must be seen as "social processes that can only be understood in relation to broader notions of power and domination" (2003: 16). As laid out in the introduction, a central aim of this thesis is to explore tuberculosis as a result of broader issues of inequality and marginalisation.

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[40] Isak Niehaus argues that in the South African lowveld AIDS related stigma is more connected to death than to sex (unpublished paper). As a result, TB related stigma may increase with increasing death rates due to syndemic interactions. Stigma is related to deadliness of the disease. Through biomedical therapy the diseases have the potential to be seen as chronic, as is the case among many young Europeans, decreasing stigma.

In her study of health and illness among villagers in the Ciskei, uncertainty in life and lack of control were mentioned by the villagers as a cause of illness (Segar, 1997: 1585). Increasingly, Eric is experiencing helplessness and frustration, and is worried about stigma, which inevitably will result in increased vulnerability to other pathogens as well as increasing the risk of his not being able to work, look after the family, adhere to the treatment and live. Eric sees stress and uncertainty both as coming from and causing sickness.

5.6 Conclusion.

This chapter has showed the relative usefulness of Arthur Kleinman's explanatory model, but has argued for a more inclusive approach combining individuals' EMs with the experience of structural forces and barriers to health care and health. Explanatory models are useful in understanding illness and responses to illness as well as patterns of health seeking, but they are incomplete if used in an analysis of socially induced diseases such as TB and HIV.

This chapter has shown that in most instances people know that *TB is curable*. They know *how* to achieve a cure. They are also aware of other factors influencing their sickness and health, although there is little awareness of the structural nature of these limitations. Due to structural constraints and barriers to care, many die of this curable disease. A large majority will never experience security, employment, education and freedom from these invisible structures. In our anthropological investigation, *barriers to care* are perhaps more important than *paths to care* when it comes to enabling people to stay alive.

Chapter 6.

Therapy managing groups and health seeking in Grahamstown.

6.1 Introduction.

This chapter explores the role of therapy managing groups (TMGs) among TB patients in Grahamstown. Therapy management involves the diagnosis, selection and evaluation of treatment and support of the sufferer (Janzen, 1987: 68). A therapy managing group is the group of people participating in the management of illness and/or disease of the afflicted individual; they provide or seek help for the illness, guide treatment decisions, and help take care of the individual. Members of a therapy management group may not necessarily share a common bond or coordinate their activities in a common strategy; they may in fact contradict each other and emphasise certain interests above another. More often than not, there is more than one sickness being managed simultaneously. Therapy managing groups do not necessarily identify themselves as operating within a group of fellow therapy managers. Thus, the notion of the therapy managing group is largely a useful analytical tool used by scholars.

The density and degree of participation of a therapy network may vary markedly between individuals depending on the nature of their household structure, kin group or neighbourhood. Some individuals may be fortunate to have a strong support network while others may suffer with weak ones. For Janzen, who coined the term, the process occurs mainly at individual and community levels and usually ends with cure (1978: 129 & 1987: 73). In Grahamstown therapy management for TB and HIV rarely ends with cure. Structural violence which gives rise to infections in the first place persists.

This chapter will identify and present examples of the ‘strong’ and ‘weak’ therapy managing groups that were encountered in the research and the way in which these impact on a person’s experiences of tuberculosis, and his/her ability to adhere to recommended therapy and cope with life after the completion of therapy. It is argued that tuberculosis patients with strong networks of social support are more likely to recover from tuberculosis than those with less social support.

The influence a TMG has on an individual's health seeking behaviour, and how this may be intrinsically linked to various TMG members' concepts of illness and healing (*i.e.* their explanatory models) will be examined. The final aspect of Kleinman's explanatory model, dealing with health seeking and treatment, is explored. It is argued that one has to situate the TMG within the broader socio-economic context of poverty and inequality, and examine how this influences their interests and ability to guide a patient's health seeking strategies and adherence to therapy. The use of traditional medicine was given some focus in the study, but data was limited as not only was it difficult to gain access to traditional healing groups, but the people I interviewed were reluctant to talk about it. I assume this reluctance was because I am white and spent much time with health workers in the clinic. As a result people may have associated me with supporting biomedicine and hence, in fear of being reprimanded, avoided the subject of traditional healing. However, it is recognised that it is likely that many patients do resort to traditional therapies. Further research is needed in this area.

It is recognised that gender influences experiences of illness and healing, but I was unable to explore this in great detail. It was however found that more men than women experience feelings of uselessness through their inability to live up to expected roles in society. Women, on the other hand, were seen to take on more responsibility for helping the sick and were more concerned about the family's well being throughout the course of sickness.

6.1.1 Aims of therapy managing groups.

The principal role of the therapy managing group members is to support, guide and care for the afflicted individual and to encourage him/her to make correct choices that will lead to recovery and the elimination of the sick role. Talcott Parsons sees the sick role as socio-structurally determined where the afflicted person is not seen as responsible for sickness, but as morally responsible for finding the sick role undesirable. He/she is also seen as being exempt from daily duties and obligations. Finally, according to Parsons, the sick person is expected to seek help from an appropriate health professional (Parsons, 1951: 437; 1978a: 21; in Shilling, 2002: 265). For Janzen, the sick role is "a way of defining and mobilising rights and duties within a community of persons who take responsibility from the sufferer and enter into brokerage relationships with specialists" (1978: 7).

Therapy managing groups often operate with limited resources. The strong TMGs observed in Grahamstown were those that encouraged the patient to get well throughout the course of his/her sickness. For biomedical practitioners, "getting well" from tuberculosis means adhering to recommended biomedical therapy; but for sick people and their TMGs the improvement of socio-economic factors is also important. Research has shown that strong social and emotional support has a positive impact on adherence to treatment among patients (see Barnhoorn & Adriaanse 1992; Blanc & Uplekar 2003: 107). In a strong therapy managing group kin will visit at home or in hospital, and motivate the patient to get well. Strong TMGs enable the sick to make choices and to exert agency, even after they have been cured. Financial resources and constraints often dictate the nature of a TMG's support.

Conversely, in a resource-poor setting like Grahamstown it was found that TB patients themselves were seen as a resource which members of the TMG hoped to benefit from due to their ability to access disability grants or make contacts with potential benefactors, such as health personnel. The problems that arise from this are explored in further detail in the next chapter.

6.1.2 Social capital and support.

Effective therapy management groups can be seen as a form of social capital. Social capital includes "trust, reciprocity, and cooperation among members of a social network that aims to achieve common goals" (Holtgrave *et al.*, 2004: 159). According to the authors, there is a relationship between tuberculosis and social capital, in that the less social capital and the more poverty and income inequality in a society, the higher the rate of tuberculosis (*ibid*.: 160). Ichiro Kawachi notes that "there is no good theoretical account of how to build social capital. On the other hand, there are many accounts of how social capital can be destroyed by various social and economic forces" (Kawachi *et al*., 1997: 1497). It is difficult for the socio-economically marginalised to build social capital and create networks of social support outside of their immediate kin group. In urban areas such as Grahamstown there is little reciprocity among neighbours.

Esther Sumartojo (1993) shows that social support networks are crucial of a patient's ability to adhere to therapy. Social capital and social support networks, mobilised through therapy managing groups, enable people with tuberculosis to adhere to prescribed therapy as well as combating social isolation as a result of illness and disease.

6.2 Who are members of therapy managing group?

In Grahamstown TMGs are notably smaller and less complex than those Janzen observed in lower Zaire (Janzen, 1978: 140). Research in Grahamstown revealed that the sufferer was often the primary negotiator in the management of therapy. Where kin were involved, the transactions between the kin and the afflicted usually took place in the home, away from the clinic setting. Members of therapy managing groups have frequently previously managed tuberculosis therapy for relatives.

6.2.1 The importance of kin.

Commonly a therapy managing group consists of the sufferer, the practitioners and the kin. If the sick person is married, or is in a serious relationship, the most important member of his/her TMG is usually the spouse or partner. For a single or young person the parents, siblings, aunts or uncles are the most common support. Grown daughters commonly assist their aging parents. It was found that women participate in TMGs more often than men. Only in Ronnie's case was no kin involved in the therapy management.

Unless the sick person is too young or old to manage him/herself, he/she usually negotiates with practitioners alone; to a large extent this is because clinic staff prefer to only consult with the patient rather than the support group. At home, the sick person will usually discuss his/her clinic experiences with kin, and plan further action.

Although therapy managing groups consist mainly of kin, this does not include all kin at all times. In the case of a stigmatised disease such as HIV, restrictions may be placed on who among the kin may know of the patient's condition. Moses has only told one of his sisters that he is HIV positive; the other sister, he says, "is too talkative" and he is concerned that she may tell non-kin about his HIV condition. Long after his cure, Eric and his wife Zoliswa are still afraid that people will blame Eric for sickness in the family, so they have chosen to keep quiet about his condition. TMGs are multilayered with different levels of trust and disclosure. The composition of a therapy managing group is not a constant, but changes according to the problem being managed.

6.2.2 Fellow sufferers and friends.

For hospitalised TB patients, fellow patients provide comfort and company. Lionel went jogging with a fellow patient when he was at Jose Pearson and found great support in being able to share in a common activity with a fellow sufferer. At Temba, patients spend sunny days chatting outside and cold days in front of the heater. Motivation from fellow patients is invaluable, although short-lived, as the relationship will usually end with discharge, death or cure. There appeared to be little interaction between out-patients in clinics.

Friends and neighbours play a limited role in therapy management. Members of kin frequently ward off neighbours, who are seen to spread rumours about the sick. The sick person tends to limit his/her external contacts because of the contagious and stigmatised nature of the condition. This may result in increased isolation and social stress.

6.2.3 Biomedical practitioners.

The clinic can be a supportive environment. Most clinics start the day with a prayer and song in the main waiting room. However, clinic personnel can also be barriers to care and frequently exhibit attitudes of moral superiority and control. Once, I wished to find out what Nomangesi’s knowledge of tuberculosis was and used a Community Health Worker (CHW) as an interpreter. Soon Nomangesi was crying and apologising that she did not know all the correct symptoms. The CHW looked at me and said dismissively: “It [contracting TB] is her own fault.” Whereas health workers can be helpful in understanding the situation of the sick and assist in therapy, their attitudes can also provide barriers to care. This is apparent in Eric’s case presented in chapter 7, section 7.2.1.

Despite the above recorded episode of insensitivity, Community Health Workers can often be important motivators and supporters. Margaret says that the volunteer visiting her from Middle Terrace Clinic had more impact on her health than professional practitioners: “She [the volunteer] has motivated me, even when I felt sick and did not feel strong enough to take the pills she was there for me and told me that they would make me feel better. Even when I was bedridden last year, she was motivating me to get better.”

Yvonne, who took treatment through the same clinic, has similar experiences. This is probably not a coincidence. Historically, Middle Terrace Clinic is located in the previously coloured area of Grahamstown which is a relatively wealthier area to the formerly black townships and has a lower rate of disease. As a result, health workers are less pressured and have more time for patients.

All clinic users living with HIV are encouraged to participate in a support group where five to ten HIV positive people talk about sickness related issues with each other and an assigned health worker. Apart from one MDR support group at V.Shumane Clinic, TB patients are not offered counselling or support. Support groups in the clinic do not play a major role in the therapy management of co-infected patients explored in this study.

6.2.4 Traditional healers.

Although I was not able to interview traditional healers in this study they can successfully be used as treatment supporters. In Hlabisa, KwaZulu Natal, patients found traditional healers to be trustworthy and genuinely concerned about their health (Colvin *et al.*, 2003). The Department of Health does acknowledge that the use of traditional healers as treatment supporters can be successfully implemented, but at the same time they warn that they have to be “selected with caution” (DoH, 1998: 69). Experience from nurses in the clinics indicate that nurses generally stigmatise traditional healers, seeing them as either causing delay in health seeking or as contradicting their therapeutic mandate.

6.2.5 Religion.

Religious groups provide support which is not kinship based. Prior to 1920, response to social problems in South Africa came mainly from religious, labour and educational organisations rather than from health and welfare organisations (Ginwala & Collins, 1991: 273). Lionel both found and gave support through religion. At Jose Pearson MDR

Hospital he gathered people for prayers in the evenings and earned himself the nickname "the pastor" from the other patients at the hospital.

Church plays a significant role in most patients' lives. Prayer at home is common, especially in female dominated households. From the patients I followed in detail, only Moses went to Church regularly, but all the other patients claimed to be religious and to find strength in their beliefs. Organised prayers in hospitals and clinics are appreciated by patients. For patients without regular visits from family, this is essential motivation and support.

