An examination of the implementation of the World Health Organisation's anti-tuberculosis treatment, the Directly Observed Treatment Short Course (DOTS), in poor South African communities

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Declaration:
This work has not been previously submitted in whole or in part for the award of any degree. It is my own work. Each significant contribution to and quotation in this dissertation from the work or works of other people has been attributed and has been cited and referenced.

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Abstract

This dissertation examines the implementation of the anti-tuberculosis treatment, the Directly Observed Treatment Short Course, of the World Health Organisation (WHO) in poor South African communities. Research for this dissertation was carried out over a two-year period in one poor community, a tuberculosis (TB) quarantine hospital and several primary care clinics. This dissertation argues that the DOTS programme is culturally inappropriate and consequently unsuccessful in meeting the WHO's TB treatment targets. It will show that the design of the DOTS programme assumes access to basic resources such as food and shelter and focuses its attention on ensuring regular access to anti-TB medication. However TB patients in many poor South African communities do not have access to basic resources and thus experience the DOTS programme and the treatment protocol as a burden. Although TB patients face these challenges to meeting their treatment goals, many of them view the DOTS programme in their communities as a source of resources from which they can access jobs, food, money and general social services. The thesis will demonstrate that there is a wide gap between what the DOTS programme offers and what the TB patients and community members expect. It will also show that this gap limits the ability of TB patients to adhere to the treatment and thus renders the DOTS programme culturally inappropriate and unsuccessful in these South African communities.

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An Examination of the Implementation of the World Health Organisation's Anti-Tuberculosis Treatment, the Directly Observed Treatment Short Course (DOTS), in Poor South African Communities

Chapter One. Introduction

1.1 Introduction

Global public health programmes designed by international organisations to abate the spread of diseases such as tuberculosis use bio-medical techniques that treat disease as a set of physical symptoms often ignoring social systems political and economic determinants that impact on health. This dissertation examines the implementation of the international anti-tuberculosis public health programme of the World Health Organisation (WHO) Directly Observed Treatment Short Course (DOTS) in South Africa of. The DOTS has proven to be very effective in many counties, curing well over 80% of new TB cases. In South Africa, however, the success rate is only 54% (South African Health Review, 2003). I argue that the DOTS programme is incongruent with local patterns of health seeking behaviour in poor South African communities, thus rendering it ineffective.

The WHO adopted the DOTS as the global strategy for TB control in 1991 and South Africa did so in 1996. The programme is comprised of five key elements that can be divided into clinical and management components. The clinical side of the strategy is focused on ensuring that greater numbers of persons positively diagnosed with TB are treated. Upon diagnosis with TB at a bio-medical facility, the patient is offered TB treatment. To access the DOTS treatment, the patient in collaboration with health care professionals, must identify a person who will be responsible for administering, observing and recording the patient's daily treatment.

Health professionals, community members and trained volunteers, known as TB treatment supporters, can administer DOTS over a six-to-eight-month period. The treatment supporter is responsible for observing and recording the TB patient's ingestion of the bio-medical chemotherapy treatment and reporting any breaks in the treatment course to the medical facility overseeing the treatment.

The managerial component of the DOTS strategy calls for political and governmental commitment to mobilise resources for tuberculosis control. This entails ensuring a regular supply of bio-medical anti-tuberculosis drugs, as well as establishing and maintaining a reliable database for monitoring the progress of national tuberculosis control programmes.

The following is an extract from WHO documents outlining the five elements that make up the DOTS (http://www.who.int/gtb/, 2003):

- Government commitment to sustained TB control activities
- Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services
- Standardised treatment regimen of six to eight months for at least all sputum smear positive cases, with directly observed therapy (DOT) for at least the initial two months
- A regular, uninterrupted supply of all essential anti-TB drugs
- A standardised recording and reporting system that allows assessment of treatment results for each patient and of the TB control programme performance overall

The WHO has stated that the DOTS was designed so that patients do not bear the sole responsibility for adhering to the treatment. Health workers, family members, members of the community and trained volunteers aid the patient in completing the DOTS treatment (http://www.who.int/gtb/, 2003). The WHO has recommended that national TB control programmes join with local community based non-governmental organisations (NGOs) in implementing the DOTS, thus broadening the network of persons who can become TB treatment supporters and thereby assist TB patients in accessing the DOTS treatment. In South Africa, local NGOs participate in many areas of DOTS implementation, including recruiting, training and monitoring non-clinic based treatment supporters and advocating for greater resources for TB control.

The research that informs this dissertation was carried out over a two-year period between 1999 and 2001 with three distinct phases. During Phase One, I spent four weeks based at a TB hospital in the Western Cape; during Phase Two, I conducted research at an informal community on the outskirts of Cape Town; and, during Phase Three, I worked with several non-governmental organisations working in the field of community based TB control. The names of all research participants have been changed to maintain confidentiality.

1.2 Methodology

My field work consisted of participant observation and semi-structured interviews. In the first phase, research participants at Brooklyn Chest Hospital were selected based on my ability to communicate with them easily. Because my command of the primary local languages Afrikaans and Xhosa was poor, I relied on research participants who were able to speak English.

The second stage of the research was conducted in a squatter community, called Imizamo Yethu, just outside of Cape Town. Research participants included local clinic staff, members of the local civic organisation and staff of the local community centre.

In the final phase of research, NGO organisational heads throughout South Africa, but mainly in the Western Cape Region, were specifically selected as participants because of their experience in the implementation of the DOTS in poor South African communities.

1.2a Field Work – Phase One: Brooklyn Chest Hospital

Brooklyn Chest Hospital was originally built in 1872, and became a quarantine health facility in 1924 in response to an outbreak of influenza that ravaged the Cape during that period. Presently hospital has 10 wards with 320 beds: 141 beds for men, 101 for women, 22 for children and 56 for infants. All medical care is free of charge since the Local Government Authority funds the hospital. Only patients with Pulmonary Tuberculosis or TB Meningitis are treated at the facility. At the time of the research, two wards were devoted to those dying from their illnesses. I was never allowed access to those wards, as the staff felt I had insufficient experience in dealing with terminally ill patients. The wards I spent time in had several different sized rooms, each accommodating three to 10 patients.

During my time at the hospital, I interviewed several patients, nine of which are considered primary informants (five women and four men). I also interviewed three nurses, two doctors and one occupational health specialist. I spent many hours at the hospital talking with staff members and patients about their illness experiences, their working environment and their families. During the four weeks I spent at the hospital, the staff and patients welcomed me and gave me access to the wards, the hospital database, staff meetings and occupational health sessions.

1.2b Field Work – Phase Two: Imizamo Yethu

The second phase of the research was conducted in an informal settlement known as Imizamo Yethu, or Mandela Park, situated on the outskirts of a wealthy Cape Town suburb. This site was chosen by a lecturer in medical anthropology as a field work site for a component of our course.

Five families established Imizamo Yethu in 1994 and by 2000 it had 6,000 residents in both formal and informal housing. The settlement was made up of a diverse collection of people, many of whom considered themselves temporary residents in Cape Town, travelling to the city to get jobs, attend school or to live with relatives. As with many settlements like it, residents reported a wide range in income, ethnicities and levels of poverty.

My first contact in Imizamo Yethu was with the local clinic staff that I was introduced to by my lecturer. Subsequently, a classmate and I decided to take a walk around the community and ended up at the local community centre. The managers of the centre introduced me to members of the local civic organisation who acted as community gatekeepers. During my four weeks of research, I interviewed three civic leaders, one TB treatment supporter and one clinic nurse. My focus during this research phase was on documenting the experiences of community members who participated in implementing the DOTS.

1.2c Field Work – Phase Three: The NGOs

The third phase of my research took the form of a six-week internship at the South African Medical Research Council (MRC). I secured an internship at the MRC after I decided to focus my attention on TB care in poor South African communities. I contacted Dr. Judy Dick[1], a respected member of the MRC's TB research team and asked for her assistance. During my first meeting with Dr. Dick she suggested that as part of my internship I could participate in a wider research project being loosely co-ordinated by the MRC and the National Health Ministry. This project was looking at the experiences of NGO managers who co-ordinated community-based DOTS programmes. During the internship, I worked on my own interviewing NGO managers and accessing MRC resources when a need arose. My research objectives set out by the MRC were very broad, allowing me a great deal of flexibility. Dr. Dick had been involved in the DOTS programme in South Africa since its inception in 1996 and during my time at the MRC she facilitated my access to NGO managers working in the field of TB control.

During this period, I had opportunities to participate in a national forum on community based DOTS implementation and to visit several NGOs and TB clinics with NGO staff members. I interviewed 12 NGO managers, six of whom became primary informants.

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[1] As Dr. Judy Dick is a respected academic who writes extensively on the DOTS I did not feel that the use of a pseudonym (in her case) was necessary.

1.3 Chapter Outline

Chapter Two provides a description of the research process. I explore the relationship between poverty and the burden of disease, and I examine the history of TB in South Africa and the public health program programmes designed to address it. Evidence brought forward in the second chapter of this dissertation shows that the design of the DOTS programme assumes that TB care can be successful by ensuring access to medication and supervision of treatment. The programme focuses on making TB medication available to TB patients through a network of individuals such as medical personnel and community members, but fails to address other social issues that are pertinent to the care of persons affected by TB. These social issues include malnutrition, homelessness and substance abuse.

Chapter Three shows that persons affected by TB in poor South African communities are often unable to adhere to anti-tuberculosis treatment because of the impact of poverty on their lives. Consequently, the inability of persons to access certain basic amenities has made the DOTS programme a burden to them. I illustrate how people affected by TB often view DOTS as a network of social support from which they try to access poverty alleviation within their poor communities. TB patients identify the DOTS as a source from which they can secure employment, food, medication, emergency poverty relief and psychosocial support. The DOTS programme's focus on the provision of medication does not recognise TB patients' histories and experiences of illness and health care, characterised by political disempowerment and poverty. With the DOTS, the inability to access basic resources such as food creates a divide between the objectives of the programme and the needs of actual TB patients, rendering DOTS incompatible with local realities and a burden on poor TB patients.

Chapter Four examines the implementation of the DOTS by NGOs dedicated to working with TB in poor communities. I argue that NGOs can play a critical role in helping TB patients adhere to their treatment by meeting their basic needs through becoming organisations that mobilise collective action for self help by the poor (Wilson et al, 1989).

Currently, however, South African TB NGOs are not organised in such a way as to meet the social needs of TB patients. They are not mandated nor encouraged to make an active and organised attack on the social and material circumstances of TB patients in poor South African communities. As a result, the number of people cured of TB is only 54% of new cases, a figure that falls short of the WHO target of 85%.

Chapter Two. An Analysis of the political economy of TB and its impact on TB care in contemporary South African communities

2.1 Introduction

In this chapter I argue that the design of the DOTS programme assumes that TB care can be successful by ensuring two things: access to medication and supervision of treatment. The programme's focus however, on making TB medication available to patients through a network of TB treatment supporters and medical facilities, fails to address the history of TB in South Africa, its distribution and the impact of social, political and economic determinants on its spread and cure.

2.2 A History of TB

Mycobacterium tuberculosis has been present in human history since antiquity. Egyptian mummies dating back as far as 24000 BCE have shown signs of tuberculosis, and its impact is widely documented in ancient Greek History. Hippocrates identified phthisis or consumption as the most widespread disease of the times and noted that it was almost always fatal. However it was only in the 17th century that exact pathological and anatomical descriptions of the disease began to appear. In his book *Opera Medica* of 1679, Franciscus de la Boe (better known as Dr. Silvius) was the first to identify the "tubercles" as a consistent and characteristic change in the lungs and other areas of consumptive patients. However it was the discovery of a staining technique by Robert Koch in 1882 that allowed him to see *Mycobacterium tuberculosis* that revolutionised the study and treatment of TB (http://www.umdnj.edu/~ntbcweb/history.htm, http://www.wits.ac.za/myco/html/h_trtmt.htm, 2004)

During the 18th and 19th century TB ravaged Western Europe and North America and was treated in a variety of ways including blood letting, surgery, collapsing parts of or all of the lung and through isolation at sanatoriums. It was only in the 1940s that research undertaken by Selman A. Waksman and his team at the University of California yielded effective anti-tuberculosis chemotherapy through the use of streptomycin. Early on it became clear that mono-therapy resulted in resistant strains of TB developing, prompting the introduction of a combination drug therapy of two or three drugs (http://www.wits.ac.za/myco/html/h_trtmt.htm),(http://www.umdnj.edu/~ntbcweb/history.htm, 2004)

During the 19th century, TB was the leading cause of death in industrialised European countries killing tens of thousands annually. Spread by the TB germ carried mainly in airborne droplets of saliva or blood coughed up by TB patients, TB proved to be highly contagious. Although it affected persons in all strata of society, tuberculosis flourished in poor communities where people lived in cramped, poorly ventilated and unhygienic conditions.

As TB ravaged Europe, visitors to South Africa noted that the indigenous population was remarkably free of the disease. European travellers and settlers, many of whom were infected with TB, are believed to have introduced TB into the colony. The dense concentration of people in the gold and diamond mining areas of the colony, coupled with the migrant labour systems of the mines that moved millions of men all over the subcontinent, in time resulted in a wide-spread TB epidemic. At the same time the Cape was being promoted as a health resort for TB patients which almost certainly amplified the epidemic (Yeats, 1986, de Beer et al, 1986).

