

Tuberculosis discourse in South Africa: a case study

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Abstract

This study examines tuberculosis discourse in order to understand the ideological factors surrounding the disease. It reveals that a dominant focus on biomedical issues and HIV/AIDS has undermined existing perceptions of the social causes of tuberculosis disease. The effect is an individualising of tuberculosis and its removal from a social context. This together with a hegemonic neo-liberal paradigm of development and state spending dictates that the biomedical reductionist treatment for certain diseases – like tuberculosis – is most "cost-effective" and thus is advocated for disease control. Consequently, the state is required to merely provide health-care in a manner that ignores the social context of disease. The responsibility for the outcome of health care (i.e. health) is therefore deferred to the individual. The unintended consequence is that as private organisations (both for- and not-for-profit) take up the state's responsibility, citizens become disempowered by their limited ability to hold the state accountable, or to engage in meaningful ways that bring about structural change. As such, an environment that further disenfranchises the poor and defeats the purposes of health care in general is perpetuated and diseases like tuberculosis continue their deadly campaign.

Keywords: Tuberculosis, South Africa, discourse, neo-liberalism, public health, citizenship, state welfare, hegemonic ideology, development, medical sociology.



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List of Acronyms

AIDS – Acquired Immunodeficiency Syndrome

ANC - African National Congress

CDC – Centers for Disease Control

CMH - Commission on Macroeconomics and Health

DOTS – Directly Observed Therapy, Short course

GDP – Gross Domestic Product

GEAR - Growth, Employment and Re-distribution Strategy

GNP - Gross National Product

HIV - Human Immunodeficiency Virus

IMF – International Monetary Fund

IUATLD - International Union Against Tuberculosis and Lung Disease

IZH - Isioniazid

JSE - Johannesburg Stock Exchange

MDG - Millennium Development Goals

MDR-TB – Multi Drug-Resistant Tuberculosis

MRC - Medical Research Council

NGO(s) – Non-Governmental Organisation(s)

NPPHCN - National Progressive Primary Health Care Network

NTCP – National Tuberculosis Control Programme

PAS – Para-Aminosalicylic Acid

RDP - Reconstruction and Development Programme

RIF – Rifampin/Rifampicin

SANTA - South African National Tuberculosis Association

TAC – Treatment Action Campaign

TB - Tuberculosis

UN – United Nations

USA - United States of America

WHO – World Health Organisation

XDR-TB – Extremely Drug-Resistant Tuberculosis



INTRODUCTION

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

Susan Sontag (1978: 3)

Tuberculosis is a complex disease. Not only can the world's most notorious killer bacteria infect millions of people without ever making them ill but it also shows remarkable resilience to man's attempts at its elimination. Its long history with humanity has led to a diverse range of associated myths and beliefs, making it a disease crammed with ambiguities. Perhaps, as Sontag suggests, the ambiguities surrounding tuberculosis "are responses to a disease thought to be intractable and capricious" – a disease not completely understood in "an era in which medicine's central premise is that all disease can be cured" (Sontag, 1978: 5). And still, tuberculosis – curable and surrounded by diseases significantly more threatening – remains the haunting white plague, the scourge of mankind and the "captain of all these men of death" (Bunyan, 1986).

Sociologists should ask why a disease like tuberculosis still plagues our societies, despite the existence of a cure for at least sixty years. It is the task of medical sociology to put such questions at the foundation of understanding health and illness (Bird, Conrad and Fermont, 2000: 2). Such questions are based upon the premise that the answers to defeating disease cannot lie only within the realm of the biomedical sciences. This study asks this type of question by examining the discourse of tuberculosis in South Africa. The aim is that in doing so a better understanding of the range of ideological factors involved in determining the persistent presence of tuberculosis can be gained.