6.3 Patient agency in therapy management.

In Grahamstown, therapy managing groups appear to have less influence than those Janzen describes in the lower Zaire, where sufferers may temporarily give up their decision making rights (Janzen, 1978: 7). Many of the patients assume a large degree of responsibility in decision making with regard to both their illness and their social responsibilities. The case below shows how the patient, Patrick, tried to take a more active role in managing his illness, and to continue providing for his family, despite the constraints on his ability to do this.

> *"…this is when I became ill. I was working and then I became tired. I was living with a lady and when I came home, she had not cooked. She did not believe that I was sick, so then I decided to move back to my parents. Then they took me to the clinic, but I did not want to go to the clinic because I wanted to work. I didn't just want to get money in my hands from my father. This was last year, in 2005, I think it was in March. When I didn't get well, by August, I moved in with my parents. They have an RDP house. [Before that] I was renting a house and worked as a contractor, making blocks. It was a hard job. I was given R 200 every week. My girlfriend was not working. I was the only one having a job. It was not easy. I have one child [1-year old boy]. He lives with my girlfriend's sister in PE [Port Elizabeth]. In August I found out that I have both HIV and TB. I was also sick with TB when I was 5 years old. My girlfriend is also [HIV] positive. I wanted to get a job so I could help my parents and build on to the house and start a spaza shop or something. Life is better now, because I can apply for a grant and maybe get for 12 months."*

(ACSA pre test)

Patrick's choices are financially rather than medically motivated and he continues to attempt to exert agency in a setting with limited resources. Although action is limited in impoverished settings, patients do their best to exert some agency within broader structural constraints.

6.4 Extended family as a support in therapy management.

Extended families can enhance the health seeking process. Although the size of the extended family network matters, the strength of the ties within the network is more important. In Botswana, Steen and Mazonde found that close to all TB patients (88%) discussed their symptoms with family members (1999: 166). This is also the case in Grahamstown. The more members of the family the patient discusses his/her sickness with, the less stress he/she experiences.

Moses is confident that he will get well, even though he has a drug-resistant strain of tuberculosis. His confidence is reflected in the strength of his social capital. Strong therapy managing groups may help the sick be less vulnerable to stigmatising attitudes. Sick people with stable support networks experience less stress and anxiety (Wilkinson, 2005: 25), and have more control over their health.

6.4.1 Multiple disease management within families.

Ironically, belonging to a family of multiple sick individuals can be a source of strength, but only if combined with other qualities and circumstances such as adequate financial resources, well-balanced stress management and supportive social networks.

Moses lives in a relatively wealthy, but sick, household which has a total monthly income of R 2340.00 – all stemming from social grants. Moses’s mother has an eye disease, but is now on an old age pension. Daniswa, Moses’ sister, has HIV and is on ARVs and was cured of TB in 2004. She illustrates the importance of having diverse assistance in management of therapy:

> *I was worried before, but now I take it as anything. I was thinking of taking my own life, but now I see that I can live for a long time because I have support from my family and the Church. There is also a volunteer at Settlers [Hospital], she also has HIV, who came to talk at Noluthando Hall. My brother asked her to come and talk to me.*

Despite his immediate support, Moses’s and Daniswa’s younger brother expresses fear for the future with loss of sick family members. Although he is healthy, he says that “most of my family is sick, so I am scared of the future – I might end up alone with my mother. I am very close to Moses. I rely on him for dealing with emotions – I talk to him about everything.”

Sharing illness with other sick family members can lessen stress on the individual, but this is only in cases where there is sufficient social and financial capital for people to be able to look after one another. Even when this is the case, isolation from the community is common, increasing the burden on the unit and making it increasingly difficult to become reintegrated into society once the burden of illness decreases.

6.5 Money as support in therapy managing groups.

Money is an important element of support in therapy management groups. It is expensive being sick or having sick dependents. Those who are dependent on someone who is sick become more vulnerable. In addition to increased medical expenses, the cost of food increases, as do transport expenses. Even with free medical care and hospitalisation Regina comments that: “I do use a lot of money, but I don’t count it. I would get a headache if I counted.”

More often than not, household income derives from temporary social grants. Money enables the sick person to exert more agency, lessens stress and worry, and increases his/her confidence and motivation. Large therapy managing groups with greater earning potential increase the financial stability of the unit, and give the sick more choice in whom to include in relationships of trust, and to disperse the burden of sickness on more people.

Large TMGs are not *automatically* more supportive than small ones – even though this often is the case. Thando, who had a relatively large TMG, was simply shifted out of this unit. Although Thando’s mother did not wish to speak to me, Thando explained that he did not feel that anyone in his family was open enough to deal with his sickness. However, Thando’s disability grant enables him to survive away from these insecure personal relationships of dependence (see section 6.8.1 below).

6.6 Success of a formal supporter role.

The ARV programme at Masonwabe Clinic does not admit a person onto the programme unless he/she has disclosed the HIV status to a close friend or family member, and a nurse and social worker have met and educated this supporter. The supporter must come to the monthly consultations at the clinic. This has a positive impact on adherence rates.

Clinic staff report that family members have been observed arguing over the supporter role leading one doctor to jokingly comment that: “Supporter jealousy – that is a new phenomenon!” In reality, this is a reflection of the poverty in the community, where family members scramble for resources – whether these are real or imagined. In some cases it is thought that being a treatment supporter enables the supporter to access food parcels, disability grants and favoured health care. This is however not the case. These perceptions are an indication of the level of initiative in the community where every possible opportunity for gaining resources is seized.

An official supporter role lessens the psychological burden of the patient and increases treatment adherence. Due to the different nature of HIV infectiousness and curability, this cannot be done in the same manner as with tuberculosis. This is nevertheless an example where the social aspect of sickness is acknowledged by people working within the formal health sector – and adherence rates increase as a result. If one is to achieve the right to health at local and individual levels, active social involvement of households should be encouraged.

6.7 Why did Lionel stop taking his treatment – three times?

This case study illustrates the complex and multifaceted nature of management of therapy and the impact that a lack of adequate social support can have:

Lionel has been “living in the streets” since he was 13 years old. His mother died when he was seven years old. His father was drinking excessively, physically abusing Lionel and his two sisters. They were poor, and the children were left to fend for themselves. “My family did their best I think, under the circumstances. Now I have no family. I don’t understand it when people talk about family. I never think about family. I am my own family.” Lionel has been in and out of prison since he was old enough to be put behind bars. His most recent sentence was four years for a number of break-ins, some of them which ended in violent confrontations. He came out in late 2003, infected with tuberculosis. He did not see a health worker in prison as ideas of masculinity in the prison gang he was a member of prevented him from seeking care.

Lionel was diagnosed with pulmonary TB in January 2004. He took his treatment through the local clinic, but did not adhere to treatment and so was sent to Temba Hospital. He protested against his institutionalisation:

> *I don't like to be locked up. I need freedom. They did not want to let me go. I forced them. I spoke to them loud and the lady at the gate know that she had no right to stop me. I have to listen to them, but they don't listen to me. I told her that I was a patient and that patients have rights too.*

He walked out the gate, and discontinued his therapy. After a few months he felt sick and started treatment again, but not for long:

> *I didn't feel like taking the treatment anymore. I had no food and my mind was going up and down. I knew that the pills would kill me if I don't eat food. I did not want the soup [given to TB patients at the clinic before they take their pills]. Food like that is for poor people.*

Although Lionel admitted that he considers himself to be poor in private conversations with me, he did not wish to publicly classify himself as needing nutritional supplements.

Lionel now lives with his wife, whom he has known since he was a teenager and married two years ago, and her child in a rented one-room corrugated iron shack in an overcrowded and muddy yard. He shares this yard with a number of other marginalised occupants. Next door to Lionel and Ntombekhaya is another corrugated iron shack, even smaller than theirs. An old man lives there. He uses crutches and has an infected sore in his leg. The smell coming from his room is unbearable. The neighbourhood is concerned about the children's health and wants the man to visit hospital because of his infection, but he refuses. A young woman who works in a fast food outlet lives in the third one-roomed shack. The fourth shack is empty, the door banged in by the last inhabitant who came home drunk one night without his key. When I first met Lionel, a retired couple was living in the RDP house placed central in the yard, the man was on TB treatment for the second time. They have now moved and a mother and her six children live there. She has a disability grant and is, according to Lionel, a shoplifter. In the main house, a three-bed roomed mud house, the landlord and his girlfriend live. None of the houses have running water, but there is a communal tap in the yard. All the homes have access to electricity (which is extremely dangerous since it is illegally wired from the main house where they pay the owner for its use), but Lionel has no money to do this. There are no toilet facilities, and people use buckets.

In June 2005 Lionel was diagnosed with MDR TB due to non adherence. Thandi, the volunteer responsible for him, had given up trying to get him to take treatment. Thandi herself suffers from HIV and as her CD4 count was below 200 she was recently put onto ARVs. Understandably she did not want to risk her own health by visiting an infectious MDR patient. Lionel was then sent to the MDR specialist hospital, Jose Pearson in Port Elizabeth, but ran away after four days. He told me: "I didn't want to come to that place [Jose Pearson]. I have been oppressed in prison for many years…such places like these [institutions]…it was another prison."

I became involved in the management of his therapy as a last resort. Lionel was now seen as being "lost to follow up" (see Farmer, 2005: 198). I spent two weeks chatting to Lionel about his health, his past and his dreams for the future. Finally, he indicated to me that he wished to speak to Sister M at the local clinic. We went to see her. He walked past the queue of waiting people, with a confident smile on his face. Lionel and Sister M discussed the seriousness of the situation and the measures to be taken.

The consultation ended with Sister M phoning to book him into Jose Pearson Hospital. Now there was no way back for Lionel. He looked at me, scared, and said: "If you don't come and visit me, I will run away again."

I visited Lionel once at Jose Pearson, but one evening I found him waiting for me outside my local supermarket. He claimed he had been walking around town the whole day, hoping to find me. He had been at the hospital for two months but had not been given the promised weekend off, so he ran away. He had been looking for me in the hope that I would advise him what to do as he now wished to continue his therapy again.

We agreed that he would go back to Jose Pearson Hospital on the Monday morning and that I would phone the hospital to explain the situation. When I phoned the hospital, the nurse told me that he was already back and had received his treatment that morning. It seemed that Lionel had finally taken responsibility for his health.

Why did Lionel not adhere to recommended therapy? He experienced severe social deprivation from a young age with the death of his mother and his abandonment by his alcoholic father, plus he was a victim of the broader structural inequalities of the apartheid system. Beyond resorting to crime he had never been given the opportunity to explore his potential or to develop confidence in himself. In a study of disease and cultural context in a urban area in Connecticut, USA, Singer and co-authors found that living in broken and impoverished homes, experiencing domestic violence, having limited exposure to positive role models, as well as having limited expectations for the future put them at risk for sexually transmitted diseases (2006: 2010). Although sexually transmitted diseases and tuberculosis are spread differently, they are both social diseases common in impoverished communities. These same factors are persistent in structurally impoverished communities and are all present in Lionel’s life, putting him at risk for social diseases such as tuberculosis. Poverty and weak family relations led Lionel to criminal activities resulting in his imprisonment, thus increasing his vulnerability to the tuberculosis pathogen.

Lionel says that he did not adhere to the recommended therapy because “there is poverty and hunger. I was suffering. You have to eat before you take your medication.” Ironically, by *not* taking the medication on an empty stomach Lionel was just following doctor’s order. He tried to explain this to clinic staff, but with the growing HIV/TB syndemic, the work load in the clinic is increasing rapidly and practitioners do not have time to listen to patients, nor can they do much to alleviate the poverty that leads to hunger.

After four months at Jose Pearson, Lionel was discharged and began taking his treatment as an out-patient at his local clinic. He now has a special relationship with Sister M – she calls him her “chum”, and has become a central part of his therapy managing group. Lionel keenly understands the value of social support and says that “sometimes people surprise you if you give them a chance”. Even clinic staff, he says, give him support, trust and encouragement. They used him as a motivational speaker at World TB Day in March 2005, in turn motivating him. “I have found a purpose now: I want to speak to others [about TB].”

6.8 Therapy management and the nuclear family.

Janzen found that in rural lower Zaire spouses play a relatively insignificant role in therapy managing groups, but with the absence of broader kin networks in the urban areas they are important. In urban areas, non-kin too play a significant role in therapy management (Janzen, 1978: 130 & 150). However, in Grahamstown, non-kin do not play a significant role in therapy management. If the sick person is married, the spouse is the main and often only social support component in therapy management outside of the clinic environment. The extended family plays a peripheral role.

Besides the medical practitioners that treat Eric, only two people are beneficial to him in his therapy managing group: Zoliswa, his wife, and me. The potential members of Eric’s TMG are looking to him for support rather than the other way around. When Eric first started receiving a disability grant for his affliction his relatives put great demands on him to share the money with them, which he did. Now he is earning a salary, and they expect him to continue with the financial support.