As the number of settler inhabitants grew in the colony, the need to regulate the population increased and health care delivery became increasingly important to the colonial administration. In 1894, the colonial administration handed down a directive that prohibited any charge being levied for services rendered by uncertified medical workers. This effectively shut down all self-sustaining missionary health care centres that serviced non-white communities and brought all health care facilities under the control of the State. The closure of the missionary centres resulted in reduced access to bio-medical care by the indigenous populations and a corresponding increase in morbidity and mortality rates (Comaroff, 1993).

In the nineteenth and early twentieth century, the South African colonial administration viewed the Black work force as a major source of contagious diseases and a threat to the White settler population. It regulated the spread of disease within the collective population by instituting strict public health programmes. These programmes limited contact and movement between the "threatening" and the "threatened" populations, culminating in the Public Health Act of 1919 that was the first legislated move to control disease in the colony. In response to an outbreak of the Bubonic Plague, the act provided for the physical segregation of the Black and White populations in an effort to protect White settlers (Comaroff, 1993). Through the Public Health Act, Black townships on the outskirts of major White settlements were established. As the colonial government sought to pursue its political and economic agenda, regulated medical services became a viable channel through which to exert control.

Blacks were forced into ghettos that were characterised by poverty, unsanitary living conditions and the spread of disease. As the British colonial administration gave way to the Apartheid State, conditions worsened and public health programmes targeting the Black population increasingly focused on treating physical pathogens in isolation from the social, political and economic conditions that contributed to the spread of disease (de Beer et al, 1986). As the regulation of individual and social bodies by the State became steeped in racist ideologies, South African social, political and economic relations of power converged to establish a set of social relations that privileged the White minority and subjugated the Black majority.

By the 1930s it was estimated that over 60% of the Black South African population was infected with TB. Incidence rates measured from notifications since 1919 rose rapidly peaking in the 1960s. Reported rates seemed to decline as the Apartheid regime grew, but this can be attributed to certain sections of the country becoming decaled independent homelands, and thus their TB figures were not included in national reports. Rapid urbanisation, overcrowding, socio-political marginalisation and inadequate health services exacerbated the spread of TB resulting in epidemic levels of infections.

For many, the standard treatment for TB throughout this period and up until the 1990s was a 12 or 18-month period of hospitalisation with biomedical chemotherapy. However, erratic drug supplies, fragmented and racially biased health services along with long distance trips to the mainly hospital based services made treatment inaccessible and unaffordable for many TB patients (http://www.hst.co.za/publications/394, 2004)

2.3 International Public Health Programmes and TB

By the mid-1900s, the TB epidemics in Europe and Africa had inverted, almost disappearing in the former and becoming firmly rooted in the latter. As early as 1943, the World Health Organisation and national governments in the industrialised world had developed TB control programmes based on biomedical chemotherapy, thereby radically reducing the spread and impact of the disease in their populations (M.C Raviglione, A Pio 2002). During this period, bio-medical developments in TB treatment virtually ceased, reflecting the success of the control programmes and the priorities of the powerful industrialised nations that directed medical, political and scientific programmemes and research. The reduced interest in TB did not reflect the continued and rapid spread of TB in most of the rest of the world (http://www.mpiwg-berlin.mpg.de/ringberg/Talks/farmer/Farmer.html, 2004 Singer, 1992 and Singer, 1995)

TB re-emerged during the 1980s and 1990s as a threat to the social order in industrialised countries and interest was sparked after nearly three decades of obscurity. Rising infection rates were a consequence of what the American Institute of Medicine identified as an increase in immuno-suppressed populations, attributable to the occurrence of HIV/AIDS and the massive movement of people from the heavily burdened countries in the South to the less affected North.

The geographic, racial and class distribution of the re-emerged tuberculosis and associated HIV/AIDS epidemics in industrialised counties was not random, but was concentrated in marginal populations such as immigrants, homosexuals, prisoners and the homeless. The paths of these growing epidemics were intricately connected to the movement of populations along social and economic lines, between the industrialised northern hemisphere and the developing southern hemisphere. In response to increased rates of TB, the WHO focused it control programme on increasing the cure rate through short course chemotherapy. This focus led to the development and launch of the Directly Observed Treatment Short Course (DOTS) strategy in 1991 (M.C. Raviglione, A. Poi, 2002).

Paul Farmer's research in Haiti on HIV/AIDS, traced the trajectory of the county's first infections and their link with the United States. His research illustrated the relationship between political economy and health, demonstrating that HIV/AIDS had spread between the Haitian and North American populations along economic trade routes of migrant labour and commercial sex, not as a function of nationality as had been reported in the press. The classification of Haitian immigrants by the press and later by the government in the US as a threat to public health in the early 1980s was fuelled by reports from the scientific community that labelled Haitians as the source of HIV/AIDS. Early in the 1980s, this resulted in strict public health measures in Florida aimed at curbing the disease in the Haitian population (Nachman, 1993 Farmer, 1996).

The increased threat of TB to industrialised nations coincided with the development and launch in the 1990s of the Directly Observed Treatment Short Course (DOTS) programme by the World Health Organisation. The Global Tuberculosis Programme at the WHO carried out a massive advocacy campaign to get DOTS widely accepted and implemented internationally. This thrust, coupled with increased international financing and investment in tuberculosis, resulted in over 127 countries adopting DOTS by 1999 (Raviglione and Pio, 2002).

Having recognised that treatment of TB patients in the West alone would not abate the local impact of tuberculosis, the WHO's programme adopted a global agenda. The DOTS was implemented with a standardised treatment protocol for all newly diagnosed TB patients. The WHO stated that the DOTS was sufficient to cure TB and curb the spread of Multi Drug Resistant (MDR) TB, a mutated strain of TB commonly developed when TB patients interrupt their treatment.

In the new millennium, the WHO began promoting a revised version of the DOTS that encouraged widespread partnership with non-governmental organisations (NGOs) and the private sector to facilitate greater access to the DOTS by TB patients world-wide. (Raviglione and Pio, 2002). It was hoped that by collaborating with NGOs, the number of TB patients treated through DOTS around the world would increase and governments would reach a target of curing 85% of all newly diagnosed TB cases.

Partnering with NGOs was also encouraged because of the assumption that NGOs are usually established to help people without consideration for electoral or economic gain. Thus, organisations operating within this NGO framework are considered apolitical, non-governmental and non-profit-making. In truth, however, the idea of the neutral and moral character of NGOs masks the political agendas and relations of power within and between these organisations (Fisher, 1997).

Far from being apolitical, NGOs are characterised by complex dynamics in which a multiplicity of agendas exists. NGOs are often actively working to politicise issues and influence relations of power utilising techniques of social, political and economic control. As social agitators, NGOs often owe their existence to sympathetic governments without whose consent they would be prohibited from operating. A permissive environment is not necessarily a reflection of the non-governmental sector's access to power and influence. NGOs that are advocates for positions contrary to those within a national agenda are often able to exist as by-products of international agreements that necessitate the existence of an active civil society. Thus, NGOs' relations with the State are frequently mediated by the degree to which national government, international financing and donor agency agendas converge. For example, organisations such as the World Bank often name NGOs as stakeholders in their loan agreements, forcing national governments to facilitate NGO activity if they are to gain access to funds. Such agreements reinforce international, national and local relations of power (Fisher, 1997).

In many cases, the relations of power between donors, the State apparatus and NGOs can best be described as a compromise. Local NGOs in need of financial support can be persuaded into carrying out activities or publicly standing in agreement with objectives that they may not fully share, but which provide access to the resources they need. In such circumstances, the NGOs that have accessed funds become bound to the donor, often resulting in a shift in their focus and potentially loosing sight of their initial objectives (Fisher, 1997; Fani, 1998; MacFarlane, Racelis & Muli-Musiime, 2000).

South Africa is one of the countries where non-governmental organisations have taken a lead role in implementing the DOTS strategy. These organisations are active in many areas of TB control, including research, training, facilitating community involvement and increasing public awareness about TB. Many of these NGOs rely very heavily on the financial assistance of external funding agencies, often falling prey to the pressures outlined above.

NGOs, however, have also been described as "organisations for change," providing a way for the poor to launch an organised assault on their negative social and material circumstances, and impacting on their daily reality of poverty and political marginalisation (Wilson et al, 1989). Self-reliance and participation in the process of change is key and calls for the intimate involvement of local interest groups from the beginning in setting the agenda for change and subsequently controlling the process of change. This cannot be imposed from above but must be initiated from the local level (Levine, 1994). In the context of international public health programmes, however, where objectives, strategies and outcomes have been directed by the priorities of powerful industrialised nations, NGOs face many challenges in exerting this type of control.

2.4 The Design of the DOTS Programme and its Impact on TB Treatment in South Africa

In his research on the treatment of Multi-Drug Resistant TB (MDR-TB) in Peru, Paul Farmer (http://www.mpiwg-berlin.mpg.de/ringberg/Talks/farmer/Farmer.html, 2004) illustrates the limitations of international public health programmes. He describes how the treatment of MDR-TB in Peru is determined by the economic priorities and cultural-bound medical systems of the WHO. He demonstrates that the WHO's international directive to treat all first time TB patients with a standardised TB treatment protocol is based on the assumption that all first time TB patients are infected with a particular strain of TB. The WHO treatment protocol does not make provision for the treatment of first time TB patients infected with an alternate strain of TB, a situation that is prevalent in a particular slum outside of Lima, Peru. Despite the fact that the alternate strain of the disease is resistant to the drugs that the DOTS program programme recommends, patients are being treated with the global approach to TB care recommended by the WHO. Consequently, the treatment programme is unsuccessful with these patients.

Farmer illustrates that the spread of MDR-TB in that community outside Lima is a function of poverty, not the failure to adhere to treatment as the WHO TB programme assumes. The WHO has claimed that MDR-TB is untreatable in many developing countries because of the high cost of the prescribed medication used for treatment. Farmer argues that the bio-medical focus of the WHO, treating the disease in isolation of social factors, coupled with a desire to keep the cost of TB treatment low, rendered the DOTS treatment protocol redundant and ineffective for MDR-TB patients (http://www.mpiwg-berlin.mpg.de/ringberg/Talks/farmer/Farmer.html, 2004).

The WHO outlined five key elements that are necessary for the successful implementation of DOTS: diagnosis of suspected TB patients; a standardised treatment regime that is observed and recorded; regular access to TB medication; a standardised monitoring system to track the success of the programme and government commitment to sustained TB control. The expressed objective of the DOTS is to improve TB cure rates with a target of curing 85% of all newly diagnosed TB cases (WHO, 2000).

The strategies the programme used to meet its objective of increasing the number of persons cured of TB provides an indication of the assumptions upon which it is predicated. The first strategy of the DOTS programme is to positively diagnose suspected TB patients. To do this, it uses a bio-medical technique that was developed over 100 years ago in Germany. This technique tests the sputum found in saliva for evidence of active TB germs. (http://www.mpiwg-berlin.mpg.de/ringberg/Talks/farmer/Farmer.html, 2004). The bio-medical tradition that is characterised by increasingly smaller units of analysis in diagnosis and treatment of disease is represented in the DOTS programme through its method of diagnosis. The development of tests such as those used in detecting TB, were aided by Western epistemologies of the 17th and 18th centuries that progressively segregated the supernatural and mundane, real and unreal, creating a dichotomy between the mind and body in explanations for disease causation and cure (Scheper-Hughes, Lock 1978, Foucault, 1977). Thus, the subsequent bio-medical focus on the physical body that identifies a germ as the pathogen in diseases in isolation of social political realities set the foundation for DOTS strategies today.

The second strategy of DOTS is to treat positively diagnosed TB patients with a standardised treatment of bio-medical anti-tuberculosis drugs, while observing and recording the ingestion of treatment. The objective of this strategy is to ensure consistent treatment and supervision. The sole use of bio-medical chemotherapy by DOTS for the treatment of TB highlights the bio-medical focus of the programme and the Western epistemological tradition that informs it. The directive from the WHO for an internationally standardised treatment regime ensures the uniform application of treatment through the programme, preventing the DOTS from being changed through influences from other medical systems. The programme thus retains the bio-medical focus of its design, treating pathogens with supervised bio-medical drug therapy to the exclusion of other cultural explanations for disease causation and remedies for cure.

The third DOTS strategy of ensuring a steady and regular supply of medication for the treatment of TB illustrates the singular emphasis on the type of treatment made available to TB patients. The centrality of the availability of anti-tuberculosis medication to the implementation of the DOTS does not allow for the inclusion of alternative treatments of TB through the programme as no other therapy is recognised as effective.

The final two strategies of the DOTS are to secure government commitment to TB control and the establishment of a monitoring system to track the success of the programme. Both of these assume the optimal TB control strategy to be the DOTS, necessitating State involvement and close monitoring to maximise the impact of the programme.