Contemporary tuberculosis discourse is located within a context of dominant neoliberal ideologies in which post-apartheid South Africa finds itself. Since 1990 South



Africa has undergone a rapid transition from an oppressive, unequal state to an inclusive, democratic one. In April 1994 the new democratically elected, African National Congress (ANC) was inaugurated into government, beginning a process of negotiated settlements for transformation with the power holders of the previous regime. Within the context of dominating neo-liberal ideologies, the ANC attempted to initiate a system of governance intended to be more equitable and geared towards serving and protecting all of its citizens. For the health care sector this implied the nationalisation of racially fragmented health systems under the newly formed Department of Health (ANC, 1994). Further it entailed a shift away from institutionalised hospital-based care towards one focused on primary, communitybased health care. Health systems were also strategically linked with the broader Reconstruction and Development Programme of the ANC and health care became viewed "as an integral part of the socio-economic development plan of South Africa" (ANC, 1994: 1). In practice however, the ANC's aim to locate health care within a welfarist framework – as a reflection of it's slightly more socialist mandate, expressed in the Freedom Charter - has been undermined by the tenets of the dominant neoliberal ideology. The ideologies underpinning neo-liberalism and welfarism are juxtaposed and this is reflected in the South African health care context, especially in tuberculosis control.

Controlling tuberculosis is vital because in combination with HIV/AIDS, it serves to cripple South Africa's budding economy and growing democracy. Tuberculosis affects one third of the world's population killing roughly 1.6 million people annually (WHO, 2007a). Only twenty-two countries are responsible for 80% of the global tuberculosis burden; South Africa is 7th highest on the list (WHO, 2007a: 137). In South Africa tuberculosis is not spread evenly, disproportionately affecting males, the poor, and the young and the non-white population groups. It is therefore the task of this study to examine sociologically the nuances and complexities of tuberculosis discourse, in an attempt to highlight how "pathologies of power" (Farmer, 2003) have effectively hindered the successful eradication of a disease, which sixty years ago was deemed curable.

It begins with the theoretical principle that discourse is not merely ideological "icing" but is something to be considered because it has very real social consequences



(Ferguson, 1990: xv). As Craddock and Dorn (2001: 315) suggest, medical discourses continue to be, and have historically become, powerful through their location in state power and the implementation of policies. This is because medical discourses are not unlinked to discourses of rationality or discourses of morality. It is the interplay of discourses that form theories, and theories are often the basis for policy. The latent and manifest effects of policy implementations – especially when based on globally hegemonic discourses - are not always known. In a significant study on "development" in Lesotho, Ferguson attempts to unpack how conceptual and discursive systems structure knowledge in powerful processes without sometimes even "determining the form or defining the logic of the outcome" (Ferguson, 1990: 275). Ferguson suggests that the influence of discourse is nuanced and its outcomes and effects should be regarded as a sociological puzzle or riddle to be solved (Ferguson, 1990: 18). With this argument in mind, this study attempts to find a space in which to examine - sociologically - the interrelationship between dominant neoliberal ideologies of development and the role of the state towards its citizens, and tuberculosis discourse in South Africa.

Doing a sociology of discourse

Examining discourse is a not an easy task, yet the level of critical reading required makes it ideally situated for the discipline of sociology. Discourses can often reveal intended and unintended outcomes of certain actions or states of being. The work of Ferguson (1990) provides an example of how discourse analysis can be combined with a sociological approach to uncover hegemonic ideological structures that underpin social behaviour. In his opinion, conceptual and discursive systems are often linked "with social institutions and processes without even approximately determining the form or defining the logic of the outcome" (Ferguson, 1990: 275). As such, discourses and behaviour may not necessarily have a cause-effect relationship but one can propose that certain actions, such as dominating tuberculosis treatment programs, are the result of an interrelation between the hegemonic ideologies about health and illness, development, and citizenship and the state.

Although this is not a dissertation on discourse in general it is important to clarify what exactly is meant when using this term/concept – particularly "tuberculosis discourse". Doing so entails a discussion of the conceptualisation of discourse and the



elements which underpin it. For many early sociologists the study of literature, linguistics and semantics was often termed discourse analysis. It was only in the latter half of the 1900s that sociologists began to define discourse as more than just language. Jürgen Habermas (1929-) and Michel Foucault (1926-1984) have been the most influential thinkers regarding this topic. Habermas and Foucault hold different views about modernity, reason, democracy, social action and power in society (Love, 1989). However, their suggestions as to what "discourse" means do not differ radically, although Foucault's work offers a clearer understanding and description. Habermas's work focuses more on the ethics of discourse and on communication in general. It is for this reason that in this study the work of Foucault is more prominent.