Eric and Zoliswa would like to divulge his condition with his employer, which may make the management of his condition easier to cope with and potentially increase his social capital. They are nervous to do this however after Eric’s past bad experience with a previous employer where his HIV status caused him to lose his job after his doctor told his employer, who then accused Eric of stealing from guests at the hotel he worked at. He is also afraid of being stigmatised in the workplace. Eric’s own family is not involved with helping him manage his condition and Eric has not told them that he has HIV. Understandably Eric is worried that he may not be able to manage his HIV infection and therapy should his condition worsen in this structurally weak therapy managing group.

Zoliswa gives this vulnerable TMG a unique strength. Not one decision is made without her. Often, Eric and Zoliswa discuss issues before raising them together with me and then making a decision. Eric says: “My wife is like a baby; when she says something, I have to listen to her. I don’t have friends. My one friend; that is my wife.” When Eric first started feeling sick in August 2003, Zoliswa suggested they both go for an HIV test. She had no sexual relations apart from with Eric and knew that if he tested positive, he had been unfaithful – and both she and their son Luvo would be at risk. Despite her strength, loyalty and support, also in dealing with Eric’s infidelity, Zoliswa does not have the confidence or ability to challenge the structural factors limiting Eric’s lack of ability to manage his illness adequately.

With regards to both social and financial capital, therapy management based only on the spouse and practitioners can be vulnerable and inflexible. Patients with weak therapy managing groups ideally need to extend their external networks beyond that of their kin, however this may increase their vulnerability to stigma. Despite these constraints sick people are not passive sufferers, but *do* exert agency within the limits of structural constraints.

6.8.1 Characteristics and examples of weak TMGs.

Social networks impact on sickness *before* it breaks out, and also continues *after* cure. Weak therapy managing groups are generally small units that are dependent on few financial and social resources. With increasing resources, social confidence and potential for increasing networks grow. Beyond the example given above on Eric’s weak TMG, the following cases provide examples of weak therapy managing groups. The first case is weak mainly due to its limited size whereas the latter is weak due to the group’s denial of sickness and fear of stigmatising attitudes.

Ronnie: Ronnie started off his TB treatment under the DOT system at the Raglan Road Clinic. When it became too far for him to walk to the clinic, he became an out-patient at Temba Hospital. His condition deteriorated further and the nurses offered him a place at the hospital. He declined the offer as he did not want to leave his house empty and his dog, his only companion, with strangers. He kept walking to get his treatment, every day a little weaker than the day before.

Ronnie's TMG consisted of himself, the practitioners and me, and he felt isolated and alone. He told me it was difficult to remedy this situation: "Who will I talk to? People will think that I am mad if I walk up to them and start talking to them about my diseases!" Eventually he became too weak to walk to the hospital and he was fetched by an ambulance and taken to Temba where he stayed for two months before he passed away. His exhaustion and delay in hospitalisation was a product of limited social capital in managing his sickness. He died alone.[41]

Thando: Thando's declining health is tragic evidence of the disastrous way in which the dual syndemic of HIV and TB is playing itself out on the ground. Thando started feeling tired and was losing his appetite in early 2005. By June, his health had deteriorated further and he was taken by ambulance to Settlers where he was diagnosed with TB. He was immediately admitted to Temba where he started his TB treatment.

> *I was very sick. I did not know what was going on. I was saying things and thinking about my father. I wanted to go and see his grave. At first [after telling his family that he had TB] they did not want to shake my hand. When I told them that my TB is under control, then they did shake my hand. Sometimes I can see that they are afraid of getting TB. They can see that it is serious.*

After two months at Temba Hospital Thando's health had improved and he started taking his treatment at the local clinic. He found Temba a depressing place in which to get well; it was a place of death: "People die here! It is not nice to look at. Every week, often twice, there are people dying. My mother was afraid of losing me." Apart from the visibility of deaths from, when occurring on its own, a curable disease, this quote highlights two important aspects related to poverty and marginalisation: Firstly, that despite Thando's perception that his mother was afraid of losing him, she did not come and visit him. Even when he was discharged, she did not support him, but isolated him further. Thando was told to move away from the main house which is always lively and full of visitors, to an empty family house and has become increasingly isolated from his family. The will or desire to help in managing therapy can be less than the ability to do so. Secondly, Thando was admitted as an in-patient to Temba Hospital. Wealthier people can afford private care and avoid hospitalisation. The structural violence that plays itself

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[41] While in hospital, Ronnie gave his house key to a former lover so that she could look after his dog.

out even at the family level means Thando has limited ability to choose how and where to take his treatment.

Thando was cured of tuberculosis over Christmas 2005. Two months later, I expected to see a vibrant, healthy young man, but when I went to visit him he looked sicker than ever. My field diary from that day reads:

> *A young woman, Thando's cousin, is sweeping the floor. She is not even 20, still at school, and has moved in to look after Thando. She looks up at me and smiles when she sees me standing in the doorway. We have met once before. I ask if Thando is at home. I was driving past and just wanted to remind him that I am taking him out for lunch later today. She goes into the bedroom and tells Thando that I am here to see him. I hear them speak in Xhosa. Her voice is soft, as if she was talking to an old man, but Thando is only 25. She signals that I can go into the bedroom.*
>
> *I hold the curtain separating the rooms to the side and see him sitting on the bed. He looks small, barely there, as he sits on the big made up bed with a plastic wash basin at his feet. His hair is as soft and thin as a newborn baby's hair. The skin on his thighs is grey, nearly see-through. I can see his bones through the grey skin. There is not much else left of him. He looks at me and says: "I think it is time now. I will go to the clinic." I look at him, trying hard to keep my tears back. I am relieved at his decision, but also angry, not at him, but at a society that allows for these things to happen. The fact that I am in his bedroom while he is half naked…What am I to him? Why am I in his bedroom? Does he trust me at last? Or is he just too weak not to? He has moved away from the family. His mother does not want him at home. Only his cousin is with him. He looks at me, nods, and says again that "now it is time". He lives outside of the world. His ears are weakened and he can't hear or speak properly. He is separate now.*

It is still unclear what Thando was waiting for before it would be "the right time" to seek help for his HIV infection. At the time of writing he is in hospital, unable to speak more than a few words, to hear or to eat by himself. It seems like Thando is experiencing a form of social death where his family has moved him away from their normal context of mutual support (see Niehaus, unpublished paper).

Thando had a weak support network, and was never encouraged to seek help for any of his symptoms. Despite this lack of support he went to the clinic every day for four months, taking TB medication and had his little green book ticked by health workers. Even so, he was never offered ARVs. Staff at his local clinic know that Thando is HIV positive. Before this, Temba staff knew of his condition. However, as is often the case, there are simply not enough human resources in the clinic to go through the process of getting ARVs for all who are in need of them. There is neither sufficient staff nor space in the clinic to counsel people confidentially. In this case, patient negligence is more due to lack of resources at clinic level than anything else. While one infection is treated, the other is allowed to develop further. As a result, the sick get sicker. Thando's case illustrates the vicious cycle that surrounds these syndemic interactions between the two diseases and the lack of capacity and resources to deal with both.

6.9 Fluidity in therapy managing groups.

The composition of TMGs is not static but changes over time. When Lionel was first sick, he felt alone as his wife lived elsewhere. He did not feel that he got enough support or encouragement from the various practitioners he encountered during the treatment process, first at the clinic, then at Temba and finally at Jose Pearson. Consequently, he was not motivated to take his treatment.

I became involved in Lionel's therapy management after the clinic personnel had given up on him. However it was when Ntombekhaya moved back to live with him that Lionel's drive to get well increased. With his increased desire to get well the clinic personnel were then prepared to motivate him to take the treatment. When Lionel was sent to Jose Pearson MDR TB Hospital, Ntombekhaya was unable to encourage him by phoning or visiting due to financial difficulties. As he was no longer the responsibility of Sister M, and the nurses at Jose Pearson did not spend much time with the patients, his motivation began to wane. Although I visited him monthly and his fellow patients encouraged him to get well, he was still unhappy and absconded from the hospital because it reminded him of prison. When Lionel was referred back to the clinic, Sister M and Ntombekhaya again became his main motivators. Now, more than two years after his first TB diagnosis, Lionel still struggles to find motivation to complete therapy.

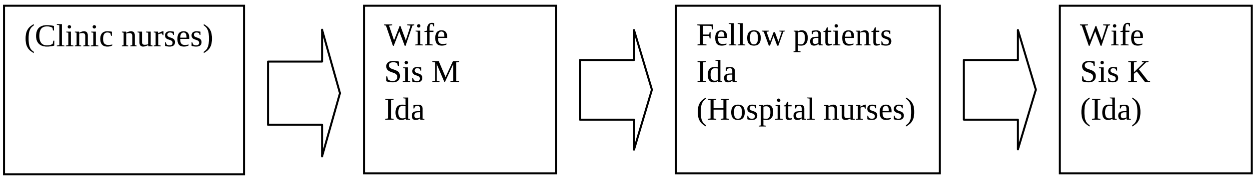

Figure 5.1: *Changes of support over time in Lionel's therapy management. Brackets indicate where the support by the member/s was relatively weak.*

When Lionel's therapy managing group was at its smallest (the first box) he did not adhere to treatment. In the two following phases the TMGs were relatively strong and Lionel was motivated to take treatment. Now, in the final phase of his treatment, his therapy management group has again decreased and Lionel struggles to find motivation to continue his treatment.

TMGs fluctuate according to changing social and financial needs of the patient, institutional and geographical movement, shifting family circumstances and structures of inequality impacting on the sick person's ability to adhere to recommended therapy.

6.10 Treatment.

All informants in this study reported that the medication made them feel better. Some said that they felt better after only a few days, whereas for others it took months. The importance of taking the treatment is well understood by the patients, even among those who periodically lose motivation to do so. Their explanations for their efficacy were not necessarily based on biomedical understandings.

Moses explained that he knew the pills were working as he could feel them move around in his stomach. Lionel understands that he must take the pills to get well, but despite this he often defaulted because of the problems caused by an inadequate diet:

> *The first time I didn't eat my medication properly in the right way. Sometimes I did not go to fetch my medicine, there is poverty and hunger, I was suffering. You have to eat [food] before you eat your medication… [but] I am just going on eating it [the treatment], because there is no other way. If you want to live, you have no choice.*

Like Lionel, people sometimes feel *too sick* to take the pills. Where people are undernourished or just plain hungry, which is common in Grahamstown, the strength of pills can make the patient feel nauseous and increase non adherence. The medication is highly toxic and includes unpleasant side-effects such as nausea and dizziness. Other patients have reported that they feel a tingling sensation in their body and mental and physical exhaustion.

6.10.1 Use of traditional healers.

South Africans negotiate their sickness and healing in a pluralistic medical system. Often different therapies are complimentary rather than conflicting, although there is potential for harmful drug interactions between traditional and biomedical remedies and between different biomedical treatments.[42] As soon as TB patients are given biomedical therapy for their sickness, clinic personnel require that they discontinue traditional remedies to prevent potentially harmful interactions.

Sharing common explanatory models limits conflicts over therapeutic choices. Among the therapy managing groups in this study, there appeared to be a general consensus regarding symptoms, causes and treatment of disease, limiting conflicts throughout management of sickness. This consensus may be superficial as they are mostly exposed to the biomedical paradigm during the treatment process and are more likely to recite what they have been told by the biomedical personnel. The conflicts that were observed in the therapy managing groups appeared to have been mainly related to financial insecurity.

Auer *et al.* report that in Manila, Philippines people with TB symptoms "shop around" for a diagnosis before beginning treatment (2000: 658). Ndeti reports from Kenya that people often see traditional healers before and during TB treatment (1972: 399). Some informants in this study admitted that they also consult traditional healers, but none admitted to me that they did so for tuberculosis. This may have to do with the fact that tuberculosis treatment in the clinic is free, whereas the patient would have to pay for therapy through a traditional healer. Some traditional healers in the area have experienced patients consulting them for TB-like symptoms, but once they diagnosed the patients with tuberculosis, they referred the patients to the clinic.[43]

The use of traditional medicine is common in many places in South Africa, particularly in rural areas lacking modern health care facilities (Edwards, 1986: 1273; Cocks & Dold,

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[42] As little research is done on this, the ARV programme has adopted a precautionary approach not allowing any patients to take dual treatments. There is scientific proof that garlic and "African potato" can counteract the effect of the ARVs http://www.essentialdrugs.org/indices/archive/200505/msg00001.php (accessed 24.10.06). In particularly weak patients, the side effects from both TB and ARV medication can produce powerful side-effects impacting on the adherence rates.