The current bio-medical explanation for TB and strategies for cure embedded in the DOTS programme do not capture the experience of TB patients. This analysis stems from the theoretical distinction between disease, illness and sickness that ground contemporary medical anthropology. The focus of the DOTS programme on treating the individual pathogen represents a classical Western bio-medical approach to health care that views diseases as objective abnormalities found in individual bodies. Contemporary medical anthropology has drawn attention to the experience of ill health, as distinct from disease, by highlighting the social distribution of disease and the process through which people may vest disease with social significance (Rock, 2003). The DOTS does not recognise the social distribution of TB, but is focused on providing a specific treatment for a disease category.

> "He [my husband] would drag me to the clinic. He would fetch the clinic sister. We had many arguments, all because I didn't want to go and take my medication. So I said, you are not my father, you don't have to come and tell me this and that. I know right from wrong. So, when he came, he came with the clinic sister, and I had to go. So I said, no, I'm coming this afternoon. He always talked to me. Now, yesterday he called and told me it is my fault that I am in hospital. It is my fault that my son is living with his aunt and my husband with his father. And he said, when is it going to stop? Are

> we going forward or what? Don't you think I get a bit tired of this? So I asked him if he wanted to go on with this life, and he said yes. He says he doesn't want anybody else, but he wants to know when I am going to get out of hospital. I told him he must give me some time. I am going to get better. He must just believe that I am going to get well." (Jude Faiz, Brooklyn Chest Hospital, 2000)

The extract above is taken from an interview that was conducted with Jude Faiz at Brooklyn chest hospital. At the time of this interview, Jude had been in hospital for seven months and did not know when she would be discharged. She was married and was the mother of a three-year-old boy. At the time of our meeting, Jude had been receiving treatment for TB intermittently since 1995. She had never completed a course of TB treatment and was classified as having developed Multi-Drug Resistant TB. Jude and her family lived approximately 20 kilometres north of Cape Town in a township established during the Apartheid era. She and her husband lived in a two-room apartment in a neighbourhood where drug abuse is common and where the residents battle with unemployment and gang warfare. Prior to her hospitalisation, Jude was unemployed and her husband worked as a part time employee at a local fish market. The family earned approximately R1500 per month and was dependent on the extended family for additional support.

Despite Jude's long history of infirmity as a result of TB, she was unwilling to access the DOTS treatment available at her local clinic. She spoke of hiding in the cupboard when local clinic sisters or community treatment supporters dropped by unexpectedly. When I asked her why she was so resistant to going to the clinic and taking the medication, she said the following:

> "I don't know really, I just didn't feel like it, and being told what to do, and when to do it. I know I should take my medication, but I didn't want to." (Jude Faiz, Brooklyn Chest Hospital, 2000)

I did not find Jude's description of her response to TB treatment uncommon in my interviews. The availability of treatment and the promise of a cure were not sufficient motivators for her to make use of the DOTS. In much of Jude's world, the social landscape was dominated by widespread and persistent unemployment, gang related violence and extensive substance abuse. The social, economic and political history of the Apartheid system that was designed to support White supremacy had left dis-empowered and segregated communities, untrusting of the state medical system, positioned on the fringe of the dominant social order. I would like to suggest that Jude's daily reality of living on the social periphery, with little access to formal channels of influence and power, characterised her environment and influenced her actions. Consequently, not conforming to medical authority becomes an act of defiance against the dominant social order and a viable means of self-expression. Non-adherence to treatment was one of the ways in which Jude could exert control in her life and over her situation. Access to, and the demonstration of power represented a strong counterbalance to the benefits of the DOTS programme and the positive impact it could have had in her life.

The DOTS programme assumes that access to medication and supervision of treatment are sufficient to treat TB because it takes for granted the existence of a specific social order that moves to the rhythms of State control and responds to the hand of bio-medical authority. However, in Jude's world and that of so many other South Africans, the dominant social order is far from the one the DOTS was designed to be absorbed into.

While at Brooklyn Chest Hospital I also met Hector Mafuleka. At the time of our interview, Hector had been hospitalised for three weeks. This was Hector's fourth incidence of TB in four years. Prior to his most recent hospitalisation, Hector worked part time at a bakery in Cape Town and lived in a small one-room house in an informal squatter settlement approximately 15 kilometres north of the city. Unlike Jude, Hector had completed all three previous courses of the DOTS treatment and had been re-infected shortly after completing each course of treatment. Hector ascribed his constant battle with TB to his poor living conditions:

> "You know I am from the Eastern Cape. I come from Port Elisabeth. I came to Cape Town to work five years ago because unemployment in my town was too high and I couldn't find work. Since I have been in Cape Town I have had TB

> four times. This is a terrible place, and I think I am moving back to PE. Even though life is hard there, at least I live in a brick house with a proper roof. Here I live in a shack with a tin roof, living like this is making me sick. I think I would rather try and find work in PE than live here like this, always sick."
> (Hector Mafuleka, Brooklyn Chest Hospital, 2000)

Hector's case is an example of how the focus of the DOTS on providing treatment does not take into account the social, political and economic influences on the spread and distribution of disease. Hector's economic position and subsequent vulnerability to TB infection was a direct consequence of the legacy of Apartheid. As a non-White, Hector was marginalised by the former political system and has remained disadvantaged in the wake of South Africa's ascent to freedom. Hector was infected by TB four times in as many years because he was poor, living in an environment in which TB spreads easily. His was a daily burden borne by millions of South Africans as a result of over 300 years of colonial rule. Access to TB treatment through the DOTS in a highly contagious environment allowed for the treatment of each infection, but did not address why Hector was continually re-infected and why he was never permanently cured of TB. In his book "Race, Class and the Apartheid State" (1988) Harold Wolpe asked if the demise of the Apartheid state would herald an era of economic as well as political freedom. He answered this question by stating: "The achievement of state power (by the Black majority) does not, however, dislodge imbedded social structures, or alter the economic facts of life." (Wolpe, 1988; 95). Although Hector had gained political freedoms, his life was still tightly bound to social inequality and long periods of sickness by his inherited shackles of poverty.

2.5 DOTS and the illness experience of poor South African TB patients

The DOTS programme illustrates the international relations of power that determine the direction of public health programmes on a global scale. To secure WHO support for TB management, governments are required to facilitate the implementation of DOTS by pledging total commitment to this system of TB control. This necessitates ensuring a responsive socio-political climate within which the DOTS can flourish. It does not, however, ensure that TB patients will benefit from the DOTS programme.

In such a climate, once the DOTS has been adopted as the national strategy for TB control, other epistemologies are marginalised within the domain of TB care and the international bio-medical approach to TB is reinforced.

The global relations of power that have resulted in the DOTS programme becoming the standard treatment protocol for TB are often reflected in the doctor-patient relationship. In the extract below, Sophia Dube recounts her experience of receiving TB treatment at the Brooklyn Chest Hospital. She began her account by explaining that at the beginning of her treatment she confronted her doctor about the type of medication he was prescribing for her. She indicated that she told her doctor that she knew that she should not receive a particular prescription as it could not treat Multi-Drug Resistant (MDR) TB, the type of TB from which she was suffering. She asserted that her doctor's refusal to acknowledge her protests regarding her treatment eventually resulted in the manifestation of terrible side effects including the loss of hearing in one ear. The extract below illustrates the way in which the doctor /patient relationship is mediated by race, class, gender and language, the consequence of which, often, is patient dissatisfaction.

> "So, I said to the doctor, I know about the tablets, but I'm MDR (Multi-Drug Resistant), so why do you give me straight TB tablets? So he said, the tablets are not your problem, they are my problem. After four months of treatment, I went to him and complained that there was something wrong with my hearing. So the doctor said it would go away. Then at seven months, the moment I got my TB medication my sight was gone, my hearing was gone, my taste, my mouth was so bitter, and then I had to grab something. The nurse told the doctor and the doctor stopped the treatment." (Sophia Dube, Brooklyn Chest Hospital, 2000)

Ferguson and Candib (2002), argue that effective doctor/ patient communication can improve outcome measures such as patient satisfaction, adherence to treatment and disease outcomes. However language barriers, physician bias including racism and a lack of adequate relationship building skills, negatively impact on the clinical relationship, affecting participatory decision-making and the provision of competent care.

Research conducted in the United States suggests that patients from ethnic minority groups, especially those not proficient in English, are less likely to engender empathetic responses from physicians. They are also less likely to establish a rapport with the physician, less likely to receive sufficient information and less likely to be encouraged to participate in medical decision-making, all of which are linked to the successful treatment of a patient (Ferguson, Candib, 2002).

Free (2002) further argues that descriptions and expressions of pain are culturally mediated thus, effective patient/ doctor communication must straddle cross-cultural understandings of pain and pain control to ensure appropriate treatment.

Sophia Dude's treatment experience as outlined above spanned a 10-month period. I would like to suggest that the race, class, knowledge and power differentials between Sophia and her physician resulted in inappropriate treatment and high patient dissatisfaction. Sophia, a Black woman expressed her dissatisfaction with the treatment she was receiving from her White, male doctor. In the years following the breakdown of Apartheid, many of the race, class and gender imbalance remained unchanged. I argue that the channels of communication between Sophia and her doctor were shaped by the history of the Apartheid state, replicating many of the same biases that had been institutionalised for decades. As a poor Black, Sophia did not possess enough social capital with which to successful challenge the authority of her doctor. She was unable to communicate in his domain and he was unable to demonstrate empathy towards her in manner she could recognise. Despite alternative treatment being available for MDR TB at the Brooklyn Chest Hospital at the time of my research, the doctor's insistence that she continue her course of treatment communicated loudly that he was in control and Sophia's experience and expression of pain were disregarded.

Through the WHO's global TB control programme, local knowledge that informs health-seeking behaviour is subverted in favour of bio-medical diagnostic and treatment approaches in the formal health care sector. Singer et al (1988) highlighted this relationship in their research with Haitian women who sought care from bio-medical practitioners for reproductive illnesses. Singer argues that the fear of ridicule and rejection by bio-medical practitioners prompted the use of particular language by poor women in the bio-medical environment. The women felt that when they presented indigenous explanations for reproductive health maladies, such as disgruntled ancestors, their illnesses were dismissed as superstition. As a result, the women chose to present their ailments in the language and epistemology that was acceptable within the bio-medical paradigm so as to avoid the doctor's refusal to acknowledge the illness experience as valid. Similarly, the international bio-medical imperative imbedded in the DOTS excludes any other method of analysis, including patients' embodied knowledge of the illness experience.

Scheper-Hughes and Lock (1987), developed the concept of embodied knowledge through exploring the role of the body in Western and non-Western medical systems. In Western medicine, the body and self are understood as distinct separate entities, with illness residing in either the body or the mind, separate from social relations. In contrast, many non-Western medical traditions do not segregate the body and mind, and social relations are integral to the health and well-being of the individual and the society in which they live. Thus, when illness befalls a person, Western bio-medicine treats the body as a series of components needing to be fixed, whereas many non-Western medical traditions treat any possible combination of the body, failing social relations and disgruntled spirits as contributors to the individual's ill health. Scheper-Hughes and Lock argue that one consequence of modern medicine's segregation of body and self is body alienation that may be experienced by patients as a disembodied self, the loss of the sense of wholeness or control as a person.

Although body alienation has been connected to disorders such as anorexia nervosa or schizophrenia, I would like to suggest that the extract above regarding the deterioration of

Sophia Dube also illustrates body alienation, as a consequence of the self/body dichotomy of the Western bio-medical tradition.

Sophia Dube and I met while I was conducting research at the Brooklyn Chest Hospital. She was 41 years old and had first contracted TB at age 12 in 1969. She had been hospitalised for treatment in 1985, 1996 and 1998. At the time of our meeting she had been in hospital for one year and did not know when she would be discharged. Sophia lived with her parents in a township on the outskirts of Cape Town. Prior to being hospitalised on this occasion, she worked as a shop assistant at a hardware store in the city. Although Sophia had completed treatment for all three prior cases of TB, she was classified as having MDR-TB.

In the extract above, the doctor in charge of Sophia treated her TB in total disregard for her embodied knowledge. Against her wishes, the treatment continued and caused the loss of 90% of her hearing in one ear and 70% of her sight. Sophia's bio-medical treatment experience was wrapped up in the patient/healer knowledge hierarchy that disregards the patient's illness experience and embodied knowledge in favour of bio-medical knowledge. This relationship and the subsequent medical treatment resulted for Sophia in a disconnection between her mind and body, the latter being treated in isolation of the experiences and knowledge of the former. She felt that she had lost her sense of connection between her self and her body, expressing feelings of helplessness at the course of the treatment, and, within the treatment relationship, she felt unable to change a course she knew was wrong and was not able to control. After her DOTS treatment, Sophia was left feeling as though she existed in an alien body that she could no longer relate to.

Lazarus (1988) examines the doctor-patient relationship in her research with pregnant women who sought health care at bio-medical facilities. She argues that doctors' and patients' relationships in bio-medical institutions are not on an equal power base. The power differential between the doctor and patient is a consequence of the greater social importance ascribed to the bio-medical knowledge of the doctor rather than the illness experience of the patient. Consequently, the doctors are invested with greater authority than the patient. Thus, in the doctor-patient relationship, the knowledge/power dynamic impacts on the therapeutic experience, leaving health seekers dissatisfied with the experience. Singer (1995) argues that much of the tension in the clinical encounter is derived from the reproduction of larger class, racial and gender conflicts in the broader society. In the example above, Sophia's protest went unheeded because the power/knowledge differential between herself and her doctor was too great for her to influence the course of her treatment in an institution that only sanctioned bio-medical knowledge.