Foucault was interested in truth among other things. In order to increase his understanding of truth he formulated a methodology by which to explore the subject. His methodology, termed "an archaeology", is supported by an epistemology that includes at least three categorical elements: experience, power/knowledge and discourse. One of the tools he used to practice such archaeology involved analysing the historical paths of discourses and discursive practices (Brown, 2000: 21). Such analyses lay bare a history of thought. Such a history is formed when groups of statements achieve unity as a science, a theory or a text. "In consequence the history of thought reveals, beneath continuities predicated upon the assumption of a sovereign subject, discontinuities, displacements, and transformations" (Smart, 1985: 38). Simply put, discourse in Foucaultian terms is not mere language but rather a more or less institutionalised way of thinking. When he spoke of discourse, "it was not to show that the mechanisms or processes of the language (langue) were entirely preserved in it; but rather to reveal, in the density of verbal performances, the diversity of possible levels of analysis; to show that in addition to methods of linguistic structuration (or interpretation), one could draw up a specific description of statements, of their formation, and of the regulations proper to discourse" (Foucault 1972: 200).

It was Foucault's aim to show "that in analyzing discourses themselves, one sees the loosening of the embrace, apparently so tight, of words and things, and the emergence of a group of rules proper to discursive practices" (Foucault, 1972: 49). Discourse



therefore refers to a linkage of symbolic representations to a series of social actions and actors. It encompasses the natural and built environments, the scientific statements, philosophical, moral and philanthropic positions as well as the "missing", silent or non-said elements of an idea. It is an arrangement of elements about a specific topic or idea and the unity of this arrangement produces social meaning. Brown (2000) suggests that as such it can be regarded as a system of rules regulating the flow of power. Additionally, discourse can be considered a field *for* analysis and therefore for coming to know ourselves better. Finally, it is an aid to understanding as well as a function to producing truth (Brown, 2000: 33). And truth, for Foucault, is a "winning set of discursive practices at any given moment in time" (Brown, 2000: 35).

A theoretical approach to studying health and illness can therefore involve the analysis of both the ideologies and the discourses that regulate and demarcate "hierarchies of what is normal or natural, neutral or immoral, worthy or unworthy" (Shepard, 2007: 159). Such an approach implies searching for common themes and issues that prevail in discourse, thereby reflecting dominant knowledge. For Foucault, dominant knowledge usually occurs at the expense of the subjugation of other forms of knowledge (Foucault, 1972). In understanding this it is possible to identify how the "tools of professional knowledge, diagnosis, and assessment influence the ways actors are rendered sane and insane, healthy and unhealthy, normal and abnormal" (Shepard, 2007: 159). It is this approach to discourse that is used in this study. The other methodological procedures utilised are outlined and discussed in **chapter one**.

Chapter two traces the history of tuberculosis development in Europe over the past three centuries before moving on to discuss the history of the spread of the disease in South Africa at the time of colonisation. This chapter therefore provides an historical background of not only how the disease was spread, but also how its treatment was formulated and conceptualised. This is important because up until the 1960s and 1970s, tuberculosis treatment had always been framed within a context of general social development. For example in the late 1800s and early 1900s patients were isolated for their own benefit but also to protect the community at large by minimising the spread of the disease. In the cities, slums were cleared, sanitation was improved, and clean drinking water was provided in order to minimise the exposure to harmful bacteria and "germs". The added benefit of such practices was the general



improvement of people's level of immunity. Although the understanding of basic hygiene, good immunity and isolation as essential elements of good tuberculosis control still exist, tuberculosis treatment regimes across the world today do not reflect this understanding. Instead they are based primarily on technological drug-regimens and do little to address the underlying social causes of disease. When examining contemporary tuberculosis control mechanisms, by comprehensively expressing the historical context, it becomes clear how some ideas have developed into prominence and others have been subjugated to the point that they have inconsequential influence.