[43] This is evident from the focus group with traditional healers.

2000; Dold & Cocks, 2000). In this study, traditional healers were often consulted for ritual purposes, some of which could be TB related, and for general medicines for the strengthening of the immune system and for combating “weak blood”– also important in order to deal with TB and HIV. The knowledge of the necessity for biomedical drugs in order to cure TB appears widespread and as a result traditional healers are not extensively used to manage TB. Traditional healers confirm this in their focus group interviews where they claim that they can not cure tuberculosis, but only “blood vomit” caused by the *impundulu* (see chapter 5, section 5.3.5).

Moses says that TB is different from other culture specific ‘African’ diseases (*ukufa kwabantu*) and that a traditional healer cannot cure it. “In fact you will get worse if you use traditional medicine,” he adds. This may also be influenced by the information given at Masonwabe Clinic. As some traditional remedies interact with the ARVs, people are not admitted onto the programme unless they are counselled on these interactions and agree not to use any sort of traditional therapies while taking ARVs. TB patients are told the same at the clinic, but they are not denied TB therapy if they take traditional medicines. Ronnie did not tell the nurses at Temba that he used traditional medicine in the weekends as he only received TB treatment on week days.

Lawrence believes in witchcraft, and uses traditional medicine to cure his depression which was a result of witchcraft rooted in jealousy. His wife Eugenia and three-year old daughter are undergoing TB treatment at Joza Clinic. Eugenia is HIV positive, but Lawrence and the child are negative. Lawrence has split his holistic notion of illness into the physical and spiritual components and claims that he sees TB as “scientific”, needing to be treated with medicine in the clinic. However, this does not mean that he always sees physical affliction as separate from the underlying spiritual causes of the disease. In addition to taking traditional medicine for his depression, he is also taking biomedical antidepressants. The biomedical treatment merely attends to the physical pathology resulting from a more spiritually determined aetiology, the latter requiring its own culture based therapy.

Lawrence does not know about any *sangomas* (traditional healers) who can cure HIV or TB and does not know of any people who see them in order to cure these conditions as people know that these need medicine from the clinic. “Sangomas,” he continues, “can only help you with things like witchcraft and winning the lotto, not diseases you can see in the lab.”

The majority of those who do “shop around” after starting recommended biomedical TB treatment are non adherent patients, wanting to get away from nurses who blame them for not adhering to the treatment. However, these patients will usually negotiate therapy between different clinics rather than between traditional and biomedical healers.

6.11 Management of illness and disease, even after TB cure.

Throughout the course of treatment, health workers tell patients to change their behaviour. Nozithembiso was told not to be in the same room as someone smoking and not to eat spicy food or drink cold, fizzy drinks. Lindelwa has taken out the carpet of their house, as it collected too much dust; however it probably increases the cold. All adults are told to stop smoking and drinking, and everyone is told that they need to improve their nutritional intake. Unfortunately these behavioural restrictions and prescriptions are not only superficial but are often unattainable (such as improving their diet). Far more fundamental changes need to be made in order to stay healthy.

Lindelwa does not have a job. She has tried to find one for many years, but unemployment in Grahamstown and the Eastern Cape Province is endemic. The only income Lindelwa has access to is linked to her children: Nozithembiso’s disability grant is R780 per month and Kuhle’s child grant is R180 per month. They do not own a house nor do they have access to a family house due to fighting in the family over Nozithembiso’s grant. Lindelwa is dependent on the children’s grants and other people’s kindness to survive. This instability makes them vulnerable. In the first year I knew them they moved four times. For Nozithembiso, who is on chronic medication and needs to see health workers regularly, this instability can be life threatening. Both Lindelwa and Nozithembiso know what is needed in their lives is for Nozithembiso to stay healthy. Providing this is more difficult.

Taking medication for an extensive period can be frustrating, especially when the diagnosis changes or is not properly understood, as was the case with Lionel and Moses.

During one of his most frustrating periods at Jose Pearson Hospital Lionel could only hope for a better future and said: “I have nothing. I have lost everything. I want my freedom. I can do anything…but when you have no freedom…but now I understand why I have to be here. But I need to move on, create something for me, with my life.” Lionel has dreams of starting a church, but with little education and limited employment experience, he has little basis from which to take risks and to invest.

Moses says that he wants to get a job when he is fit enough to work, but he does not want to work as a security guard again as that is where he got cold and wet feet, what he thinks resulted in his tuberculosis. He lost his job because of HIV-related tuberculosis and was not given the Unemployment Insurance Fund (UIF) money he was owed. He has a disability grant, but this is only a temporary measure. Moses hopes that he will be able to work again, but with endemic unemployment, the chances are that a person with HIV and years “lost” due to MDR TB will never get a secure job again.

Initially, I was hoping to find out in what way tuberculosis was a life changing experience for those suffering with it. In most cases, it is the *combination* of TB and HIV which has the most life changing impact. As Packard (1990) shows, tuberculosis is a fairly common occurrence in this region. The changes to people’s lives occur mainly through co-infection with HIV. This is precipitated largely by poor socio-economic conditions that are both the product of and result in increased poverty and insecurity.

Social and medical factors are mutually linked in the HIV/TB syndemic. Moses lost his employment due to tuberculosis, as did Margaret, who now depends on an old age pension and feels “useless” as a result. Eric lost his job due to HIV. Nozithembiso had to adapt to a new place and make new friends after TB cure; Nomhle gave up beer selling and moved in with her sister, increasing her dependency. Thando was reinfected with tuberculosis shortly after he was cured. Apart from Margaret, all these individuals are infected with HIV. Even after ‘cure’, the sufferer and his/her TMG have to continuously negotiate their precarious social and medical positions with practitioners, social workers and officials who control social grants. Stress and insecurity increase, making them vulnerable to relapse and damaging their health further. Richard Wilkinson points out that it is directly damaging to health not to have control over one's work or one's life. This, he continues, has more to do with social than natural limitations (2005: 241).

In contrast to John Janzen's study in lower Zaire (1978) where therapy management networks were strong and extensive, usually resulting in the resolution of the sick role of afflicted individuals, this study has revealed that weak and fragmented TMGs caused by broader structural forces prolong the sick role and make successful recovery more difficult to attain. As argued throughout, structures of inequality impact on every aspect of sickness and health, and it is essential that anthropological theory and practice make this an integral aspect of their analysis.

In the focus group interviews with (TB negative) community members it was often mentioned that people who have completed TB treatment and are cured are respected and considered strong people acting as good examples to the community at large. One participant said that she saw a cured person as "a strong person because she was able to endure the pains", whereas another termed a cured person as a hero.

Strong therapy managing groups can limit stigma and increase the confidence of the sick. A Joza patient was told by his employer that he should only return to work after he had finished the entire course of treatment. The patient told a CHW about this instruction and she promptly went to speak to the employer. As a result of her intervention the TB patient was allowed to return to work. The importance of "making social of disease" and of ensuring both medical treatment and social empowerment is apparent. A physical cure in itself is often not enough to remain healthy. The ability to sustain oneself after successful treatment is an important aspect of therapy management.

6.12 The syndemic.

As explored in chapter 2, section 2.12, and shown throughout this thesis, the concept of a syndemic is useful to understand how structural, historical and socio-economic realities interact to give rise to certain diseases and how these create new medical and social problems and challenges (Singer *et al.*, 2006: 2011). Strong therapy managing groups are best equipped to deal with both the social and biomedical challenges that contribute to the HIV/TB syndemic. The TB/HIV syndemic has now permeated many people's perceptions in South Africa, since the two are increasingly found together. A number of TB patients report that they are now judged negatively, since people believe that if they have TB they must also have HIV, a highly stigmatised disease in South Africa. Patrick notes that: “If you look sick, people don’t want to touch you or sit next to you and you have less support.” For the general population, looking healthy means that you are healthy. Sick people are perceived to have HIV, resulting in increased stigma and delays in health seeking, including those only suffering from TB.

Thando observed that the TB/HIV association causes delays in health seeking behaviour. Ironically, this was also the case when Thando himself was reinfected with tuberculosis. Before he had TB, he did not know of anyone with the disease “because these people are hiding, even with TB. I think it is because you lose a lot of weight. In the township, people think you have HIV.” This association of the two diseases increases stigma, also for those who are *not* co-infected. I argue that measures to strengthen social capital and therapy managing groups can enable the sick to deal with the syndemic at both medical and social levels.

6.13 The anthropologist’s role in illness management.

My involvement in illness management has been a fruitful research tool and beneficial to some of the sick people I have studied. I observed that the weaker the therapy managing group, the stronger the applied component of my research was. Assisting those in need, while not creating relationships of dependency was a fine line to walk. Although I found myself assisting with patients’ socio-economic problems, I also helped them understand the progress of their therapy management. I was also asked to explain the clinical results of certain tests such as X-rays and the biomedical diagnosis to patients when this was not done by the doctor.

Being available to talk to patients and show an interest in them was a great strength to how they responded to their condition and their therapy. Eric’s social capital was limited. He did not talk to anyone apart from his wife and me about his life: “My friends…that is my family, the people I trust, and also you. I talk to you, Ida, about my problems.” Eric’s illness management has been, and still is, complex. He would consult me on where to move, whether to rent a house or not, what to do with Fundiswa (his HIV positive sister-in-law), and which school Luvo should go to. I have been asked to read and check on the finer details of his employment contract and the papers on the house they live in. I have also been invited to an *umsebenzi*, a traditional family council for Zoliswa's extended family, where funeral arrangements for a deceased relative in Johannesburg were made (Eric's case is explored in some detail in the next chapter, section 7.3.1 and 7.6.1).

These interactions are not mentioned merely to emphasise my personal involvement. Rather, they are emphasised to demonstrate the importance of social capital in helping marginalised people cope with the demands of their daily lives. They will grasp at any chance to enable them to exert some agency in accessing rights in their lives and in shaping their futures.

6.14 Conclusion.

Therapy management is a social process where strong social ties and networks are more likely to produce a healthy outcome for the sick than weaker networks. Generally, large therapy managing groups are more flexible and have the potential to limit the impact of stigmatising attitudes on the patient. In the light of the pressures that illness brings people often reexamine relations with kin (Nichter & Lock, 2002: 14), health personnel and friends.

The marginalised are excluded from macro oriented networks of social solidarity. The data gathered in this research challenges notions that the cure of tuberculosis stops at the biomedical cure. It is shown that therapy management is dependent on socio-economic factors and embedded in a context of structural violence. Most importantly, it has been shown that a disease such as tuberculosis can best be managed through the involvement of social support networks in the healing process.

Chapter 7.

Social grants: a trade off between rights to health and social security for the structurally poor.

> Throughout the world, those least likely to comply are those least able to comply…these settings are crying out for measures to improve quality of care, not the quality of patients.
>
> Paul Farmer, 1997b: 353

7.1 Introduction.

This chapter explores social grants and their impact on patients' ability to adhere to recommended therapy. Whereas some cases explored do not deal directly with non adherence, structural factors limiting agency of the sick are evident. Terminologies of compliance and adherence are discussed and it is argued that although adherence is a less judgemental term than compliance, another approach to adherence is needed in a context of extreme poverty. Farmer points out that although people may be "non compliant", this notion has limited use value (2005: 151). People act within a context of structural poverty and marginalisation, making strategic and rational choices concerning their health, and in many cases continued illness.

A number of social scientists have looked at and identified health beliefs as one of the main causes of non adherence to treatment (see de Villiers, 1991; Vecchiato, 1997; Barnhoorn & Adriaanse, 1992; Liefooghe *et al.*, 1995). In Grahamstown, most cases of difficulties in adhering to therapy are a result of complex structural factors beyond patients' control.

According to clinic personnel, the "defaulter rate" in Grahamstown is approximately 25%, but due to insufficient data capturing, this figure is unreliable. There is a lack of understanding among medical personnel as to *why* patients don't adhere to treatment. This is a result of a number of factors: firstly medical personnel are rarely privy to a patient's day to day life, struggles and the factors that guide their decision-making; secondly non adherence is regarded as a negative act which can lead to the patients receiving severe reprimands and harsh treatment from the staff at the clinics, which makes them subsequently avoid going back. Consequently, it is difficult to evaluate policy or practice to improve rates of adherence.

Social grants such as child grants (R180 per month), disability grants and old age pensions (each R780 per month) are indispensable incomes for people living in abject poverty and with little hope of finding permanent employment. The South African welfare system is built upon the idea that a person’s potential for full employment is a given fact (Nattrass, 2005: 3), notwithstanding illness, age or disability. This is far from reality for the millions of unemployed in the country who, although eligible to work, find it difficult to secure any form of employment due to lack of opportunities or skills. Grants are actively sought after by this large group of unemployed individuals, who change their behaviour considerably either in order to access grants or to be a dependant of someone who has access to one. Sadly, although a lifeline for many, the grants themselves have generated ‘perverse incentives’ that impact negatively on the treatment and management of illness, especially HIV and TB (Nattrass, 2005: 14).