In Sophia's case, the international relations of power that set up the DOTS programme within the Western bio-medical paradigm as the only acceptable treatment course for TB collided with the patient/doctor knowledge hierarchy to permanently scar Sophia on both a physical and emotional level.

2.6 Conclusion

The impact of TB on both industrialised and industrialising countries has had a long history. For decades, TB was not a priority on the international public health agenda because its impact on Western populations was minimal. The emergence of HIV/AIDS with a TB co-infection in the 1980s, coupled with the movement of migrants along social-economic trade routes between the North and South, re-introduced TB into industrialised populations. The re-emergence of TB and the threat it posed to the stability of industrialised nations pushed TB treatment and cure back onto the international public health agenda. The shift in focus towards TB research, care and control resulted in the WHO's launch of the DOTS as the international response to TB control.

The DOTS approach to TB control is firmly rooted in the Western bio-medical tradition, excluding alternative epistemologies in the explanation for disease and remedies for cure. The singular focus of the DOTS programme on providing bio-medical treatment negates the experiences of TB patients in poor South African communities. Living in cramped, unsanitary conditions is as much a contributor to the spread of TB as any bio-medical explanation, but the DOTS programme does not address this. Focused on treating the pathogen in the body, the WHO's international public health programmes for TB control alienate the TB patient from the treatment experience. The DOTS' bio-medical paradigm monopolises explanations for ill health and prescriptions for cure. The disconnect between treatment and factors that influence the spread of TB limits the impact of the DOTS in environments characterised by economic and political marginalisation, leaving patients to make choices that do not necessarily include DOTS. Sophia and Hector, two patients at the Brooklyn chest hospital, experienced TB as a consequence of political, economic and social poverty. However the DOTS treatment of TB focused exclusively on the isolation and elimination of the biological pathogens identified by the Western bio-medical epistemology.

Chapter Three. DOTS as a Social Network of Support

3.1 Introduction

In this chapter, I explore the impact of poverty on the completion of the anti-tuberculosis treatment regime as set out by the DOTS programme in poor South African communities. I argue that persons affected by TB are often unable to complete anti-tuberculosis treatment because they are unable to access certain basic necessities such as food and shelter that are integral to the implementation of the DOTS. I will illustrate that the gap between what persons affected by TB have access to and the prerequisites of the DOTS programme make the DOTS programme a burden to them.

I also argue that people affected by TB (TB patients, family and members of the community) view the DOTS as a network of social support and a point of access for poverty alleviation within their poor communities. The DOTS programme does not, however, include local construction of support, rendering it incompatible with the local realities and limiting its effectiveness. The analysis in this chapter covers the three key groups of actors in the DOTS: TB patients, TB treatment supporters and TB NGOs.

In his work on the cultural context of social support and support networks, David Jacobson (1987) argues that one of the primary challenges faced by networks of social support are differences in meaning ascribed to acts of support by givers and receivers. Differing needs and social circumstances produce dissimilar interpretations of the significance of particular acts resulting in conflict between members of the support network. Jacobson also argues that, in addition to different interpretations of an act, the standards used to judge an act may differ. For example, a TB patient may complain that his/her TB treatment supporter is difficult to contact because he/she are rarely home, preventing the TB patient from readily accessing treatment. At the same time, the TB treatment supporters feel that they are easily accessible because they have allotted specific times in the day for TB patients to collect their treatment. Thus, having the intention of being supportive (in this case making treatment available to TB patients at a particular time of day) does not guarantee that the action will be perceived in that way. The extract below is from an interview with a community based TB treatment supporter. What the treatment supporter offered as support (access to her home for treatment) was not interpreted as sufficiently supportive. TB patients wanted more of her time and greater flexibility in access to their treatment.

> "Most of the patients give me many problems. In most cases they come at very irregular times, and late in the evening, to fetch their treatment. I just had to get up and give their treatment to them. Some of them are very impatient at times." (TB Treatment Supporter- A, Imizamo Yethu, 2000)

3.2 TB patients' experience of the DOTS

The DOTS offers support to TB patients through the supervision of treatment either as an outpatient or in a hospital. At the time of my research, Richard Shwalofo had been a DOTS patient at Brooklyn Chest Hospital for three weeks and expected to be there for another six months. Richard was the primary caregiver for his three children who lived with him in an informal settlement outside of Cape Town. Prior to his hospitalisation Richard worked as a builder on a construction site earning a minimum wage.

> "Q: How are you feeling about the length of time your treatment here will take?
>
> "A: It's bad man, because I left my children behind and now they are suffering. There is nobody to support them. My mother is taking care of them for now, but I don't know how long she will be able to. This is the problem that is facing me. That is why I am saying that six months here is just too long.
>
> "Q: Does your family come and visit you here?
>
> "A: Yes they used to come, but now I told them not to come anymore. Once my child came here and told me she was hungry, so I told my mother not to bring her back. It makes my heart pain." (Richard Shwalofo, Brooklyn Chest Hospital, 2000)

Richard's narrative exemplifies the conflicts inherent in the DOTS programme between the type of support the programme offers, and the type of support the patient deems necessary. Richard was admitted to hospital to receive the DOTS treatment but the treatment and support provided were in conflict with his social reality of being the sole caregiver and breadwinner for his family. I argue that TB patients in poor South African communities do not share the cultural interpretation of support intrinsic to the DOTS programme, which assumes access to, and supervision of treatment as sufficient support for TB patients to complete their treatment. Without patients' access to basic subsistence, the programme is compromised and does not meet its goal of increasing the number of persons cured of TB. For Richard, access to a support network to care for his family during his DOTS course at the hospital was critical to the success of the treatment. Richard's roles as caregiver and breadwinner for his family were not fulfilled, causing him to question his ability to complete the TB treatment.

The type of support the DOTS programme offered Richard was designed outside of his local reality of poverty. Poverty produced different needs from those that the DOTS programme was designed to meet. The DOTS does not incorporate local realties of poverty. Consequently, it was not perceived by patients as providing support but as being a burden. The heavy hand of poverty was an ever-present reality in Richard's life, affecting his perception of his ability to complete his treatment. Richard, as a father of three, lamented the real implications for his family as a result of his stay in hospital. Not only was he unable to continue to work to support his children, but also he was unable to rely on anybody else to assist them for the duration of his treatment.

The dichotomy created in Western bio-medicine between the "self" and "other," explored by Scheper-Hughes and Lock (1987), resulted in the DOTS programme alienating Richard from his responsibilities. The DOTS made no provision in its design for the disruption of support networks resulting from TB patients' participation in the programme. In Richard's case, it separated his social and individual needs from his medical needs, treating his body in isolation from his social role as provider.

> "Often, to get the patient into hospital, the nurses tell them that if they go, and they are good, they will see about getting them a disability grant." (Nurse-A, community clinic, 2000)

As the extract above illustrates, nurses at the clinics in the community and in the hospitals are acutely aware of TB patients' needs and the possible impact that participating in the programme could have. During my time at the hospital, the nursing staff told stories of grieving patients who could not or would not eat while at the hospital because they knew their family members were starving at home. These acts of self-deprivation prevented TB patients from successfully completing their treatment, as food was a critical component of the DOTS. TB patients at the hospital were not permitted to take medication if they did not eat, as treatment without the correct nutrition amplified common side effects of the drugs such as nausea and produced other complications such as the erosion of the lining of the stomach by the harsh chemicals in the medication. Protests by TB patients such as the ones described above against the impact of poverty on their lives posed serious risks to their health and had a direct impact on their ability to complete their treatment.

A second consequence of the patients' refusal to eat and subsequent lapse in treatment was the possible re-infection of other TB patients at the hospital. Protesting TB patients remained highly contagious until a full course of treatment was initiated. Thus their condition would not improve and their lack of ability to complete treatment could negatively impact on the rest of the hospital's population. In such cases, the support offered to TB patients from TB treatment and supervision through the DOTS, directly conflicted with their obligations as adult caregivers in their families and communities. Access to three meals a day, a dry bed and TB medication at the hospital was not considered support but too great a burden to carry while their loved ones starved and suffered in other ways at home.

The conflict between accessing daily doses of TB medication through the DOTS and meeting other social responsibilities was not confined to the hospital setting. The following extract was taken from an interview with Nurse Sandra McKenzie, a nurse at the community clinic on the outskirts of Imizamo Yethu. She had been working at the clinic for seven years at the time of our meeting and had been responsible for the DOTS in Imizamo Yethu for five years:

> "We have patients who work on the fishing boats that dock in the local harbour. Jobs are scarce, so if they get a chance, they will take a job for up to two weeks on a deep-sea fishing vessel. When they come back they want to resume treatment, but it is too late by then." (Nurse Sandra McKenzie, Imizamo Yethu community Clinic, 2000)

TB patients were classified as treatment defaulters by the bio-medical establishment after five consecutive days of missed anti-tuberculosis treatment doses. Once classified as defaulters, the treatment course was terminated and they had to start a whole new course of medication to treat their TB. Repeated interruptions of treatment can lead to TB patients developing MDR-TB, a strain from which only 30% survive (www.who.com, 2003). Poverty, social networks of responsibilities and interpretations of support play pivotal roles in determining TB patients' treatment outcomes.

Thus far, the examples given have been of patients who felt that the DOTS programme did not offer enough support. The extract above illustrates an alternative experience of the support offered by the DOTS, in which patients interrupt their treatment and come back to it, because they view the DOTS programme as a source of support. In such a circumstance, a patient's interruption of treatment was based on their knowledge that the objective of the DOTS programme was to increase the number of persons cured of TB. They believed the DOTS facilitated access to medication and treatment supervision when treatment was most convenient for them. They interrupted their treatment with the expressed objective of resuming it when they saw fit. To some patients the DOTS was a burden because it conflicted with their social responsibilities, but to other patients the DOTS was recognised as a support network that could be accessed when the need arose.

DOTS implementers, through local clinics or NGOs worked hard to encourage employers to act as TB treatment supporters in an effort to overcome the challenges of workers missing DOTS treatments because of job commitments. However, workplace treatment support was often rejected by TB patients who were interviewed, for fear of being discriminated against because of the social stigma associated with TB.

> "People think that you have AIDS when you have TB. I don't want to bring my life to my work." (Clinic attendee, Imizamo Yethu, 2000)

However, the biomedical establishment heavily sanctioned treatment defaulters. The DOTS could not in fact be accessed as often or at times that were necessarily most convenient for TB patients. The threat of an MDR-TB epidemic had curbed the DOTS implementers' enthusiasm for re-initiating treatment with defaulters. Bio-medical practitioners ultimately decided if and when a patient receives access to the DOTS. Thus, the illness experience of the TB patients was subordinate to the bio-medical treatment protocol of the DOTS. The social struggles of the wider society that were shaped by hundreds of years of class, race and gender conflicts were replicated in the relationship between the DOTS and the TB patient in the therapeutic experience. The DOTS patients did not have access to sites of power and authority within the DOTS programme that would allow them to influence their treatment protocol and outcome. Thus, the support offered through the DOTS programme was conditional. The objective of increasing the number of persons cured of TB was only applicable to persons who agreed to access the DOTS within the guidelines set by the bio-medical fraternity.

The negative impact on TB patients' social networks of support as a consequence of participating in the DOTS programme was a result of different understandings of support. The DOTS programme offered support through treatment and supervision, but TB patients often experienced this support as a burden. Nevertheless, some TB patients viewed DOTS as a true network of social support and a point of access for poverty alleviation within their poor communities.

The extract that follows was taken from an interview conducted with Dr. Peter Hammer, at the Imizamo Yethu community clinic. As the most senior resident medical staff member at the clinic, Dr. Hammer was responsible for overseeing all the activities of the clinic, including the community DOTS programme. Imizamo Yethu had been an early site for the implementation of community-based DOTS and Dr. Hammer worked closely with a local TB NGO and Nurse Mackenzie, the DOTS co-ordinator, in implementing the programme.

> "There are the unemployed and those who see no likelihood of ever being employed. They can steal, rob, do bank heists or they can get a disability grant from the government whilst they are on treatment. But if they get better, they lose their disability grant, and these are the facts out there in the township. They don't really want to get better." (Dr. Peter Hammer, Imizamo Yethu community clinic, 2000)

In an effort to alleviate the crushing impact of poverty, the South African Government established the Department of Welfare in 1994. The Department was given the task of phasing out the disparities in social welfare programmes inherited from the Apartheid regime whilst meeting the needs of the poorest South Africans. In July 2000, the Department of Welfare was renamed the Department of Social Development and adopted a wider mandate that was committed to the agenda of social transformation, poverty reduction and social integration. To this end, the Department of Social Development and its provincial offices offered a wide variety of services including disability grants, war veteran's grants, a care dependency grant and a social relief from distress grant.