It is not enough though to only lay bare the historical background of the disease in order to understand the persistence of tuberculosis in our society. It is also necessary to grasp the political and economic factors that frame our conceptualisation of health and illness in general. This is the aim of **chapter three**. For example, how we view tuberculosis, as a disease resulting from individual behaviour or as a disease of social consequence will determine how responsibility for treating it is defined. When looking at the post-World War Two globalising environment from a political and economic perspective, it is evident that from the 1940s up until the 1980s a fairly dominant social welfare conception of democracy dominated. In this ideology the state was charged with the responsibility to provide its citizens with certain basic services, such as comprehensive health care. But by the late 1970s and 1980s global economic recession and the collapse of the social democratic norms facilitated the growth of a neo-liberal paradigm, which proposed that the de-regulation of markets spurs on economic growth, leading to general social development.

The conditions for development were therefore now defined by the ability of individual capitalist interests to grow and expand and by the "withdrawal" of state interventions in the economy. In particular this meant a dramatic decline in state social provisioning as social services were privatised, in whole or in part. In Africa in particular, the state's responsibility was thereby reduced to the task of creating policies that protected the interest of individuals/capital to operate freely in global markets. The outcome was a weakening of state autonomy and hence an undermining inter alia of its ability to provide basic welfare services to its citizens. The unfortunate consequence being that the rich became richer and the poor become poorer, with the additional disadvantage that the latter could not rely on the state's welfare safety net.



Liberation in South Africa occurred at the height of the neo-liberal revolution in Africa in the 1990s, yet the effects on health care of this dominant ideology were similar to those experienced by other democratised African countries that had gained independence in the 1960s. **Chapter four** traces the influence of global changes and dominant ideologies on the development of health care systems in a few African countries. For the most part Eastern and Southern African countries, like Zimbabwe and Tanzania, implemented health care systems based on a strong welfare model copied from post World War Two Western European nations. But during the 1980s they were also negatively affected by economic recession and by the tightening trade policies of the developed nations.

In order to maintain economic independence, many African states were forced to take loans from the World Bank or the International Monetary Fund. Doing so necessitated their conforming to the lender's neo-liberal economic "conditionalities" and to implement structural adjustment policies that resulted in their opening up of markets and to their diminished capacity to fund social health care services. This was not quite the case in South Africa as the apartheid government mostly borrowed from private banks in Switzerland. Full democracy only came to South Africa in the 1990s and the adoption of neo-liberal policies was part of a negotiated settlement – aimed at protecting white capitalist interests – and not the result of forced so-called structural adjustment programmes. As such South Africa's experience, as a democracy struggling to provide social welfare to all its citizens as well as trying to foster economic growth in a neo-liberal global market, is different to that of many other African countries. Yet the new ANC government attempted to learn from the health care mistakes and achievements made by it's neighbouring countries, influencing the current health care system found in the country today.

The end of chapter four sees a move away from a contextual analysis to focus more specifically on tuberculosis discourse in South Africa. This results in a flow of analytical ideas from a global level to a more concentrated, local one. Chapters five and six examine the dominant characteristics of tuberculosis discourse evident over the past period of political transformation. Two dominant characteristics, set against the backdrop of a hegemonic neo-liberal ideology, are identified. The first



characteristic and its associated relevance are discussed in **chapter five**, and deals with the dominance of the biomedical paradigm in tuberculosis discourse. The second characteristic of the discourse concerns the issue of HIV/AIDS. This is discussed in **chapter six**. The dominance of biomedicine and issues of HIV/AIDS in tuberculosis discourse have the result of subjugating the ideas concerning illness resulting from various sociological factors, including for example political, environmental, economic and social conditions of disease. As a result illness tends to be detached, or removed from the social context in which it occurs. This can be evidenced in the growing "silence" in tuberculosis discourse concerning issues of, for example poverty, migration and gender.