7.1.2 Rights to accessing grants.

With the advent of democracy in South Africa a new constitution, including the Bill of Rights, was introduced (amended in 1996). The Bill of Rights guarantees all South Africans the right to access to health care services, social security and to life.

People with tuberculosis have the right to access a temporary disability grant (DG) for the duration of treatment. For pulmonary TB this is six months whereas it is eight months for retreatment cases. Extra pulmonary and MDR TB qualify the patient for a 12-month DG. None of these grants are guaranteed and allocation is at times random. New guidelines are in the making, but it is unclear as to what these will entail. Confusion and frustration are as common among patients as they are among practitioners.

Dr B is employed by Makana municipality to examine TB patients at the clinics and sign grant forms. Patients have to fetch the grant form from the Department of Social Development and present it to the doctor during consultation. According to the doctor being responsible for signing grant forms “is quite a strenuous job, because there is [so much] poverty [and stress is increased]…”. Dr B visits each clinic for one or two hours once a week and sees on average 15 patients per hour (an average of four minutes per patient). As was also found in a study in Khayelitsha, Cape Town (Macgregor, 2006: 50), most of these patients are seeking the DG. The Provincial Department of Social Development ultimately decides whether the grant application will be successful or not, but for patients, health practitioners are the face of this powerful decision-making body. Legally, the applicant has the right to an answer within three months, but this is seldom the case, with many dying before their cases are even considered (Hardy & Richter, 2006: 90). Hence, the sick have their rights infringed upon even by the government which is there to assist them.

Disability grants can also be accessed by people living with HIV. Previously, people living with the disease were given a permanent grant reviewed every five years or so, but with the introduction of ARVs, people now get the grant for 6 or 12 months, and only if their CD4 count is below 200 or if they have reached the WHO clinical Stage III.[44] After that, they have to reapply and enclose a recent CD4 count with the application. The DG will only be reallocated if the CD4 count is less than 200. HIV is no longer seen as a permanently disabling disease as people now can live active lives with antiretrovirals. Although HIV/AIDS is chronic, ARVs increase the period of which the sick are able to work. Unfortunately, they are severely weakened in a strained employment market.

The definition of “disabled” is contested. If health is defined as “the ability to work”, as it is in biomedical practice (Waitzkin, 1989: 222), then to be disabled means to be unable to work. For the Department of Social Development, the grant is compensation for people who are disabled, i.e. medically or physically unfit for work. The Social Assistance Act of 1992 (amended in 2001) defines a disabled person as someone “who has attained the prescribed age [18] and is, owing to his or her physical or mental disability, unfit to obtain virtue of any service, employment or profession the needs needed to enable him or her to provide for his or her maintenance.” As a result, the grant lapses when the patient is able to work again. The poor and sick have a different and perhaps more nuanced

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[44] A CD4 count of 200 is also the upper limit for being admitted onto antiretrovirals. Before that, people are generally healthy enough to manage their infection through good nutrition. For the poor, this is difficult to achieve. The WHO Stage III is characterised by a number of chronic persistent symptoms such as chronic diarrhea, oral thrush, fever, weight loss and, notably, pulmonary tuberculosis within the previous year (Hardy & Richter, 2006: 94.).

perspective on the disability grant. For the marginalised, the grant is seen as a means to alleviate poverty in communities with endemic unemployment. The disability grant is seen as compensation for being poor and sick, not for being unable for work. People are disabled through structures of violence.

7.1.3 Defaulting, compliance or adherence?

Esther Sumartojo argues for the use of adherence rather than compliance as the latter "has the unfortunate connotation that the patient is docile and subservient to the provider" whereas the former "reflects the active role of the patient in self-management of treatment and the importance of cooperation between patient and provider" (1993: 1311). For Donovan and Blake to comply is "to obey, submit, defer or accede to instructions" (1992: 507) whereas Trostle describes compliance as part of an ideology "based on the proper relationship between physicians and their clients" (1988: 1303). Ideologies, he adds, "help to transform power (potential influence) into authority (legitimate control)" (*ibid.*: 1300).

Paul Farmer emphasises that the notion of compliance implies that we are all equally able to comply (1997b). Within the constraints of structural violence this is not the case. Changing our terminology, Jessica Ogden argues, is a step in the right direction, but can only solve part of the problem. "More fundamentally," she argues, "what is needed is a shift away from the reductionist tendencies in biomedicine" (1999: 230). Practitioners' attitudes to the sick are expressed through their choice of terminology. Thus advocating for a change in terminology is to advocate for a change in clinic practice, where the patient is not blamed for 'irrational' behaviour judged as 'wrong' by clinic personnel. Through a change of terminology barriers to care can be deconstructed (see Donovan & Blake, 1992; Ogden, 1999; Sumartojo, 1993; Trostle, 1998).

Donovan and Blake argue that non compliance is an issue for the practitioner more than for the patient. The patient is concerned about needs, costs and constraints in their lives. This is missing from much of the compliance literature (1992: 507-8). Nevertheless, they conclude their paper by focusing on clinic interactions, saying that "the key to improving rates of compliance…is the development of active, co-operative relationships between patients and doctors" (*ibid.*: 512). Problems related to non adherence have to be solved *outside* of the clinic more than within the confines of the clinic.

7.2 Adherence in South African as caused by "culture".

A study of patients' beliefs in Limpopo Province in South Africa found that the cultural and social context of the patient influenced adherence to treatment. Tuberculosis was believed to come about through breaking sexual taboo. Resulting disease could only be cured by traditional healers. The same study found that patients had difficulties in accessing clinic care and once they were attended to, health worker attitudes were, according to the authors, unacceptable (Edginton *et al.*, 2002: 1075). The study shows the relevance of cultural beliefs to health seeking behaviour, but regards cultural beliefs as separate from the problems encountered within the clinic environment. The authors fail to draw a connection between the reported negative experiences in the clinic environment with patients' alternative health seeking strategies. In addition, they fail to see that the clinic too is a cultural space, not neutral as is often thought.

Care must be taken not to explain the causes of non adherence, late case presentation, or sickness itself, exclusively as a result of "culture" or "cultural belief" (Farmer, 1997b: 352). There is a complex mix of factors that may lead to it and among these are the issues surrounding what Nattrass terms the "perverse incentives" of disability grants (2005: 14).

7.3 Perverse incentives and trade offs.

Throughout South Africa's history, structural violence has impacted on people's ability to make healthy choices. Recently, it has been reported that trade in TB positive sputum has been flourishing in the Eastern Cape as a way for people to access grants. It is alleged that in the Transkei, people are selling TB infected sputum so that buyers can access a disability grant, taking the infected sputum rather than their own sample to the clinic for testing (Siqoko, 2005: 1). The sick remain sick to be able to produce and sell positive sputum, while others are put at risk through the circulation of TB infected sputum. Sputum buyers are strategically abusing the system to access a monthly income of R780.

The perverse incentives (Nattrass, 2005) to remain sputum positive both to be able to sell sputum and to qualify for one's own disability grant prevent impoverished people from getting well. Spokesperson in the Provincial Department of Health Sizwe Kuphelo says that “people must stop acting out of ignorance and putting other villagers at risk in the process” (Siqoko, 2005: 1). This trade is driven by poverty and/or possibly greed, but not ignorance. Sputum buyers and sellers are making rational choices in a context of extreme poverty. Another aspect enabling this trade to take place is the extreme workload in the clinics. According to the practical guidelines for the South African tuberculosis programme, nursing staff are to collect sputum samples *in or outside the clinic*, and not send patients home with bottles to bring back for testing once the sputum has been expectorated (Department of Health, 2000: 13). Staff at all the clinics in Grahamstown send bottles home with patients for themselves or their family to produce a sputum sample to be brought back to the clinic the following day. Their work load is simply too big for them to follow the national guidelines. This of course means that abuse of the system such as sputum selling can easily occur.

For people living with tuberculosis and HIV, improved health brings the risk of losing the disability grant which is often a main household income. For the person with a disability grant, the “perverse incentive” to remain sick is further increased as the grant is used to benefit entire households. All recipients of disability grants spent money on food. This was also found in a study by the AIDS Law Project (in Hardy & Richter, 2006: 88). Today’s criteria to access disability grants force marginalised sick to choose between the right to health and the right to social security, both guaranteed in the Bill of Rights (Macgregor, 2006: 44).

From a Pietermaritzburg hospital in KwaZulu Natal it has been reported that some nurses are alleged to sell patients’ HIV positive blood results (CD4 count) to HIV negative people so that they can access disability grants.[45] For the actual patient, the process to access health care has to start all over again, causing worsening health as a result of further delays. Perverse incentives are the reality also for overworked and underpaid nurses.

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[45] Penny Bernard, pers. comm., 12.10.06.

7.3.1 Disability grants and household composition.

Disability grants are a source of relative financial stability. It has been found that the disability grant supports economic growth, enables some income distribution and increases the level of education (Hardy & Richter, 2006: 85). Grants enable receivers to exert some agency and increase social and geographical mobility. Geographical mobility is sometimes used to get away from increasing financial demands from relatives wanting access to the grant. Disability grants also have the effect of changing household compositions and therapy managing groups. Eric, Ronnie and Nozithembiso all had family pressures and expectations to meet when it came to the matter of their disability grants:

Eric: When Eric was discharged from Temba, his girlfriend Zoliswa and he wished to move away from Zoliswa's family. Eric had been allocated a six-month disability grant. With no income herself, Aya (Zoliswa's sister) was worried about her financial future and wanted Eric and Zoliswa to move to a house closer to her. Whereas the DG led Eric to wanting to split away from the household to reduce demands on his grant, Aya wished to keep Eric close by to access it.

Family expectations and pressures to share resources are widespread in Africa. In John Janzen's study in lower Zaire, a person working at a clinic dispensary was expected to pay for kin visiting the dispensary. Eventually, the stress of not being able to meet obligations made him sick and he wanted to move to get away from the demanding relatives (Janzen, 1978: 93-94). Likewise Eric, after he "won the lotto" as he himself says,[46] was expected to support Zoliswa's sisters, and therefore decided to move to Bathurst, a village some sixty kilometres away. Ironically, Eric still does support Aya with his grant, instead of it being the other way around as one would expect in therapy management.

Fundiswa, Zoliswa's other sister, also moved to Bathurst. She has HIV and wanted my help to access ARVs. I arranged a meeting for her with a nurse at her local clinic in Grahamstown, but Fundiswa did not go to her appointment. It was not in her interests,

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[46] The expression is also noted by a journalist elsewhere in the Eastern Cape (Nattrass, 2005: 15).

financially, to be treated with ARVs. She had now moved in with her boyfriend's family, and was spending the grant in their household without disclosing her status to them.

For Eric and Zoliswa, who saw themselves as part of Fundiswa's therapy managing group, the problem was not that she was back with her boyfriend, but that she was in denial of her disease. In fact, it may be that she was not in denial, but did not want to lose her grant by getting well. According to Zoliswa, Fundiswa's boyfriend would send her back to them to manage her sickness. They argued that instead Fundiswa should be spending the money on her mother and sisters Aya and Wendy. "Fundiswa," Eric said, "should feel responsible for her family. The way she spends her grant [on her boyfriend's family], that is total wrong. Me, I still support Aya." The grant, in Eric's view, belongs to Fundiswa's family, not to her, and should be shared on the basis of need among people in the family network.

Ronnie: The disability grant gave Ronnie some company before he passed away. Although his ex wife came to see him only to access his grant, he was grateful for the visits. She left him for a man with a disability grant in 2001, but now told Ronnie that she missed him. Ronnie, unemployed, was realistic about his wife's fickleness and said that the grant was the reason she left him for this man: "Money does things to people. Now when I am getting a grant, my wife is interested in me, but it is too late now, she has made her choice." He nevertheless would give her money, sometimes R 100, so that she could buy "something", which he ruefully hoped was not alcohol.

Nozithembiso: Lindelwa, Nozithembiso and Kuhle live off the children's grants, constituting a monthly income of R 960.[47] When Nozithembiso qualified for a DG as a result of her TB, her aunt Nosipho, Lindelwa's older sister, wanted Nozithembiso to stay with her. Meanwhile, Lindelwa had been looking after Nozithembiso since Nozithembiso's mother died ten years previously and says that Nosipho is after the money. Lindelwa, Kuhle and Nozithembiso have been living "rent free" in a one-roomed shack in Nosipho's yard, but the extended family living in the three-bedroomed main house have continuously demanded favours and grant money from Lindelwa in return. In

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[47] This includes Nozithembiso's disability grant which is R780 pr month, and Kuhle's child grant which is R180 pr month.

the end, the obligations became too much and Lindelwa moved to regain control of her life. Regardless of who are looking out for the children's best interests, it is clear that social grants play a crucial role in the conflict this family is experiencing. This conflict split the family and Nozithembiso's therapy managing group.