During the course of my research many respondents spoke candidly about their desire to access the disability grant; however few were able to do so as the criteria for selection were very stringent. A TB patient would have to provide the following information on application:

- The applicant must be a South African Citizen or a permanent resident;
- The applicant must be resident in South Africa at the time of application;
- The applicant must be between 18 to 59 years of age if a female and 18 to 64 years of age if a male;
- The applicant must submit a medical / assessment report confirming disability;
- The applicant and spouse must meet the requirements of the means test;

- The applicant must not be maintained or cared for in a State Institution;
- The applicant must not be in receipt of another social grant.
- The applicant must submit a 13 digit bar coded identity document. (http://www.welfare.gov.za, 2004)

TB patients who were able to meet the requirements but whose application was unsuccessful were allowed 90 days within which to appeal the ruling in writing. The most important factor in accessing any grant was the applicant's financial position. In determining eligibility for part of or a full grant, the income and assets of the applicant and spouse were assessed. At the time of the research, the maximum amount awarded for a disability grant was approximately R700.00 per month. Successful applications were regularly reviewed to ensure that grantees were still eligible for support. (http://www.welfare.gov.za, 2004).

The South African political economy characterised by poverty, violence and marginalisation, has influenced local health-seeking behaviours. TB patients in poor South African communities tried to alleviate the impact of poverty on their daily lives through the DOTS programme. Patients had to meet certain criteria in order to access resources that the extract above illustrates. The TB patient had to demonstrate a total inability to be self reliant as a result of the TB infection, forcing some patients to choose the option of ill health or "forced" disability to access resources to survive. Many TB patients saw their TB infection as a point of access to the disability grant offered by the state. Patients who received the grants were envied by those who did not but the former fought hard to retain the grants, an option that was impossible if they were ever cured through the DOTS.

While the design and implementation of the DOTS programme do not make provision for the financial support of TB patients during the period that they are on treatment, the South African government does do so through a disability grant. Access to a disability grant was contingent upon TB patients' participation in the DOTS programme. Once treatment was completed, patients lost access to the grant even though their social and material circumstances might not have improved. Thus, poverty motivates some TB patients to deliberately interrupt their treatment so as to remain uncured and retain access to a government subsidy. The objectives of the DOTS programme thus become perverted as TB patients try to take control of the type of support they can access through the programme.

Dr. Hammer, Nurse McKenzie and Alisa Nash (an NGO worker) facilitated my access to doctor/patient consultations at three different health centres located in two townships on the outskirts of Cape Town. In all cases, I requested access to the consultations to observe the relationship between TB patients visiting clinics in poor South African communities and the medical staff treating them. Once the attending nurses or doctors received permission from the patient, I was allowed access to the interview portion of their meeting and left the room during any physical examination. One afternoon, while accompanying a doctor from Brooklyn Chest Hospital on a trip to a health centre that served a large township on the outskirts of Cape Town, I sat in the waiting room as he examined a patient. As I waited, I observed a man in his early 40s get up and go in for a consultation with another doctor. A few moments later I heard raised voices, then the man stormed out of the consultation room, slamming the door behind him. When I asked a nurse what had happened, she said that the man had been trying to access a disability grant for some time and had come to see the doctor in the hope that it had finally been granted. The doctor, however, had told him that, as a persistent treatment defaulter, there was no hope of him getting the grant. The grant was only available for persons on treatment, not persons who continually defaulted from treatment. This fine distinction in eligibility for the disability grant is an example of the “cat and mouse game” often played between TB patients and the DOTS implementers, as patients try to extract a specific type of support from the programme.

While the State sponsored disability grant generated much discussion among my informants, the grant eluded many of them. The grant was provided by the State as a “stopgap” to help support indigent TB patients during their recovery. The need, however, far outweighs the available resources and, in an effort to improve their chances of accessing the grant, TB patients deliberately defaulted on their treatment, hoping that being sicker would increase their chances of being awarded the grant.

3.3 TB Treatment Supporters' Experience of DOTS

The DOTS programme was designed to provide bio-medical TB treatment to diagnosed TB patient through a network of monitors. These monitors, known as TB treatment supporters, are asked to assist TB patients in completing their treatment by storing, administering, observing and recording patients' treatment programme five days a week, for two to six months. The programme makes no provision for any financial support for the work of TB treatment supporters and, thus, volunteers fill these positions. I argue that in the context of poor South African communities, community treatment supporters experienced volunteerism in the DOTS programme as both a burden and a possible means of securing resources for social support.

As key participants in the fight against TB, treatment supporters based in non-clinic settings within poor communities faced several of the same challenges as the TB patients they supervised. TB treatment supporters also experienced unemployment, poor housing, unsanitary living conditions and malnutrition (Nurse McKenzie, 2000). As with the TB patients, community-based treatment supporters often experienced the DOTS as a burden. The gap between what the DOTS' architects and the community treatment supporters viewed as support, brought pressure to bear on the volunteers the programme relied so heavily on.

The DOTS programme assumes that supervision, observation and medication are the three components necessary for successful treatment. However, in a resource-poor setting with limited social services, the tasks associated with providing TB patients with access to treatment are not reflected in the design of the DOTS, thus making the programme burdensome on treatment supporters. The extract below is from a training manual for community based TB treatment supporters developed and used by South

African TB NGOs. It outlines the roles and responsibilities of treatment supporters within the DOTS programme in South Africa.

Functions of the TB Treatment Supporter-Urban Model:

Observe Therapy and record Adherence for five days a week
Follow up absent clients after 1 skip
Remind clients of clinic appointments
Report inconsistencies to DOTS Co-ordinator
Support and encourage clients
Refer clients to relevant services
Refer suspect TB cases to the clinic
Create awareness about TB in the community
Attend ongoing training sessions
Attend monthly meetings

(TB treatment Support Training Manual, 2000)

Although the WHO did not develop the list above, it is a good reflection of the basic functions of community-based treatment supporters. To successfully perform all the tasks associated with providing treatment (storing, monitoring, dispensing, observing and recording), treatment supporters must call on many more resources than the DOTS programme makes available to them.

TB treatment supporters face significant challenges daily, including being viewed as a source for financial and material support by TB patients, particularly by the very poor. Treatment supporters were seen as community-based sites of the DOTS and the resources available to the programme. Many TB patients in poor South African communities are simply too poor to access treatment and, as with TB patients in hospital, taking TB medication on an empty stomach has negative side effects and is strongly discouraged. Many TB patients, however, do not have sufficient resources to access daily meals, preventing them from taking their medication. Consequently, TB patients tried to complete their treatment by accessing resources such as food from treatment supporters.

> "One of my clients did not want to take his treatment as he was hungry. I told him there was nothing to eat here but he still refused to take his treatment. I then decided to organise something for the client to eat even if it was my last piece of bread, so that he could take his medication. These are some of the problems I encounter." (Treatment Support- B, 2000)

The relationship dynamics described above often push the treatment supporter to make a choice between the treatment needs of patients and their own personal needs, frustrating their efforts to successfully implement the DOTS programme and burdening them with responsibilities the programme does not support.

3.4 DOTS as a Resource for Community Based Treatment Supporters

The myriad tasks performed by volunteers outlined in the previous section are part of a complex negotiation between TB patients, treatment supporters, the DOTS programme and clinic staff. Volunteers from poor communities who provide the support of observing and recording the ingestion of treatment to TB patients took on a great deal more than anticipated because poverty and its impact on the lives of DOTS participants had not been considered in the design of the programme.

The DOTS programme made no provision for the support of TB patients or treatment supporters to maintain treatment. Volunteers who participated in this study often faced many of the same problems in their lives as TB patients. With limited support from DOTS or the formal health sector in providing food, clothes or housing to TB patients, the successful implementation of DOTS was severely hampered. TB patients regularly petitioned treatment supporters for financial and material support. As the perceived points of access to the DOTS outside of the clinic, treatment supporters were viewed as commanding greater access to the resources DOTS could offer. The following extract was taken from an interview conducted with Maryellen Gunter, a community-based treatment supporter in Imizamo Yethu.

> "When I fetch the treatment from the clinic, people in the street will ask me if I am receiving payment for what I am doing. I tell them it is a voluntary service, and they laugh and say I am mad." (Maryellen Gunter, 2000)

Increased access to TB treatment was the primary motivation for incorporating TB NGOs and non-clinic based community treatment supporters in the implementation of the DOTS. However, without support from the DOTS programme, the home environments and financial stability of treatment supporters were frequently challenged. As a result, treatment supporters tried to access a wide range of support and services through the DOTS programme and local clinics. They also sought recognition and reward from local health authorities for participating in the community DOTS programme. However, there were no provisions for remuneration or reward, thus frustrating treatment supporters and straining relations with clinic staff. The gap between what treatment supporters expected and what the DOTS programme offered often left treatment supporters feeling undervalued by the clinic staff. Treatment supporters viewed themselves as part of the health team working in the fight against TB; however, their participation was not recognised in a fashion they deemed acceptable, exasperating the volunteers further.

Treatment supporters were denied access to the levels of recognition that would have placed them socially and finically on a par with bio-medical practitioners and firmly establish them as health care team members. Medical personnel at the clinics from which TB supporters operated often view the TB supporters' desire for recognition as members of a health team as a desire to achieve the authority invested in doctors, nurses and health workers. A desire for inclusion was often deemed as impertinent by the medically trained staff. Nurse Elizabeth Meer's quote below represents the minority in her profession, most of whom do not view TB supporters as valued and equal members of the DOTS programme.

> "Some of the people are past the lip-language phase. Like I mentioned to you yesterday, when these people are trained, they are welcomed by the clinic staff and feel part of the team. However, have they really been recognised as part of the TB team? This is the reason I had that evaluation workshop last

> year. I was aware of two clinics where the people were not being recognised because they are lay people. These sisters in the clinics, I suppose, felt threatened because they felt that they studied for four years and now their work is being taken away from them by people who in some cases, are illiterate and underwent only three days of training."(Nurse Elizabeth Meer, 2000)

Conflict between bio-medically trained staff and community treatment supporters over perceived rights of access to medical authority was ever present. The role of treatment supporters as the implementing arm of a bio-medical strategy was in conflict with the socially established rights of access to authority, based on class, race, gender and knowledge. This conflict manifested itself in several areas of the DOTS programme, particularly as it related to rewarding treatment supporters for their contribution to the fight against TB in the community. TB treatment supporters identified two main areas of reward and recognition they desire. Treatment supporters felt they should be given special consideration when vacancies in the clinic arose and also be given access to training opportunities. Yet when opportunities did arise, they felt overlooked by the clinic administrators. The extract below was recorded at a monthly TB supporters meeting organised by the DOTS co-ordinator Nurse McKenzie in collaboration with the TB NGO working in the community.

> "Q: Are there any ways in which the service you provide as treatment supporters is appreciated?
>
> "A: No
>
> "Q: Why do you say no?
>
> "A: (Laughter) If there are jobs at the hospital or the clinic, we would like to be informed. E.g. DOTS supporters must be considered for cleaner jobs, so we can have some income. We expect the hospital and clinic to give us first priority if vacancies are available. But we are not considered." (Nurse McKenzie, 2000)

TB treatment supporters' desire for increased levels of integration into the formal health sector conflicted with their social position as poor and marginalised members of the wider society and as volunteers in the DOTS programme. Formal integration would have required TB supporters being repositioned within the complex South African social hierarchy from the less valued unemployed and often illiterate class to the superior educated and medically trained class dominated by the white elite. In addition, the formalisation of volunteer positions into paid health worker posts was not part of the design of DOTS and, as such, no formal provision was made for the integration of community based volunteer treatment supporters into the formal health sector.

Many TB treatment supporters believed they were actively addressing their need for formal employment through participating in the DOTS programme as volunteers. They hoped that they would have been rewarded either with a position at the local clinic, or begin to receive payment for their work as treatment supporters. Community based treatment supporters viewed the DOTS programme as a source of social and financial support from which they could gain access to resources including money, education and food. However, securing what they deemed as appropriate support from the DOTS programme had proven to be extremely difficult. The extract below was taken from an interview conducted with Mary-Ann Ottumwa, a TB NGO manager who had been working for over twenty years in the South Africa's oldest NGO dedicated to TB.

> "Nobody is prepared to actually support an incentive scheme for community treatment supporters. The government is, I think, a bit wary about getting involved because it might be seen as paying salaries and that would have all sorts of complications with unions and everyone else you can imagine. And this is why we are very conscious to stress that any reward is an incentive, not a salary .... the other thing is that SANTA National, which is the big national TB organisation, has always used volunteer treatment supporters. Volunteerism has been one of the organisation's selling points with donors who obviously, prefer if someone can do the job without paying anything. The donors find favour with volunteer based treatment support programmes instead of supporting those people who are doing the job with a salary." (Mary-Ann Ottumwa, 2000)

At the time of my research, NGOs were the primary implementers of community-based DOTS in South Africa, and there is often tension between them, the State and treatment supporters. The conflict mainly surrounded the level of support provided to community treatment supporters and NGO funding needs. As the extract above illustrates, some NGOs were in favour of formalising the volunteer position of treatment supporters by providing a salary, but securing funds to meet the demand for salaries has often been made difficult by political agreements between the State, international organisations and local trade unions. Other TB NGOs did not want to transition treatment support into paid positions because the use of volunteers gives them a competitive advantage in seeking funding from national and international donor agencies, leaving the treatment supporters with few options within the DOTS programme.