As will be seen in the case of tuberculosis control, the state now only has the responsibility for biomedical intervention of the epidemic. This includes, among other things, ensuring cheap and reliable drug supply, case identification, standardised treatment regimes and "enough" clinics and hospitals to cope with disease numbers. This leaves the state with the task of merely addressing the individual nature of tuberculosis (i.e. its effect on individuals). The social aspect of tuberculosis – and as will be shown the disease is clearly social in nature – is left to the responsibility of the "community". In this context the community implies all manner of social arrangements – private business, charities, aid organisations and residential neighbourhoods. Upon the shoulders of these citizen groups rests the task to ensure their own poverty alleviation. Women are encouraged stay at home to care for the sick, businesses are encouraged to provide tuberculosis treatment supporters in the workplace, and charity organisations are encouraged to provide food to tuberculosis patients who cannot afford the meals with which their medication should be taken.

In conclusion, the argument of this study in brief is the following: heath care institutions, such as the World Health Organisation (WHO) or a country's national Department of Health, generate their own form of discourse, and this discourse simultaneously constructs certain diseases – in this case tuberculosis – as a particular kind of knowledge. Doing so creates a structure of knowledge around disease, on which interventions are created and organised. These interventions may have many failings in their own right (such as poor adherence to treatment or poor cure rates), but they also may have the unintended consequences of firstly, undermining the general



advancement of health and wellbeing, and secondly, suppressing the ability of citizens to engage with the state in meaningful and significant ways that are able to bring about structural change. The result of these unintended consequences is that they disempower citizens, thereby perpetuating an environment that further disenfranchises the poor, defeating the purposes of health care in general.



CHAPTER ONE

Methodology

"What matters in science is not the pursuit of power but the knowledge gained. We must realize this afresh every day, just as every true doctor wishes for nothing more than to be able to help his patients even more with every new day"

Gerhard Domagk¹

1. Research Statement

By using the case of the National Tuberculosis Control Programme this study will advance the argument that tuberculosis discourses in South Africa have changed since the early twentieth century and are presently dominated by biomedical and technocratic discourses, while the social conditions of the disease have been systematically marginalised. This transformation in the hegemonic discourse has had a negative impact on tuberculosis sufferers.

2. Research Objectives

At the start of this project four research objectives were identified as follows:

- To identify the main tuberculosis discourses in South Africa
- To identify the main tuberculosis discourses globally
- To locate changes in global and national (South African) tuberculosis discourses in historic, political and economic contexts since the mid 1900s
- To explore how dominant global discourses interlink with local ones and to analyse the interrelation in a sociological manner so as to draw conclusions about their effects on health and illness

3. Research Design

Because of the field of enquiry, and in order to address these four objectives, this study uses a qualitative research approach. This method employs an empirical approach that utilises both primary and secondary data sources. Discourses are not exclusively present in the spoken words of individuals, such as tuberculosis control

¹ Winner of the Nobel Prize in Physiology and Medicine in 1939 for his contribution to the discovery of a cure for tuberculosis (quoted in Ryan, 1992: 342)



managers, but are rather made up "of vast fields of spoken and written statements" (Smart, 1985: 39). According to Smart (1985: 39) "these statements may form a unity by virtue of:

- reference to a common *object* of analysis,
- presence of a certain manner of reference or mode of *statement*,
- deployment of a system of permanent and coherent *concepts*,
- evidence of an identity and persistence of a *theoretical theme*."

As such, it is possible to identify common themes in tuberculosis discourse expressed in newspapers, medical journals, on websites, in published literature (by the state, private institutions or non-governmental organisations) as well as in the spoken words of those key individuals involved. It is for this reason that in this study, primary data includes documentary sources; such as newspapers, medical journals, books, websites, government documents and other published literature, whilst interviews constituted a secondary data source.

Additionally, this study involves a sociological approach that Farmer refers to as being both "historically deep and geographically broad" (Farmer 2004: 4). This entails being aware of sociological factors such as politics, history and economics that are involved in forming the ideological structures that underpin health care policies. It therefore entails recognition that the treatment of diseases – notably infectious ones like tuberculosis – at a local level are always located within global political economy, ideology and hegemonic ideologies.