7.3.2 The grant as essential household income.

Nattrass estimates that by 2010, 1.1 million South Africans will receive a disability grant at the cost of R 9.3 billion in 2002 prices. This would necessitate an increase in the disability grant budget of 75% compared with the 2002 budget (2005: 10).

Although it is unclear as to what the exact rate of unemployment in Grahamstown is, it is probably well over 50% in the previously black and coloured areas – but it could be as high as 70%. Regardless of whether the figure is 50% or 70%, it is unacceptably high. Radical structural approaches to dealing with poverty and unemployment are needed. In this environment, social grants become an important, and often only, source of household income. Nattrass notes that among households in Khayelitsha with social grants, the grant comprises 41-49% of the total income (2005: 13). In Grahamstown the grant comprises an even higher proportion of household incomes in 300 households with one or members on the ARV programme.[48] Many depend *exclusively* on social grants as a source of income.

Grants are an important source of income for the structurally marginalised. Although grants are temporary, people plan their lives around them knowing that there are few other opportunities for an income. Five out of eight of the people living with TB that I followed in detail throughout this study (see chapter 1, section 1.3.2) come from households entirely dependent on social grants at some stage of research. Getting a social grant, and *keeping* it, becomes an incentive concerning life or death. As people regain their health, they lose the grant – and in some cases the ability to remain healthy.

Moses: Moses, who lives in a household with three disability grants, retains some flexibility in therapy management even if his DG is discontinued. His sister, Daniswa,

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[48] By the end of 2006, about 700 people in Makana sub-district had been admitted onto the programme. The 300 patients referred to here are people presented at the meetings I attended.

has a “permanent” grant she got before the rush of HIV positive applicants began and the Department of Social Development realised the magnitude of their policy on giving people “HIV grants”. The family is not aware that even “permanent” grants are reviewed every five years. This misunderstanding has been reported also by Hardy & Richter (2006: 90). Hence, seemingly stable household incomes are in reality insecure.

In 2005, Moses was allocated a 12-month temporary DG. His mother, Regina, was disappointed that the grant was temporary, as Moses is experiencing serious and long term syndemic interactions. She shook her head in despair over the government’s priorities: “If they are going to take the grant away, then they must give them [the sick] jobs first!” Where doctors and health care personnel see *sickness* as a fair criterion for a DG, Moses’ mother sees *poverty* as a fair criterion and the DG as a means by which the government should alleviate poverty when there are few alternative sources of income.

7.4 Short term positive impacts of the grant.

Although the process of application for the disability grant increases the work load for health workers, it has some positive implications in improving the health of the sick. Less financial stress lessens patients’ vulnerability to other pathogens, increasing their general status of health (see Wilkinson, 2005: 13). Control over their own lives increases confidence and the ability to withstand social pressures such as stigmatising in the communities. In their focus group, youth claimed that grant recipients were respected in the community and that the ability to sustain oneself with the grant increased social support and inclusion in the community. Mirriam, a Temba patient, confirms this: “Yes, we do get respect from the people because they no longer look down at you just because you are sick and can’t do things on your own.” Another patient, Vuyokazi, agrees: “It is like when you receive the grant you are able to buy for yourself food that’s good for the blood as well as the pills [that] will help you more if eating good food.” A focus group respondent without TB emphasised that the grant would help people disclose their TB, increasing cure rates and decreasing infection rates.

Social strategies for survival, such as negotiating grants and sickness, are produced by inequalities in our communities. According to Wilkinson, “…psychosocial factors reflect material life because material life is a source of stress, whether in the form of unhappiness, depression, insecurity, anger, or depression" (2005: 62). However, this newfound empowerment and confidence which grant recipients gain is temporary, and can only be exercised within the local impoverished community. Poor people receiving grants are still disadvantaged, dependent, disempowered and unable to exert much agency outside of their local communities. Insecurities prevail.

The extract below is from my field diary, illustrating Lionel's joy at receiving a grant and how he sees his new temporary wealth:

> *I went to see Lionel a week after he got his first monthly disability grant. He had visitors and loud reggae music was coming from his shack. Ntombekhaya invited me in. Lionel's eyes were glowing and his smile covered his face all the way up to his newly cut hair. From his first grant he bought a TV, shoes for himself and Ntombekhaya, a cell phone for her and things to sell in their newly opened spaza shop in their home. He had bought a stereo to attract customers with music. His confidence has increased and he tells me that he has seen a RDP house selling for R 8000. He is dreaming of what it would be like to own a house: "There is life beyond TB, you can do it. I feel that I have a purpose now and that I will never die. I feel free now when I have accepted that I have TB. And you know that I never used to have hope. Now when I have this money, life is easier. It is fine, I don't have to stress anymore."*

Two days before Lionel could go the pay point to collect the next month's grant, he phoned me, apologising and asking for money, as he had no food in the house. The food he had bought with the grant money was finished. For Lionel, life in structural poverty continued even with access to a grant. He was quite frank with me as to his own failings:

> *Silly me. I didn't do the budget properly. I am not used to it, I did the wrong budget. If you have never had money, you don't know how to spend it. When I got into the shop, I looked around and I didn't know what to buy. It makes you confused when you are not used to it. I bought some rice and I have never bought a packet of rice like that before, so I did not know how long it was going to last for. But now, now I know that secret of life in Grahamstown: money. Money is the secret to a good life in this place.*

7.5 Therapy itself as de-motivating.

> The most serious problem hampering tuberculosis treatment and control, is patients' non-compliance with therapy.
>
> Menzies *et al*, 1993: 35, cited in Farmer, 1999: 225

Non adherence to prescribed therapy *is* hampering measures to control tuberculosis. But to blame the sick as being the source of "the most serious problem" in controlling tuberculosis is both untrue and counter productive in solving the fundamental problems that make tuberculosis a social disease. Existing biomedical perspectives on compliance have a narrow focus on the patient in the clinic.

Donovan and Blake critique many of the studies on compliance, as they call it, for not taking into account how patients feel and think about their illness (1992: 508). “Non compliance may not be deviance,” they argue, “but reasoned decision-making” (*ibid*.: 512). Nonetheless, they conclude their paper by focusing on clinic interactions, arguing that “the key to improving rates of compliance…is the development of active, co-operative relationships between patients and doctors” (*ibid*.). They limit the scope in which reasoned decision-making is made and ignore the influence of broader structural forces. Other scholars argue that patient deviance is not the leading cause of non adherence. Substance abuse, unemployment or low income, lack of social support, homelessness and dissatisfaction with clinic personnel are all impacting on patients' ability to adhere to treatment (Hopewell *et al.*, 1988, in Sumartojo, 1993: 1312).

The drugs themselves are decreasing patient motivation to complete therapy as they have unpleasant side effects, including nausea, headaches, and tingling in the body, and these effectively disable the patient. When experiencing side effects it is difficult to remain motivated to take treatment, particularly after symptoms have stopped. Generally, the poor experience strong side effects as they have less nutritional strength to counteract the harmful effects.

Lionel, who is on MDR treatment, felt so nauseous and dizzy that he could not walk straight after taking medication. After taking his treatment in the clinic, he had to lie down for an hour before going for a walk. By the time he felt that he had counteracted the daily side effects, it was past lunchtime. When combined with antiretrovirals side effects are further increased. Hence the medication itself disables one.

Although the actual swallowing of the medicine is quick, walking to the clinic, and waiting before returning home can take hours. Even when DOTing with a CHW at home, patients have to wait for the CHW to come to their house with the medication. With a six-month duration of therapy for pulmonary tuberculosis, this has a major impact on peoples' lives and their ability to adhere to therapy.

A new and improved therapy for pulmonary tuberculosis is in the pipeline, halving the duration of treatment. It is hoped that this will impact positively on adherence rates by lessening the inconvenience and negative impact on the patient medically and socio-economically. In the focus group at Temba, one patient responded that: "We would be very happy because we spend most of the time here and when we go home perhaps a lot of our belongings will have been damaged [by people breaking into the empty house]." Another patient argued that case finding would increase, as people would be more willing to present themselves at the clinic if they knew the treatment is not so onerous on one's time, resources and energy. It was also thought that adherence would be positively affected by this new therapy: "People get bored of taking the pills for a long time and they end up pretending to have eaten them while they [actually] spit them out."

In the focus group interviews with people who did not have tuberculosis, responses to the possibility of shortening the length of therapy were positive, although embedded in stigmatising attitudes:

> *It would be the right thing [to lessen the 6-month course of treatment] because then the government won't be wasting money because to me it seems as if when he [the government] gives the grant to people with TB, to some the money is just wasted because the government could have used it in other important things…some people receiving the grant have homes that [they] can afford and when that person receives that money, it will be used on other things like drinking [liquor]…*

Although halving the duration of therapy is likely to have major positive implications on therapy management among the sick, the structural context in which sickness occurs must be approached too.

7.6 Health worker perspectives on grant allocation and adherence.

Potential determinants of compliance include personal characteristics of patients, features of the disease and/or treatment, and patients beliefs and attitudes.

Menzies *et al*, 1993: 35, cited in Farmer, 1999: 226

Non adherence to treatment in order to access disability grants is not new in Grahamstown. In a study of epilepsy patients at a Grahamstown clinic, Julia Segar found that both patients and practitioners view non adherence as a way of accessing grants. “The socio-economic background of patients,” Segar concludes, “is the single most important component in the compliance equation” (1994: 295).

At the TB Quarterly meetings at the Makana sub-district, clinic representatives present their data. Adherence is a main concern. Unfortunately, there are problems with data capturing at clinic level and with capacity to record data at sub-district level, resulting in unreliable data at times. There is also an inability to look beyond the data, problems with attitudes and measures to find creative solutions to increase case finding, adherence and incidence rates.

Sister K says that patients at Raglan Road Clinic default because once their symptoms improve, they consider themselves better: “They feel that they are cured, so they don’t want to come to the clinic.”

Two patients from the small rural town of Peddie ran away from Marjorie Parish Hospital, the TB hospital located in Port Alfred, about an hour’s drive away from Peddie on the coast. They went to fetch their disability grants but never came back. Because Peddie is in a different district, the patients were not traced. During apartheid, when the health system was fragmented, the tuberculosis service was only allowed to follow up about 50% of TB patients as many were registered in different homelands falling under other departments of health (Lee & Buch, 1991: 290). The problem of non adherence among the marginalised is not a new phenomenon. Blacks in urban areas who were diagnosed with TB in the middle of the last century lost their jobs and temporary rights to reside in white South Africa as a result of contracting the disease, resulting in financial crisis for many families (Packard, 1991: 51). Although the pass laws[49] are now abandoned and anyone can stay in urban areas and receive treatment without fear of being repatriated, the attitude that it is hopeless to trace patients who have gone back to

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[49] The Population Registration Act of 1950 was one of the cornerstones of the apartheid regime, dividing the country into separate homelands. Even prior to that, movement of blacks were restricted, and through the Natives (Urban Areas) Act in 1923, they were obliged to carry passes (http://www.south-africa.org.za/history/segregation.php, accessed 12.12.06).

areas that were formerly designated as homelands still seems to prevail in Makana sub-district. The concept of being "lost to follow up" is still accepted in TB care (Farmer, 2000: 198).

Community Health Workers at Middle Terrace Clinic report that people who stop taking the treatment often do so towards the end of the six months as patients feel better and think that they are in fact cured. They also lose motivation to continue to the end of the prescribed six months as people, one volunteer explains, do not want to be seen as healthy and able to work, because then they lose their grant.

> **Jackie:** *"They want the grant. They say they will come, and the whole day we wait, but they don't come. They don't want to understand that TB – it's curable. It is not necessary to have money for it. They don't want to understand that."*
> **Ida:** *"Is there a link between the grant and adherence to treatment?"*
> **Marian:** *"Yes, because there was this guy, I don't want to mention names, he stopped after 5 months. He left last year and he came back only this year and he is sick, sick, sick. He did have a grant while he was sick, for two years. If there was no grant, he would have been healthy by now. What can I do when they disappear and do not want to come to the clinic or take treatment anymore?"*
> **Noxolo:** *"They know that it is curable, but they want the money and spend it on other things. Like the child grant [I receive], that is not for me, it is for my child. They want the grant to spend it on other things like drinks and alcohol. The grant is making our job more difficult."*

Patients do understand that tuberculosis is curable, but they also understand that the disability grant is an essential income in impoverished households. Sister L says the Department of Social Development is making it difficult for the nurses to do their job, because "people want to be sick". Nurses are forced to send home patients with CD4 counts over 200, saying that they are too 'healthy' to apply for a DG or to receive ARVs. The patients are told that they have to wait until they are sick enough to qualify for the grant. The sister says she feels disempowered, unable to explain the problems that grants pose to dealing effectively with HIV and TB to the people at the Department of Social Development: "They sit in their offices, but down here, their policies don't work. They make it difficult for me to do my job. It is very frustrating."