NGOs implementing the DOTS programme did recognise that the success of the programme is limited by the social and economic realities of poor communities and its impact on persons' ability to successfully complete the treatment programme. They agreed that the needs of TB patients and treatment supporters were not being met, but there was no consensus on the role of TB NGOs, the DOTS programme or the State in addressing those needs. One way in which TB NGOs and the State tried to improve the social conditions of TB supporters was to provide them with training. There were, however, significant differences in the perceived value, need and impact of the training between NGOs, the government and treatment supporters, as illustrated below.

> "I have heard some of them say that they do not want to receive only pieces of paper, but paper which have some value, certificates that could be recognised."
> (TB Co-Coordinator-B, Northern Province, 2000)

> "We are not considered for further training. They take people from the hospital and send them on DOTS training, which means they have forgotten about the DOTS supporters in the community. We would like top managers to come back to us and fulfil their promises. We are not getting any support."
> (Community Treatment Supporter-C, Northern Province, 2000)

> "There are no bonuses, no paid leave days, none of that sort of thing, but what the project has done for many people is provide a little bit of education and training that has given them a hand up to go on to better things."
> (Silvia Gordon, NGO Manager, 2000)

The conflict between the volunteers and managers of the DOTS programme regarding the perceived value of training stemmed from NGO managers' view that the training in itself was beneficial to the treatment supporters. They saw the value of participating in the training as providing access to education that many treatment supporters would otherwise be unable to obtain. The NGO managers perceived the training as an end in itself. It ensured that the DOTS programme was correctly implemented whist at the same time providing volunteers with an opportunity to learn more about TB care.

Treatment supporters, conversely expressed a need for the training to have some value other than simply, the transfer of knowledge. They wanted the training to be recognised by external bodies. They wanted their community participation to open doors to future employment with other organisations through accreditation, if the training did not lead to employment within the DOTS programme itself.

The disparity between the desired impact of training as viewed by NGO managers and community treatment supporters reflects incompatible interpretations on the value of support. NGOs that provided ongoing training felt their efforts were contributing to improving the lives of treatment supporters and improving the implementation of the DOTS. Frustration in the volunteer core associated with unmet expectations of the training leading to employment or financial security through the DOTS programme resulted in a very high turnover of volunteers. Consequently, a cycle of recruitment, training and recruitment added pressure to NGO mangers and community participants alike.

NGOs that participated in this study employed a variety of strategies to address the constant pressures of high volunteer turnover, low adherence to treatment and the poverty of both TB patients and treatment supporters. Many of the approaches, however, were fraught with challenges, as the extract below illustrates.

> "Q: You said earlier that all the treatment supporters you work with do it on a voluntary basis, why is that so?
>
> "A: It has been our policy for many years. We would like to change it, but my experience shows that unless somebody gives me money, and that person gives me money for 10 years to give to these people, then I'll take it and say we'll pay them. But at present, we don't have that assurance. If somebody gives me 60,000 Rand to give the volunteers this year, fine, then I will give it to them, but we don't want to say we'll pay you per patient supervised. We just don't have the money. The State cannot provide us with that money. All these people have no jobs. Unemployment is rife and people are hungry but we can't pay them....But we give them something: incentives.
>
> "Q: Like what?
>
> "A: Like we take them on trips around the Cape Peninsula, up Table Mountain, to the beach and to the wine farms. Last year we went to Cape Point, 32 of them. Many of them had never been to Cape Point and they loved it. We try and do something for them once a year." (Silvia Gordon, 2000)

The quotation above is based on a conversation between Silvia Gordon, a TB NGO manager for over seven years, and me. The conversation was focused on the challenges of paying community treatment supporters in the unstable financial climate experienced by many NGOs. On a number of occasions during interviews, NGO managers, treatment supporters and clinic staff raised the issue of paying treatment supporters. All felt that treatment supporters should be remunerated to some degree for their participation in the community DOTS programme. A perception that community-based DOTS was a mechanism through which the gap in service delivery by the State was being met fuelled their discussions. TB control was considered to be the State's responsibility and the DOTS programme was doing this job for them. In addition, the poor economic condition of many TB supporters was recognised as a possible barrier to the successful implementation of the programme, thus necessitating some financial support.

However, no NGO that participated in this study had successfully secured funding to pay treatment supporters a salary. In an effort to address volunteer retention and maintain high morale in the volunteer body, many NGOs provided incentives ranging from a small sum of money allotted to treatment supporters for each patient they supervised, to tee-shirts, special trips and certificates. Although generally appreciated by treatment supporters, incentives did not meet the needs of either the programme or the volunteers. The incentives often worked against the efforts of TB NGOs to reduce expectations of a possible job within the volunteer body. They often simply created a sense of possibility that the incentives could one day become a salary.

3.5 Conclusion

In medical anthropology theory there has been a theoretical battle waged between medical culturalism and political economists. The culturalist perspective argues that illness is given meaning through a socially constructed system of values and cultural norms. Political economists argue that medical systems, like all cultural systems, must be analysed in relation to the wider social forces that have been historically situated, highlighting relations of power that confer power. A position that incorporates both the cultural construction of illness and the social, political and historical determinants of illness argues that, though both these positions are useful, the illness experience of the individual is not explored by them as both an arena of investigation and the site of micro-level activity and reaction (Singer et al, 1988).

The reality of tuberculosis for many poor South Africans is illustrative of the intricate relationship between historical determinants of disease distribution, socially constructed systems of meaning and the very personal experience of illness. TB in South Africa is influenced by the social reality of economic impoverishment, resulting from years of racial, political and gender oppression that has disadvantaged non-Whites. The relations of power between Whites and non-Whites in South African's history positioned the latter to be at higher risk of contracting infectious diseases such as TB that flourish in poverty.

The illness experience of many TB patients is characterised by bearing the burden of meeting the requirements of the DOTS programme and viewing it as a source of economic and social relief. Additionally their experiences are mediated by public health programmes that has been influenced by economic relations of power that recognised or rejected the significance of TB based on its impact on Western societies.

Socially constructed systems of meaning that prevent TB patients from being able to access sites of power within the dominant bio-medical discourse of DOTS prevented them from accessing the support they need as a result of their illness experience. The community-based implementation of DOTS is thus, a microcosm of the power relations, cultural meanings and historical foundations that are evident in the wider society of South Africa.

In this chapter, I have demonstrated that the design and implementation of the DOTS programme does not take into account the experiences of TB patients and community treatment supporters, rendering it a burden on both groups. As such, reliance on volunteers who face harsh social and economic realities without providing them with the access to the power and support that address their challenges impedes the successful implementation of the DOTS programme.

Calls by community treatment supporters to be incorporated into the formal health sector have not been heeded as the DOTS programme does make such provision. The need for formal accreditation, job creation and poverty alleviation, although sporadically addressed by NGOs working in the field, is not built into the design of community based DOTS. In an environment where TB treatment supporters are providing psychosocial support to TB patients to ensure completion of treatment, the success of the programme depends on providing greater access to sites of power with social value.

Chapter Four. Non-Governmental Organisations as catalysts for social and economic change

4.1 Introduction

In this chapter I examine the implementation of the DOTS by NGOs focused on TB care in poor South African communities. As key participants in the DOTS programme, TB NGOs are at the forefront of TB care in South Africa. I argue that TB NGOs can play a critical role in helping TB patients in poor communities complete their treatment by helping them overcome many of the socio-political challenges that contribute to the spread of TB. As organisations that mobilise collective action for self-help by the poor through the DOTS programme, TB NGOs could impact the social landscape of poor communities by challenging the social distribution of power inherited from the Apartheid State. However, TB NGOs currently do not play that role because they are not mobilised to make an active and organised assault on prevailing social and economic realities.

The main role of TB NGOs in the DOTS programme has been to co-ordinate the implementation of community-based DOTS through their cadre of volunteer non-clinic based TB treatment supporters. They recruit, train, oversee and manage their volunteer bodies in collaboration with primary health care clinics that serve the communities in which they implement the DOTS. Much of the focus of TB NGOs has been on mobilising funds to support their activities. These funds are either solicited directly from donor agencies or distributed through local health authority to the NGOs by the government who contract the NGOS to implement elements of the DOTS.

I argue that the overwhelming focus of NGOs on accessing funds has limited their ability to significantly impact the lives of TB patients beyond the provision of bio-medical TB treatment. They are yet to reach their potential of being catalysts for change in a dominant social system that disadvantaged the vast majority of South Africa's population.

In his study of critical medical anthropology, Singer (1995) argues that serious practitioners must move from the "ivory tower" of academia into the institutional and individual realities of the post-modern bio-medical experience. Singer argues for a medical anthropology that moves away from "non-reformist reform" work that simply critiques the bio-medical paradigm but does not challenge or seek to change it, to applied work that complicates and mystifies, rather than simply unmasks the source of social inequalities and ill health. Critical praxis in medical anthropology, as understood by Singer (1995), is focused on understanding and responding to the interaction between macro-level political economy on national and institutional levels and the illness experience of the individual. This approach is particularly concerned with "on the ground" features of the social experience and seeks to effect change through community-based organisations, health clinics and similar entities by heightening social action to make permanent changes in the social alignment of power.

In the community development arena, discontent with the failure of international organisations to significantly impact the economic and political realities of economically disadvantaged populations has facilitated the emergence of a position that seeks to engender social mobilisation to effect change. This approach is similar to critical praxis in medical anthropology, in that, it encourages community mobilisation for social change, recognising the impact of wider socio-political power relations on the health and well-being of populations (Escobar 1995, Mohan & Stokke, 2000). In a ground breaking study on the impact of poverty in South Africa and strategies for change, Wilson et al (1989) argue that grass roots community based organisations represent sites of struggle for political and economic change within oppressed and marginalised communities. Through collective mobilisation, these organisations present a challenge to the existing socio-political configurations of power by challenging the status quo through harnessing mass social action (Wilson et al 1989).

Lynos and Smut (1999) have suggested that community participation in development programmes has become a key aspect of governance in post-Apartheid South Africa. The government, through its support and encouragement of various community-based initiatives has emphasised the importance of community agency and participatory democracy in the management and development of projects designed to meet the needs of local communities. I argue that the implementation of community based TB control through the DOTS programme is one way in which the South African government has tried to harness community agency for social change.

Despite the government's commitment to social change, programmes such as the DOTS, have not addressed the root causes of the TB epidemic and thus only go part way in addressing the problem. The implementation strategy of community-based DOTS falls short of critical praxis and grass roots mobilisation for social change because it fails to address the impact of socio-political determinants that contribute to the spread of TB and therefore fails to affect in a positive way the illness experience of persons affected by TB.

Scholars who have studied the political economy of health have argued that disease cannot be reduced to a pathological entity in nature but must be understood as the product of historically located socio-political relations of power and processes (Tuner, 1987 Singer, 1992 Singer, 1995). As such, a comprehensive assault on disease and illness cannot exclude the social and economic determinants that impact on health. Thus the NGOs working in TB control within the DOTS programme could increase their impact by expanding their focus beyond the inclusion of community members as volunteer treatment supporters and patients to include organised social action to reduce poverty and challenge prevailing relations of power and systems of control.

In the following section, I present an example of collective mobilisation for community health that is focused on changing the socio-political configurations of power. This is followed by a presentation of three ways in which TB NGOs manage the implementation of community-based DOTS, and an analysis of the operational challenges TB NGOs face. I present these examples to illustrate the shortcomings in the implementation of community-based DOTS in South Africa at the time of my research. I illustrate how the current TB control strategy's failure to impact the socio-political reality of poor TB patients, has resulted in a limited number of persons successfully completing TB treatment through the DOTS in South Africa today.

4.2 Organised Social Response to TB Control - The Example of Imizamo Yethu

Five families established Imizamo Yethu in 1994. At the time of my research, the last community census indicated that in 1998 there were approximately 6,000 residents in both formal and informal housing. The population of Imizamo Yethu was very diverse, including legal and illegal immigrants from Namibia, Zimbabwe, Botswana, Mozambique and Angola, as well as migrant labourers from other South African provinces. Most people considered themselves temporary residents of the settlement, having come to Cape Town to secure employment, attend school or to live with relatives.

Imizamo Yethu or Mandela Park (as it was called by some residents) was situated on the outskirts of Hout Bay, a larger wealthy predominantly White suburb of Cape Town. Hout Bay provided the main source of employment for residents of Imizamo Yethu in casual "days work", domestic work and seasonal deep sea fishing. At 20,000 residents, Hout Bay was also the main commercial hub for Imizamo Yethu providing access to stores, medical facilities and recreation. However, unlike their mainly White neighbours, residents of Imizamo Yethu lived in varying degrees of poverty, and suffered heavily from associated illnesses such as malnutrition and TB. At the time of my research, the local clinic that serviced Imizamo Yethu was responsible for treating approximately five hundred diagnosed TB patients, one third of whom had also been diagnosed as also suffering from HIV/AIDS.

At the suggestion of a lecturer, the practical anthropology masters class of five students enthusiastically took on the challenge of doing research in Imizamo Yethu for four weeks. We arrived at the local clinic with our professor who introduced us to the clinic's community DOTS co-ordinator. With a few words of instruction and encouragement, the class broke up into pairs and went off to explore the community. My classmate, Natalie and I walked from the clinic, up the main road and into the middle of Imizamo Yethu, towards the largest formal structure in the community.

With some trepidation, we entered the building that later turned out to be the local civic centre. Much to my relief, the two ladies we encountered first were of a particularly sunny disposition. That day, Julia and Susan Albright showed us around the centre that they had run for three years and told us about the services they offered and the facilities that they had at their disposal. The sisters were members of a local church based in Hout Bay and ran the centre as part of their outreach work for the church. After receiving a tour of the facility and being introduced to all the staff and volunteers who managed the operations, including a computer learning centre, feeding programme for community members and a craft project, we explained that we were planning to conduct research in the community. They invited us to join them the following Monday for the "Monday Club" prayer meeting to meet some possible community informants, as well as the local community gate keepers, the Civic Organisation.

Excitedly, Natalie and I arrived a few minutes early for the Monday Club. As we waited for the meeting to begin, approximately 50 people from the Imizamo Yethu community arrived, collected chairs from different parts of the centre and sat in a semi-circle in the middle of the main hall. About half an hour later, Julia arrived and led the group in an opening prayer that was followed by an hour of singing, prayer and sharing. After the Monday Club meeting, Julia introduced me to Thabo, a member of the local Civic Organisation. I used our introduction as an opportunity to ask him about his work. He told me that he was a voluntary member of the local community Civic Organisation with the responsibility for safety and security. Thabo said the job of the Civic Organisation was to try to improve the community through its work in various portfolios. I asked Thabo if he would be able to introduce me to the head of the Civic Organisation and the person responsible for health. He agreed and we arranged to meet the following week. The following week, Thabo introduced me to the head of the local Civic Organisation, James Pooe, but informed me that the Civic member responsible for community health, Matthew Ingoma, was out of town on family business in the Eastern Cape Province. As a result, other Civic members served as my information sources on the community heath portfolio and the activities it carried out.

The Civic leadership (executive committee and community portfolio managers) was elected from community members. Civic members were responsible for developing and leading community responses in housing, land and agriculture, sports and recreation, safety and security, education, essential services, environment and tourism and health and welfare. The Imizamo Yethu Civic was part of a larger national organisation that replicated the civic structure on regional and national levels. The National Civic Organisation provided the overall structure, mandate, vision and mission as well as a system of accountability through regular nation wide reporting.

The national and local Civic Organisations focused on addressing the underlying problems that result in social, economic and health problems in poor communities throughout South Africa. The Imizamo Yethu Civic leader, James Thambo, was an active member of the ruling political party, the African National Congress (ANC) and of the local government and, at the time of our interview, had been the Civic leader for three months. The previous executive committee had been deposed by the present one for failing to successfully advocate for change with key power bases, such as the local business community and government departments, on behalf of the community. James had been living in Imizamo Yethu for five years with his wife and three children, and still maintained a home in the Eastern Cape Province. At the time of our interview, James found occasional work on one of the local fishing vessels. However, during the South African liberation struggle, James had served as a General in the armed wing of the ANC. As a leader during the struggle for political independence, James had been well sensitised to the impact of socio-political relations of power on the lives of non-White South Africans. In his new role as Civic leader, James sought to challenge the local systems for the control put in place during the Apartheid era:

> "As the chairperson, I am responsible for making sure that the needs of the people are met, as far as possible. Matthew is in charge of the health and welfare portfolio. His job is to know

> what health issues the people are facing and try and address them. For example, the Hout Bay local council has a health committee. Matthew attends the health committee meetings to bring our needs and concerns to the table, and works with the local council to get better health services for the people of Imizamo Yethu." (James Thambo, Imizamo Yethu 2000)

In addition to being the chairperson of the health and welfare portfolio, Matthew was an active member of the local Reconstruction and Development Programme Forum (RDP), a government initiative focused on community development. Matthew used the RDP forums that he and his colleagues attended, as well as meetings with other interest groups (such as service clubs and local health committees working in and around the community and local City Council) to bring the needs of Imizamo Yethu residents to the attention of the wider Hout Bay community. Matthew and his colleagues advocated for change in areas that impacted on health, including poverty alleviation, access to good housing and greater access to education. One of the successes of this approach was a feeding programme, supported by a local church, for the children who attended the community nursery. Many of the young children of Imizamo Yethu suffered from malnutrition, which hindered their ability to fight infection. The provision of thrice-weekly nutritionally balanced meals significantly improved their health and reduced the number of times children missed school as a result of sickness.

Tuberculosis was a major health concern in Imizamo Yethu and, as such, TB control was taken very seriously. The chairperson of the health and welfare portfolio, along with a representative from each community portfolio, met regularly with clinic staff, TB NGOs working in the community and community based treatment supporters. Together they developed strategies for dealing with TB care and control in the community. TB supporters who were having problems with clients brought their concerns to these meetings and the civic representatives assisted them in finding solutions for the challenges they faced. As the community gatekeepers, clinic and NGO staff consulted the Civic Organisation when any new TB projects were developed for the community. TB treatment supporters did not have to be members of the Civic Organisation, but the Civic was considered central in the implementation of the DOTS and participated in monitoring the work of TB treatment supporters. Abigail Thornton, quoted below, was the DOTS co-ordinator with a large TB NGO working in Imizamo Yethu. She describes the process by which the DOTS programme was typically introduced in communities:

> "The criteria which is used (when recruiting DOTS workers) is usually people in the community that are recognised by the community...We go through the community leader because you involve the community structures, the local health committees, and the Reconstruction and Development Forums and all those people. They assist in the selection process and they make recommendations. We also go to the nurses at the clinic because they are also pretty au fait with who's in the community." (Abigail Thornton, Imizamo Yethu, 2000)

The TB epidemic in Imizamo Yethu was managed through this collective effort. The Civic Organisation recognised the need for a comprehensive assault on the social, economic and political factors that impacted on the spread and management of TB. Administering the health and welfare portfolio entailed advocating for social change to improve access to formal housing, jobs and education. Critical praxis in Imizamo Yethu was implemented by establishing a system-wide approach to effect health changes for poor community members. Despite the many successes of the health and welfare portfolio, which also included establishing a regular garbage collection schedule with the local municipality, working with the local harbour masters to facilitate TB treatment on some deep sea fishing boats and securing RDP funding for several community based income generating projects, they faced several challenges.

The most significant challenge to the Civic Organisation's comprehensive approach to health care was the rigid socio-political hierarchies inherited from the previous political dispensation. The racist ideologies of the Apartheid era that privileged one race over all others were still very pervasive in Hout Bay and its environs. This inherited power differential was replicated in many aspects of the national response to health care, and limited the impact the Imizamo Yethu Civic could have in the wider Hout Bay community.

4.3 TB NGOs - Their experience of implementing community-based DOTS

In the following section I present three different ways in which TB NGOs manage the implementation of community based DOTS in poor South African communities. The most significant factor impacting on the TB NGOs' implementation of DOTS was the unreliable and insufficient access to funds to run their programmes. The lack of resources resulted in several organisational constraints that often limited their programmes to the basic provision of treatment to TB patients. The strategies the TB NGO managers employed to overcome limited financing affected all aspects of the programmes they designed and implemented. The table below outlines the core operational characteristics of the NGOs that participated in this study.

<u>Table 1: Characteristics of Non-governmental Organisations</u>

(Kironde &Jacobs, 2002)

	Training TS[*]	TOTs/TOFs[†]	Payment[§]	Activities[¶]	Empowerment[‡]
NGO1	Yes	No	No	Local	Yes
NGO2	No	Yes	No	National	Yes
NGO3	Yes	No	No	Regional	Yes
NGO4	Yes	No	Yes	Local	Yes
NGO5	Yes	No	No	Regional	Yes
NGO6	Yes	No	No	Regional	Yes

[*] Participation in training of TB treatment supporters

[†] Training of Trainers and Facilitators for community-based TB treatment

[§] Giving monetary incentives to treatment supporters

[¶] Scope of activities

[‡] Community development component in training programme

4.3a NGOs Solely Dependent on Traditional Sources of Funding

The organisations that fall into this first category developed and maintained a reliance on traditional sources of funding such as government grants, corporate donations and international donor funding. They framed their programmes in terms of meeting a community need that the State, due to its own limited resources, was unable to meet. As such, their projects were typically defined within the parameters that the South African government had set for the DOTS programme and they work closely with the State apparatus.

The programmes they implemented aimed to provide access to treatment through community treatment supporters who supplied TB medication to TB patients in the communities in which the NGOs operated. The programmes these organisations ran, were not designed to address systemic social problems, such as malnutrition and poverty, but focused exclusively on filling the gap left by the State in providing access to TB treatment. These organisations typically advocated for volunteerism, since they were under financial constraints that prohibited payment to community treatment supporters. They operated with a small staff and relied heavily on volunteers and local clinic staff to implement their programmes. The following is a quote from an NGO manager that illustrates some of the power dynamics that influenced their operations. NGOs in this category typically recognised bio-medial treatment of TB as the only strategy for managing the epidemic.

> "The clinic is ultimately responsible for the client (TB patient). There needs to be one point within the community where the client is treated and where a professional is taking responsibility for the client's treatment. Community based DOTS does not take that responsibility away from the health services. It's actually an extension of their services. It brings the treatment closer. It's not taking over from the clinics." (NGO Manager-C)

4.3b NGOs that Access Diverse Funding Sources

NGOs in this second category accessed funding from a wider range of sources, facilitating more comprehensive programme designs. They tapped into non-traditional resource bases such as fund raising through professional service clubs, special national and international interest groups, as well as developed strategic alliances with like-minded institutes to access grants. NGOs in this category recognised the impact of socio-political dynamics such as poverty, racism and gender, on the distribution, experience and treatment of TB. These NGOs typically developed programme that aimed to address the impact of socio-political forces on the lives of both the TB patients and community treatment supporters. The design of their programmes reflected a shift away from the traditional DOTS programme to more comprehensive interventions.

These NGOs were characterised by a younger breed of managers trained in business management and programme design. Many of their programmes included elements traditionally employed by the corporate world such as marketing drives and advertising, in an effort to boost their income and increase their independence from funders. One organisation hosted an annual jazz fund raising festival supported by famous local artists. Organisations in this category viewed TB control as the responsibility of the State, and themselves as partners with the State in the provision of services.

> "You see, there have been other projects that were here before, like the TB Alliance project. They paid people, and tried to work outside of the norm. Now where are they? Their funds ran out. What is the use of you having a community based DOTS programme if there is no sustainability. With NGOs you never know whether your funder is going to renew funding from year to year, or what is going to happen."
> (NGO Manager –B)

As the above extract from an NGO manager illustrates, NGOs in this category felt very vulnerable because of a lack of steady income. Despite their best efforts to widen their scope of operations, the close association with the State and thus the traditional DOTS model, impacted on their ability to maintain funding for extended periods for innovative programmes. Participating in poverty alleviation strategies was a central concern for programmes run by organisations in this category, but the approaches they employed such as paying a salary to treatment supporters were within the conventional approach to poverty alleviation and difficult to maintain.

4.3c NGOs that generate their own funding

The final category of community-based DOTS implementers typically designed programmes aimed at addressing wider social issues that influenced the TB epidemic. These organisations tended to have lower operational costs and overheads as well as greater levels of participation by TB treatment supporters and patients in the design and implementation of their programmes. Organisations in this category had deliberately broken away from the traditional DOTS model to incorporate the wider needs of the communities they served. These organisations faced tremendous obstacles in maintaining their projects and often sought funding from alternative sources. Their programmatic positioning often forced them into a place of self-reliance resulting in the freedom to design programmes with wider scopes of influence. The extract that follows was taken from an interview with a TB NGO manager who worked in a very rural community in the northernmost Province of South Africa. Although the organisation she worked with implemented TB programmes that addressed other social factors that contributed to ill health and the spread of TB such as drug abuse and malnutrition, they were often challenged by TB patients' own views that bio-medical treatment provided by the local clinic was the only thing needed for the successful treatment of TB.

> "We are working towards trying to get the community to take responsibility for their own individual health and the health of the community. To be quite honest, up until now we have not been receiving any kind of funding for the TB programme. We have been doing it (funding the community DOTS programme) out of the projects that we do, to be sustainable. We've got several income generating projects that we do that involve TB patients and treatment supporters, and several of them bring in

> money. We are using that money to fund this project of ours."
> (NGO Manager –F, 2000)

Access to funding was the most significant challenge faced by TB NGOs directly impacting on the types of programmes they implement. However, other barriers to NGO operations existed. The management style and the socio-political position of TB NGO executives significantly influenced the NGOs' scope of operations, including competition over financial resources, sustainability and professional competition.

4.4 Competition Over Financial Resources

Although most TB NGOs received some degree of financial support from the State, most NGOs felt that the resources allocated were insufficient to run their projects. TB NGO managers were primarily concerned with the allocation criteria for resources from the State. They felt that, in order to access resources, they were forced to design programmes that fell within the government's implementation agenda and strategy. As a result, there was a great deal of overlap in the programmes NGOs were seeking funding for and, thus, they were in constant competition with each other for limited resources from the State.