With infectious diseases such as HIV and TB and the dangers of developing drug-resistant strains of the diseases (MDR and XDR), non adherence to treatment is a more critical and community oriented issue than it is for epilepsy. Poor patients are experiencing a deadly dilemma with perverse incentives: To remain sick and keep their family alive or to get well, but be unable to provide the family with a healthy life. The grant turns patients into providers, increasing their confidence and pride, but also their responsibility towards the family. At the same time, they become less committed to deal with own sickness. Many opt to remain sick, or to become sicker.

7.6.1 Examples on the disability grant's impact on adherence.

Eric: Eric and Zoliswa work for the same employer, an agency which trains game rangers, making R1500.00 and R1000.00 a month respectively. They get no pay slip and thus have their labour rights infringed upon. The employer deducts R50.00 off each of their salaries to pay to the Unemployment Insurance Fund (UIF), but they get no receipt for this. UIF payment is 1% per month, but Eric does not dare ask what happens to the remainder of the money deducted. They both have employment contracts, but don't know how to make sense of the language used. They are afraid of using their employment rights as they feel that it can create tensions between them and their employer. Eric has previously been forced to resign from his job due to illness and is afraid this may happen again.

After Eric had failed to come to two appointments at Masonwabe Clinic and had run out of ARVs as a result, I, at Eric's request, tried to arrange a final chance to make up for the missed appointment. Dr A told me: "…and to be honest with you, he does not have the best of records. He just doesn't pitch. He doesn't phone or send anyone to tell us. He can't just come when it suits him. We do try to be flexible, but he said he would come with his wife and then she never came, he needs to take more responsibility." Apart from the fact that Eric did not phone to arrange for another appointment because he does not have enough money to make a phone call and Zoliswa could not come because her employer did not give her time off, Dr A has a good point: Eric must take responsibility for his own therapy. However, the solution to this is not to be found in the clinic alone. The social worker at Masonwabe Clinic is a strong and lifesaving link between the medical and social aspect of therapy management. The doctor can only address the symptoms of the social ill, not the structural sickness of society.

The complexity of his employment situation and his fears of dismissal should his employer find out about his HIV positivity has a major impact on Eric's ability to get well. They have been offered the house Aya currently lives in to buy, but with no payslip and difficulties in managing their employment situation and Eric's health concurrently, they cannot borrow money. They cannot afford to take risks or invest long term in their and their son Luvo's future. They have few alternatives to improve their lives, even with jobs.

Because of the high incidence of the HIV/TB syndemic and its common socio-economic associations, a case study of ARV non adherence and poverty, and practitioner attitudes to this is presented below:

A patient at V.Shumane Clinic had been through the lengthy social and medical process of gaining access to ARVs and with a CD4 count below 200, was given a six month DG.[50] While on the ARVs, his CD4 count was taken again. It had risen to 267 and as a result his grant was stopped. He went to V.Shumane Clinic and let out his frustration at Sister L: "I am not going to take the ARVs if there is no food." Doctors admit that using the CD4 count as a measure of disability is problematic, but there is no better measurement available at present. There is not necessarily an overt difference in the status of health between a person with a CD4 count of 200 and 267, or of 50 and 300 for that matter.

With regards to the above patient, Dr C commented: "He is a very arrogant man, this one. He's got that problem. It means that they don't want to be healed…There is really nothing we can do. Unless we bypass them [the Department of Social Development], but then we have to give all with a CD4 count above 200, even those who have 800 and 9000." She recalled when the patient in question did not let Dr A look at his ears: "…so he is a problematic patient. He is a defaulter. His [grant application] form is scratched." Just like they sometimes recommend a DG for people in a difficult financial situation, Dr

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[50] Before a patient is given ARVs, he/she is counseled about HIV and treatment at the clinic. A supporter has to come with the patient. A home visit is conducted and the social situation assessed. Various medical tests are taken. If necessary, a psychologist is involved. The patient is then presented before a panel of doctors, social workers and nurses and a decision is made as to whether the patient is "ready" to take on the responsibility of life long therapy and, sometimes, certain lifestyle changing measures.

C suggested that they sign and write a recommendation to the Department of Social Welfare that he does *not* get a grant because he is “a defaulter”. From this perspective, one can see why patients think, correctly, that the medical practitioners are the ones who make decisions concerning grant allocation.

Dr C is less likely to recommend a “deviant” patient than a cooperative one for the grant, even if their CD4 count and medical situation are the same as a “compliant” patient.[51] In the Khayelitsha study, Macgregor notes that clinicians recommend “deserving” patients for the grant whereas “undeserving” or “irresponsible” patients are not given the same encouragement or recommendation (2006: 50). Adherence should not be seen as a personality trait (Sumartojo, 1993: 1317). The problem is that people are not able to comply, not that they are deviant and refuse to do so. In resource poor settings, non adherence can also be a result of rational decision – making, not patient deviance (Farmer 1997b: 353).

Lindiwe lost her grant as she regained her health on ARVs. As a result she started drinking excessively again (she had stopped while taking ARVs) and soon stopped taking her treatment. She stopped eating healthy food as she did not have money and lost motivation to regain her health. She felt hopeless and in financial despair. Eventually, in desperation she approached Temba Hospital, asking to be admitted so that she would be “forced” to take her TB and HIV treatments.

Excessive use of alcohol *does* cause non adherence among TB patients, but the structural causes of this are not recognised by health workers and policy makers. Practitioners and adherent patients express attitudes of perceived moral superiority. Alcoholism is common in Grahamstown East as it is in areas with high levels of inequality, insecurity, unemployment, marginalisation, violence, stress and weak social networks as well as feelings of uselessness and inadequacy (Wilkinson, 2005).

The grant is also a common topic of conversation at the waiting room at Masonwabe. Patients note that if their grant is taken away, there is little meaning in getting well: The

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[51] Dr C, who was sent to Masonwabe Clinic by the Provincial Department of Health, is in the process of leaving Masonwabe at the time of writing.

financial constraints will be acute, the stress levels will increase and they will become even sicker.

Putting one's health and life at risk to obtain and keep the grant is based on necessary and rational choices. The sick are constantly evaluating their health against the hopelessness of poverty, assessing when it is time to ask for ARVs at their clinic, and when to wait. Their approach conflicts with that of practitioners. Whereas Sister K wished to get Fundiswa (Eric's sister in law) on ARVs with a CD4 count of 64, Fundiswa felt healthy and wanted to wait and keep her grant. It was only when her grant was stopped six months later that she was willing to start taking therapy. The process of mobilising rights and duties, and establishing and maintaining relationships with practitioners are extended as a way in which to maintain the sick role as a means to accessing life saving financial resources. Often, the balance is not reached and people die before they can access therapy.

7.7 Challenges to motivation due to pressures in the clinic.

Health workers often fail to diagnose and initiate treatment. Incorrect diagnosis results in delay of cure and increased risk of increasing patient non adherence. Public health decisions, rather than pure clinical decisions, are made in order to save money and patients are sent home with cough mixture and "good advice" rather than having expensive tests taken of them to diagnose tuberculosis or other diseases. Delay of TB diagnosis is common as a result of the structural financial constraints nurses have to work under. Practitioner control of knowledge is based on a DOTS programme where the patient is seen as subservient to the health practitioner. With less practitioner control, it may be easier for the patient and his/her therapy managing group to question and participate in reaching diagnosis and in planning the path to cure. Although the following case of Moses is not an example of non adherence, the problems he experienced in being diagnosed made adherence difficult. "Without my family," he says, "I would not have made it."

Moses: When I met Moses at the end of April 2005 his health had not improved since he started TB treatment in January. Nurses were concerned that he might have MDR TB, but when Moses' health improved two weeks later, they decided not to test for MDR. Moses and his mother however were concerned that he still might have MDR, as his condition was unstable. At the end of September the nurses were again considering the possibility of MDR when discussing Moses. After another few weeks, they sent a sputum sample for culture to the lab. When the result finally came in the last week of November, Moses was told that he was infected with a drug-resistant strain of tuberculosis and was transferred to Jose Pearson to start his treatment all over again – this was 11 months after he had started his standard TB treatment.

Had staff been more open to concerns raised by his therapy managing group, Moses may not have experienced 11 months of delay in his treatment – nor would he have been contagious with a potentially untreatable drug-resistant strain of tuberculosis in a tuberculosis hospital with 90% TB/HIV co-infection rate. Practitioner control combined with excessive workloads can result in an increase of the burden of sickness for the patient.

7.8 Lack of opportunities to choose health.

Vecchiato argues that “in particular, the identification of the socio-cultural determinants of ‘patient compliance’ has proved critical in the success or failure of tuberculosis therapies” (1997: 185). The socio-cultural determinants he identifies include health beliefs, perceptions of severity, aetiologies and degree of medical knowledge (*ibid*.). The similarities with Kleinman’s notion of the explanatory model are apparent. Vecchiato does mention that “practical, financial, social, structural and geographical considerations” do also play a role in management of illness (*ibid*.: 195), but does not actually focus on this in his analysis.

The sick in Grahamstown have limited choice when it comes to avoiding risks such as overcrowding, stress, insufficient nutrition and housing (see Wilkinson, 2005). Stigmatising attitudes, also among health personnel, provide barriers to care which are not caused by patients’ cultural beliefs. Adherence has less to do with cultural values than social circumstances caused by broader structural factors (Farmer & Nadell, 1998: 1014; Rangan & Uplekar, 1999: 278), including lack of adequate resources in the health care system to ensure patient care.

For those employed prior to sickness, the result is often unemployment, further impoverishment and insecurity as a result of sickness. Even when people do have employment, jobs are insecure and the payment low. This is also noted by Nattrass in Khayelitsha, Cape Town (2005: 13). People remain physically weak for a long time after a TB cure, and in many cases they are still left dealing with an HIV infection.

7.9 The cost of ignoring syndemic reactions and structural causes.

> The question of relapse is not a question of compliance only anymore.
>
> Gloria, matron at Temba Hospital

The matron at Temba Hospital is experiencing the HIV/TB syndemic first hand and knows that immuno compromised TB patients are more likely to experience relapse of TB than HIV negative patients. With each relapse, the danger of developing a drug-resistant strain of tuberculosis is increasing. Thembile, a HIV positive V.Shumane patient, died of MDR TB at the age of 30 years after having had tuberculosis three times in five years. He never missed a single dose of treatment. Even rigorous adherence to biomedical treatment is no guarantee for recovery. It is evident that the increasing prevalence of drug-resistant strains of tuberculosis is caused by syndemic reactions.

In the speech delivered by the South African Minister of Health, Manto Tsabalala-Msimang, on World TB Day 2006, she noted that ordinary TB treatment, which in most cases do not require hospitalisation, costs about R400 per patient whereas treatment of MDR TB costs R24 000 per patient.[52] The treatment for the recently emerged XDR TB is reported to cost R84 000 (Makhubu, 2006: 1). With people stopping and restarting their ARVs as a means of accessing grants, it is also likely that drug-resistant strains of the HI virus will develop – and spread through new infections.

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[52] http://www.doh.gov.za/docs/sp/sp0324a-f-html (accessed 24.04.06).

7.9.1 The Makana TB manager's perspective on fighting tuberculosis.

> We need personnel to do advocacy and social mobilisation that will work in a preventive manner. I am really having a passion on that. Through awareness we can manage the disease. You'll find that people don't know about TB.
>
> TB programme manager, Makana sub-district

According to the TB programme manager, education and awareness are needed in order to combat tuberculosis in South Africa, but information itself is insufficient to change risk-related behaviour (Porter *et al.*, 1999: 363). Again, the structural causes of risks to social disease are overlooked. Mrs H replies: "Poverty, I do see that problem, but people lack information. Only then do people know how, what and when." Explaining the high numbers of TB cases in the Eastern Cape, the TB manager blames the lack of information and awareness which results in delays in health seeking and an increase in infection rates. As shown throughout this thesis, people know "how, what and when", but they are restricted in their ability to act upon their knowledge. The knowledge of tuberculosis among patients, members of their support network and in the general community in Grahamstown is good, but infection rates remain high.