> "I think there is still a lot of overlap in our programmes and, what I suppose you could say, unfairness in funding. I mean, certain organisations are funded through the local health budget, channelled from National Health Ministry. You know, you have big organisations like SANTA[2], who really, I don't know what they have done since 1944. They should have made some sort of impact by now. And they are so heavily funded by the government, one wonders, you know, are they heavily funded because then that way they are not going to rock the boat? You don't bite the hand that feeds you; or have we just become so entrenched in this whole thing that it just goes on and on and on until somebody comes along and sort of shakes things up?" (NGO Manager –C, 2000)

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[2] SANTA -South African National Tuberculosis Association

NGOs competed over limited financial resources to implement similar programmes in the same communities. The availability of resources was dictated by the requirements of the fund and how well the NGOs fit into what the donors wanted. This battle to secure funds limited NGOs' capacity to implement programmes that fell outside of the traditional DOTS approach thus, their focus was mainly on the provision of medication to TB patients.

4.5 Sustainability

Access to, and competition over resources speaks directly to the issue of sustainability. Many of the organisational heads were under constant pressure to secure funding to continue running their programmes. Many TB NGO's were unable to attract long term funding for programmes, particularly those that designed programmes that fell outside of the operational objectives of DOTS as outlined by the WHO and the South African government. The example of a TB NGO that was forced to shut down its operations and re-launch as a different organisation was given by every one of the NGO heads working in the Western Cape as an example of the conditions under which they worked:

> "You see, there were other projects that were here before, like the TADSA[3]/TB Alliance project. They paid people, and then where were they when the funds ran out? Gone. So, what is the use of you having a community based DOTS programme if there is no sustainability?" (NGO Manager –D, 2000)

The need to secure regular and reliable funds limited NGOs' capacity to address issues other than access to, and the provision of, TB medications. The WHO objective to provide TB medication to diagnosed TB patients, inherent in the DOTS programme, influenced the type of funds available to NGOs. NGOs' perpetual search for money was time consuming and demoralising, often affecting NGOs' interest and ability in developing extra-ordinary approaches to TB care.

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[3] TADSA- TB DOTS Alliance Support Association

4.6 Professional Competition

Professional competition and turf wars were a common aspect of the discourse on NGO management by participants. It was most evident in heated discussions about the volunteerism and the payment of treatment supporters. Several TB NGO managers regard opposition to their position on the issue as not only a personal and professional slight but also damaging to the success of their funding proposals. The passionate representation of the need either to pay or not to pay extended to the establishment of collaborative relationships. When two organisations did not agree on this issue, they both implemented their versions of community-based DOTS in the same area, duplicating many activities. The duplication created false expectations within the community as some treatment supporters were "paid" and others were not. The competition extended to influencing alliances within the TB NGO community. NGOs joined forces in advocating for a particular position promoting their agendas at every possible opportunity.

Singer (1995) exploration of NGO operations suggests that many possible sites of critical praxis fall short of transformation because of organisational constraints. Many programmes face inhibiting factors in the social and political terrain they negotiate in their daily operations, preventing them from achieving serious social change. I argue that the possibility of critical praxis is further undermined by the socio-political position of NGO managers. As discussed above, NGO mangers had different views regarding what facet of ill health to treat and the factors that contributed to ill health. NGO managers, who did not hold the political economy of health perspective and were able to meet their goal of providing access to health care, were unlikely to implement programmes that sought to orchestrate significant social change. The community-based DOTS programme in poor South African communities was fractured by differing perspectives and undermined the possibility for collective action for social change. The overriding focus on securing and maintaining resources narrowed NGOs' focus to the provision of TB medication. This focus excludes addressing the social problems that impact on TB patients and affect their ability to recover from TB.

4.7 Conclusion

In this chapter I examined the implementation of the DOTS by TB NGOs in poor South African communities. I argued that TB NGOs can play a critical role in helping TB patients in poor communities complete their treatment by working to overcome socio-political relations of power that contribute to the spread of TB.

NGOs can be sites of critical praxis by mobilising communities for change in areas such as poverty, unemployment, malnutrition and illiteracy. I argued that NGOs can effect change by moving away from only providing access to medication and by working to address wider social problems impacting on health and the distribution of disease. The Imizamo Yethu Civic Organisation with an integrated approach to health care that included trying to improve housing, access to water and sanitation, community security and job creation, was presented as an example of critical praxis in action. However, many other NGOs experienced crippling organisational challenges that hinder their ability to move their programmes beyond meeting the need for access to medication.

In this chapter, I outlined some of the many areas of conflict impacting on TB NGOs' choices for programme design and implementation. Many of the obstacles faced were directly related to their access to resources, and included a lack of programme sustainability, competition for resources, turf wars and professional infighting.

Despite the many challenges they face, NGOs can mobilise and have mobilised communities for social change. However, isolated pockets of resistance to the dominant social order have only a limited impact on the historically positioned relations of power that affect TB patients in poor South African communities today.

Chapter 5. Conclusion

The field work for this dissertation was conducted over a period of two years in one government run tuberculosis sanatorium, one poor urban South African community and with several non-governmental organisations working in the area of community based TB control. The research was born out of need to highlight some of the challenges faced by poor South Africans, the national health service and community based NGOs in accessing and disseminating effective TB treatment.

Since 1997, the South African Government has used the World Health Organisation's TB control programme as the national standard for TB treatment and control. Directly Observed Treatment Short Course (DOTS) is based on the premise that TB can be effectively managed by securing reliable access to bio-medical TB chemotherapy and ensuring adherence to the treatment regime by TB patients. The WHO set a standard for the DOTS programme that aims to successfully cure a minimum of 85% of newly identified TB cases. However, at the time of my research, only 54% of all newly diagnosed TB cases were successfully treated through DOTS.

In this thesis I have argued that international public health programmes have been designed to abate the spread of diseases on a global scale. It is an established understanding in medical anthropology, however, that medical systems are cultural systems that are developed and mediated through local values and norms (Kleinman, 1995). I argued that programmes that are designed to control diseases such as tuberculosis on an international scale are based on a bio-medical and cultural system that treats disease as a set of physical symptoms, often ignoring the social, political and economic factors that impact health.

This separation between the social and physical determinants of health and disease in Western bio-medicine has been described by Scheper-Hughes and Lock (1987) as the Cartesian Dichotomy. The Cartesian Dichotomy informs the Western bio-medical tradition and thus the international public health programmes that are based on it.

Cultural systems that recognise the social, physical and spiritual as active components in disease causation and cure are common internationally and at odds with the Western bio-medical paradigm. Thus many epistemologies are at odds with WHO's global TB treatment protocol programme, Directly Observed Treatment Short Course (DOTS) reddening global implementation challenging, without appropriate modifications to the programme.

The successful use of indigenous or international health systems by local actors in the treatment of disease is influenced by local knowledge, explanations for disease causation and cures (Singer et al, 1988 Nachman, 1993 Farmer, 2001). In this dissertation I have argued that the treatment regime for tuberculosis designed and implemented internationally by the WHO is incongruent with local realties of poor South African TB patients. The DOTS is focused on providing access to TB medication and supporting TB patients in completing their course of treatment by observing and recording their daily intake of medication.

The focus of the DOTS on the provision of medication does not, however, meet the other social needs of patients that directly impact on their ability to complete their course of medication. Unemployment, poverty and malnutrition are ever present and constant factors that affect the illness experience of poor TB patients in South Africa. These are critical determinants in the spread of TB, re-infection and effectiveness of the bio-medical therapeutic process. Ignoring these social realities limits the success of the DOTS programme because basic necessities for TB care such as food are not always readily available. This, hinders patients' ability to meet the programme goal of uninterrupted treatment five days a week for two to six months, thus decreasing the number of TB patients cured.

I have argued that the successful implementation of DOTS in poor South African communities is hindered in the following ways:

1. The Premise of the DOTS Programme

The DOTS programme was designed as a mechanism through which bio-medical treatment could be dispensed. The axes of DOTS as outlined above are access and adherence to treatment. However, individual access to treatment is determined by continued adherence, as treatment defaulters are released from the programme. Adherence is determined by access to subsistence resources such as food which is a prerequisite of taking the medication. The DOTS programme assumes TB patients will be able to meet their subsistence needs, thus, ready access to TB medication and supervision of treatment are sufficient to ensure an 85% cure rate. However, in resource-poor settings common throughout South Africa, the DOTS programme is unable to be supported by local infrastructures, thus hindering the effectiveness of the programme.

2. Poverty

As a primary element in the experiences of many South Africans, poverty has influenced all aspects of life, including the choices made in the treatment of diseases such as TB. Limited access to resources to support basic needs such as food, clothing and housing, often forced poor TB patients to make choices about their treatment that negatively impacted the treatment outcome. The DOTS programme was seen as either as a hindrance to accessing scare resources or as a legitimate point of access for poverty alleviation impacting on the programme's ability to meet its objectives.

In the first instance, DOTS was considered a hindrance because the observation of treatment often interfered with TB patient's ability to access resources. For example, primary care givers who were hospitalised due to their illness or were required to travel through the migrant labour system would be unable to meet their social obligations as care givers, providers and protectors for family and community members if they adhered to the DOTS programme. However, DOTS made no provision to meet their obligations when adherence impacted on their ability to maintain jobs, and consequently, the difficult choice between continuing or suspending treatment would have to made.

As a programme implemented in the community, through community participation, DOTS was often seen as a legitimate point of access for poverty alleviation. Community members who volunteered as treatment supporters often hoped it would lead to a job in the health sector, formal accreditation or ready access to additional resources that were made available through DOTS. Similarly some TB patients viewed the DOTS programme as a mechanics through which they could access disability grants offered by the government to indigent TB patients. However these expectations of support were seldom met by the programme, resulting in high levels of dissatisfaction by treatment supports and deliberate treatment interruption by some TB patients, rendering it incongruent with the local daily realities.

3. TB NGOS

The WHO's recommendation to scale up DOTS implementation through the use of community based NGOs has placed the non-governmental sector as a critical role to ensure the success of the programme. However NGOs focus on maintaining and managing their operations has left little time for innovation and social advocacy. NGO are uniquely positioned to mobilise collective action for social change to impact the dominant social order that has long disadvantaged the vast majority of South Africans and fostered an environment in which disease such as TB can flourish. Few NGOs had the capacity to implement DOTS whilst seeking to challenge the social order by addressing poverty, job creation, education and life skills as part of the response to TB.

Despite the many challenges to the implementation of community based DOTS, I argue that DOTS can have a greater success rate. An example of how this can be done, can be found in the operations of the Imizamo Yethu Civic Organisation. Imizamo Yethu, a squatter community located on the fringes of a wealthy Cape Town suburb recognised that TB was a serious challenge to the residents of the community. However, unlike many TB NGOs, the Imizamo Yethu Civic incorporated TB control in a wider programme aimed at social change.

The Civics' operations were organised around nine portfolios including housing, land and agriculture, sports and recreation and health. Each portfolio was led by a Civic member with the responsibility of ensure growth and development in their portfolio. The Civic actively worked with the local government authority, NGOs and charities operating in the surrounding communities to ensuring an integrated response to the need for social change. TB was dealt with as a disease affected by all facets of life whilst recognising the importance of access to and supervision of medication in the overall treatment outcome.

Recommendations for Future Actions

- Implementers of global health projects would benefits from local consultations with key stakeholders such as government agencies, civic originations and the non-governmental sector to ensure programmes are suitably modified to fit local situations.
- Continuous assessment of programmes to identify the challenges to successful implementation and the reconfiguration of programmes to meet the needs of local community members.
- TB focused community based NGOs and other social interest groups should work together to manage TB within the context of wider social change, thus ensuring a responsive social fabric that aims to meet the needs of South Africans.
- Community mobilisation should be informed by research conducted both locally and internationally so as to benefit from the experiences of others.
- Possible areas for future research include;
    - The impact of communication and relationship building skills training for physicians on the treatment out come of poor TB patients
    - The impact of access to appropriate support by poor TB patients on adherence and treatment outcome
    - Gender dynamics of adherence to DOTS and its impact on treatment outcomes.

The legacy of the segregated and oppressive Apartheid system is a social, political and economic reality that threatens poor South Africans' health with poverty, malnutrition and violence. The social experience of living in poor South African communities predisposes large sections of the population to TB infection, which flourishes in cramped, poorly ventilated impoverished environments. The DOTS programme assumes the existence of a specific infrastructure such as access to regular food to support the type of treatment the programme offers. The assumption of access to certain resources precludes their provision through the DOTS programme. However, many poor TB patients and treatment supporters do not have access to the necessary resources to complete TB treatment resulting in the programme being a burden on them.

The implementation of the DOTS through community-based NGOs is aimed at increasing the number of places a TB patient can access care. However, the lack of resources available to TB patients has negatively impacted the success of the programme. In addition, TB NGOs' constant struggle for financial support has limited their ability to engage in critical praxis and move towards social change to impact health whist changing the existing socio-political system. NGOs could mobilise poor communities for social, economic and political change through collective action, but their focus on survival and their chosen agendas for TB care must also facilitate mass action for change.

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