Although the programme manager briefly emphasises the importance of social support, she does not seem to be aware of the structural issues that deny some citizens social capital. She has a challenging task ahead of her and can perhaps not be blamed for her frustration, because addressing these structural problems is beyond her powers. She is also trained within a fragmented biomedical system, failing to adequately take these factors into account. As she notes, "there is nothing you can do" when people "choose" not to take their treatment. The TB manager in Makana sub-district cannot take responsibility for and repair decades of continued structural violence and its impact on the status of health in Makana.

7.10 Conclusion.

Through social welfare and health policies, global and state level discourses are played out in the individual and local communities. The legitimacy of the state as an authority upholding the rights of its inhabitants can be questioned. The most basic of human rights, the right to health and to life, are challenged through dilemmas faced by the underprivileged.

None of the cases presented in this study are extraordinary. They are commonly shared lived experiences among a growing number of South Africans. For practitioners, the frustration and emotional burden is immense. They have to some extent had to become "immune" to the suffering in the communities in which they live and work in order to perform their jobs. More than once I have heard doctors tell their patients that "you are sick because of the DG, *wena*,"[53] and more than once has the patient agreed: "Yes, but I have to buy food and vegetables." Whereas the practitioners meant that patients were choosing money instead of health for reasons of irresponsibility, the patients saw themselves as making rational choices and self – sacrifices enabling their family to eat nutritious food, at least for a while. Among practitioners there is recognition that the sick are choosing continued sickness to keep the disability grant, but this is seldom seen as rational action in a desperate situation prohibiting the patient from adhering to biomedical therapy. Social grants have become an integral aspect of the illness experience and are strategically used in therapy management, but their short term benefits tragically often backfire.

By focusing solely on interventions in the clinic or at individual levels through allocation of disability grants, structural causes of patient dilemmas are ignored. As a result, active TB cases and rates of non adherence increase. As a means of intervention, a Basic Income Grant (BIG) has been suggested by some authors (Hardy & Richter, 2006; Nattrass, 2005). This has the potential to increase nutritional levels, economic activity and education in households living on the breadline, but also has major political implications which are not explored here. In fact, social grants can be seen as an intervention to alleviate poverty (Hardy & Richter, 2006: 88), but it is unsustainable, in some cases preventing cure. However, in some instances, social grants are seen as improving experiences of illness and quality of life for patients. Incentives facing the sick are indeed perverse.

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[53] *Wena* is Xhosa for *you* and is a word commonly used also among English speakers. In this sense it is used in a derogatory way implying that "*you* are the problem".

Chapter 8.
Conclusions.

Article 25:

> Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

Article 27:

> Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and in its benefits.

Universal Declaration of Human Rights

8.1 Health and human rights.

One of Paul Farmer's central arguments in *Pathologies of Power* is that social and economic rights must be an intricate part of both the health and human rights agenda. The right to health *is* a social and economic right (2005: 238). Connecting these should not be considered naïve.

Seeing health as a human right is, compared to rights to freedom of expression and religion, a relatively recent development, and has only been a perception for the last 50 years or so (Dujardin, 1994: 1261). In South Africa, post apartheid civil rights have not given people the right to health or indeed to life itself. More than a decade after the abolishment of apartheid, we are still faced with challenges in realising rights to health. As this thesis shows, there are clear links between employment rights, rights to social security, educational rights and rights to health.

Tuberculosis, as a disease inherently linked to poverty, has been used as an indication of how far we have come in South Africa in terms of managing to achieve social justice. It has been claimed that "the conquest of tuberculosis in the ensuing years will be one important indicator of progress towards social justice in this new order" (Benatar & Coovadia, 1991: 1). 15 years after this statement, the incidence rate of tuberculosis has increased.

8.2 Tuberculosis as medical and social.

> The history of TB is a history of medical failure. This seemingly harsh indictment reflects the paradox that modern treatment for TB is among the most effective and inexpensive of all therapies for life-threatening diseases yet TB remains the leading infectious cause of morbidity and mortality worldwide.
>
> Zumla & Gandy, 2003: 237

It is correct to assert that a failure to rid the world of tuberculosis is the failure of an exclusive biomedical approach, but as important, it is also the failure of the global community to be committed to social justice. Whereas the paradox presented in the quote above by Zumla and Gandy is real, it cannot be solved in a biomedical context alone. Hence, the failure does not lie solely with biomedicine, but with the social, political and economic order in the world in which we live. This thesis has shown that tuberculosis is a social disease – a symptom of a larger social ill.

My attempt has been to identify and present the complexities of these processes and how they affect not only treatment outcome, but also experiences and perceptions of the sickness of tuberculosis itself and of those who are carriers, and sometimes perceived carriers, of these sicknesses. This has been related to dynamics and limitations in the health care system and the broader macro socio-economic context in which the sick live their lives. Risks of contracting tuberculosis are structural, as are the risks of non cure and death. Despite “free” medication and health care for the poor in South Africa, the burden of sickness and the social and financial cost related to this, are immense. The marginalised are also more likely to experience social stigma and increased marginalisation as a result of illness.

Whereas it is understood that biomedical treatment is necessary to combat tuberculosis in the individual, it is also emphasised that the poverty and illness trap needs to be addressed at broader structural levels and not blamed on marginalised individuals’ so-called irresponsible or irrational behaviour as the ethnography often demonstrates. In short, this thesis has shown that tuberculosis occurs in an unrandom manner demanding a more inclusive and social justice oriented approach. This is an ambitious approach, as

Paul Farmer comments: "…if we lack ambition, we should expect nothing less than a harvest of shame" (Farmer, 2005: 245).

8.3 The thesis in a nutshell.

After first outlining the theoretical frameworks used, this thesis has explored global approaches to health care and the manner in which these are implemented at national and local levels. Although global frameworks are biomedically sound, these have until now largely failed to deal with social aspects of disease. However, the World Health Organisation is increasingly advocating a poverty related approach, enabling some hope for the global goal of eliminating TB by 2050. Achieving this goal in South Africa demands a government committed to clamping down on corruption and mismanagement while at the same time increasing its commitment and funding towards social and economic policies.

Health workers perform their duties in increasingly over burdened and under funded institutions, resulting in growing stress and dissatisfaction affecting their ability to provide care for the sick. It has been argued that patient experiences of barriers to care at clinic level cannot be blamed solely on practitioner attitudes, even though this commonly is how it is experienced by the sick.

The use of voluntary Community Health Workers as primary health care givers for TB patients has been explored. It is shown that although their motivations are partly altruistic, they too feel increasingly undervalued and unappreciated. The sustainability of a system of TB care that centres on DOTS yet fails to recognise the role of volunteers is questioned and it is argued that increased education and remuneration of voluntary health workers are necessary in securing sustainable TB care in South Africa, to enable it to deal with growing challenges of co-infections and drug resistant strains of TB.

Explanatory models (see Kleinman, 1980) of tuberculosis have been explored. It is shown that patient knowledge of the aetiology of tuberculosis is in line with biomedical aetiologies. However, stigmatising attitudes that see TB as a moral disease are prevalent, and these are also found among health workers. This influences perceptions of illness and negatively influences health seeking behaviour. Although not looked into in great detail, traditional aetiologies of tuberculosis are explored and it is shown that although perceptions of causes can be based in traditional beliefs, patients use symptom specific biomedical therapy in addition to more general traditional remedies.

Therapy managing groups (Janzen, 1978; 1987) are investigated and it is shown that these are crucial in influencing the sick person's ability to act upon his/her knowledge of how to achieve cure and to get well. People invest in relationships as a broad insurance policy enabling them to deal with physical and social aspects of sickness. The ethnography has shown that social support is crucial in managing sickness and health. It has also been shown that the marginalised have limited social capital and as a result are facing difficulties in managing their sickness and reaching cure – even when the will do to so is strong.

Disability grants are explored as an aspect of sickness management. The deadly paradox between the right to health and the right to social welfare is prevalent in impoverished settings such as Grahamstown. The sick are indeed faced with "perverse incentives" (Nattrass, 2005), having to choose between cure or being able to meet obligations to feed the household with the social grant. The potential for TB patients to qualify for the disability grant influences health seeking and adherence to recommended therapy and in many cases prevents people from acting on their knowledge of how to get well. Importantly, in looking for ways of accessing social grants, the sick are in fact exerting agency and making strategic choices, sometimes with dangerous outcomes.

8.4 Tuberculosis – the social disease.

Tuberculosis is a social disease, with risk factors such as

> a lack of a sense of control, depression, hopelessness, hostility, lack of confidence, lack of social support, bad social relationships, stressful life events, family conflict, stress at work, bereavement, being single or divorced rather than married, and job and housing insecurity (Wilkinson, 2005: 60).

The links are all too clear in the ethnography presented in this thesis. The World Health Organisation sees health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. This definition of health can only be realised through a holistic approach making visible – and challenging – structural limitations within which the marginalised act. The fact that few participants in this study see how structural poverty and inequality influence their ability to get well from their afflictions is an indication of their marginalisation. One must be careful not to explain all experiences and actions of the sick as a result of structural limitations. Patients do have agency and make decisions according to the constraints in which they find themselves. These may put not only themselves, but others, at great risk.

Targets concerning incidence, adherence, and cure–rates of tuberculosis can only be achieved through a holistic social justice based approach to health. To achieve this, national, provincial and local governments should adopt a system of cross departmental collaborations and increased cooperation between the different programmes in the Department of Health. The potentially devastating HIV/TB syndemic and the enormous costs it poses to the country as a whole requires new, imaginative and brave approaches to health care. Morale among over worked and unappreciated staff is decreasing as the burden of illness and the need for committed clinical care are increasing.

To realise rights to health we need nothing less than a “major shift in our way of thinking about the future” (Benatar, 1998: 297). Following Paul Farmer’s argument, this thesis has shown that human rights are best understood from the perspective of the poor (2005: 17). If it is a fundamental aim of anthropology to give the “voiceless” a voice and if medical anthropology is fundamentally an applied sub-discipline, which I strongly believe it is, then it follows that part of the anthropological message should be to allow “sufferers to discover the possible social causes of their suffering and, thus, to be relieved of the blame” (Bourdieu, 1993: 944, in Farmer, 1999: 282, Farmer’s translation).

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Appendix.

Appendix 1. The treatment used to treat tuberculosis in South Africa is shown below. The phases are based on treatment five times pr week. The amount of pills to be taken depends on the weight of the patient, but patients with pulmonary tuberculosis take approximately five or more tablets per day whereas a patient with a drug resistant strain of TB can take ten or more tablets daily.

1. Treatment regimen of pulmonary tuberculosis.

First Two Months (initial phase)	Isoniazid
	Rifampicin
	Pyrozinamide
	Ethambutol
Four Last Months (continuation phase)	Isoniazid
	Rifampicin

2. Re treatment regimen of pulmonary tuberculosis.

First Two Months (initial phase)	Streptomyicn injections
First Three Months (initial phase)	Isoniazid
	Rifampicin
	Pyrozinamide
	Ethambutol
Five Last Months (continuation phase)	Isoniazid
	Rifampicin
	Ethambutol

Source: Department of Health, 1999

3. Standard treatment regimen for multi drug resistant tuberculosis.

First Four Months (initial phase)	Kanamycin
	Ethionamide
	Pyrazinamide
	Ofloxacin or Ciprofloxacin
	Ethambutol or Cycloserine
Last 12-18 Months (continuation phase)	Ethionamide
	Ofloxacin or Ciprofloxacin
	Ethambutol or Cycloserine

Source: Department of Health[54]

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[54] http://www.doh.gov.za/tb/index.html (accessed 12.10.06)

Appendix 2. ACSA scales in English and Xhosa.

MY LIFE IN THE PAST

BEST:

WORST:

MY LIFE NOW

As good as my **BEST** period of life
Almost as good as my best period of life
Good
Not as good as my best period of life
Still on the good side
Neither good nor bad / in between
On the bad side
Not as bad as my worst period of life
Bad
Almost as bad as my worst period of life
As bad as my **WORST** period of life

UBOMI BAM KWIXA ELIDLULILEYO

ELONA XESHA BUHLE NGALO:

ELONA XESHA BUBUBI NGALO:

UBOMI BAM NGOKU

Bulunge njengakwelona xesha bakha ba**BUHLE** ngalo ebomini bam

Phantse babuhle njengelona xesha bakha babuhle ngalo ebomini bam

Buhle

Abubuhlanga njengakwelona xesha bakha babuhle ebomini bam

Busebuhlana noko

Abubuhle bungebubi kuphele

Buthande kuba bubi

Abububanga njengakwelona xesha bakha babubi ngalo

Bubi

Phantse baba bubi njengakwelona xesha bakha babubi ngalo

Bubi njengakwelona xesha bakha ba**BUBI** ngalo