Selection of the Case

In an attempt to better understand tuberculosis discourse and the ideologies surrounding the disease this study focuses on the National Tuberculosis Control Programme (NTCP) of South Africa, which acts as a case study. In essence this is a *health care programme* and not an office or institution, yet an office for its management does exist. The NTCP is a post-apartheid construction and provides the ideal example of how the new government has struggled to conceptualise health care as part of a "social welfarist" mandate, but located within a neo-liberal paradigm of development. The management of the tuberculosis control programme is centralised



via the head office in Pretoria/Tshwane² but in fact consists of a complex, dispersed network of provincial and district managers, public health officials and administrators throughout the country. Lower-ranking officials are not necessarily tasked with the control of tuberculosis only. They may be delegated responsibility over other health care issues as well. The actual implementation of the programme varies slightly by province, district and private area (such as in the mines or other workplaces). As the primary institution for tuberculosis control, the NTCP embodies the dominant discourses surrounding this disease. It is also a central point around which other tuberculosis discourses take place.

In this study it is not the effectiveness of the NTCP as such which is being considered, but rather the discourses surrounding the programme in general, and tuberculosis in particular. To this end, these discourses are regarded as being articulated by individuals within the NTCP – referring to those directly employed by the government to implement the aims of the NTCP – as well as by those "outside" of the NTCP – referring to individuals or organisations entirely independent of the NTCP – such as academics, private practitioners, charity organisations, etc. Additionally the discourses can be embedded in the public documents of the NTCP or Department of Health, in newspaper articles, in academic articles and books and in publications made by non-governmental organisations (NGOs) interested in tuberculosis. Dominant tuberculosis discourses are therefore regularly expressed in the numerous documentary sources produced by institutions as well as within the utterances of those individuals who exercise a certain degree of responsibility and power within these institutions.

4. Data collection

Deconstructing documents

Analysing documents to uncover discourse requires a clear understanding of what discourse is. This has been outlined. But it also requires a tool of analysis and not just a random reading of various texts. For the purpose of this study it was found that

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² In 2006 the greater Pretoria area and surrounding districts were renamed Tshwane while the Central Business District remained Pretoria. There is still much confusion as to what to call the city, which is the administrative capital of South Africa. For this reason both names will be used simultaneously hereafter.



using a simplified deconstructionist technique was most useful. Deconstruction is essentially a poststructuralist method developed in response to the structuralist predisposition preceding it. "One might say that one of the poststructuralist *raison d'être* is to decentre the subject, to oppose the humanist subject-centeredness that insists on regarding everything in terms of such foundational assumptions, concepts and procedures" (Van Niekerk, 2003a: 17). Unlike humanist structuralists, difference is essential for poststructuralists. For poststructuralists "meaning can never be fully present or presented" in a text (Van Niekerk, 2003a: 18). Understanding a text can therefore best be done by using a Derridean style of reading that strives "to see how text *produces* meanings, to see how the text functions as a text (Van Niekerk, 2003a: 27 italics mine).

The point of a deconstructive reading, then, is not to find *the* one "true" meaning of a "system of signs, but to destabilize the very notion that there is such a thing as literal or 'true' meaning" (Fuchs and Ward, 1994: 482). This is because the "traditional belief is that certain objective facts, such as the author's intentions or the text's sociocultural location, provide independent clues for correct interpretation" (Fuchs and Ward, 1994: 482). It is thus partly to allow for differences, to break the restrictive bonds of attempts to find the essential meaning of a text, that Derrida developed the 'critical practice' of 'deconstruction'" (Van Niekerk, 2003a: 27). Deconstruction "objects that an author's intention and social context are not given – that they, themselves, need interpreting. There is, in other words, no time out from interpretation" (Fuchs and Ward, 1994: 482).

Deconstruction is therefore a way of reading and analysing texts, which seeks to "inscribe within the text that which attempted to govern it from without" (Derrida, 1981: 6 quoted in Van Niekerk, 2003a: 26). In other words deconstruction is a method or tool that can be used to interpret and *provide* a sociological meaning to texts and to words. This implies that, for example, documents produced by the National Tuberculosis Control Programme in South Africa, such as the *Practical Guidelines* of 2004, can be read with an understanding that the text is formed ideologically within a social context dominated by a neo-liberal economic thinking of development. Therefore the meaning of this document, which comprises a set of guidelines for implementing the DOTS tuberculosis control strategy, is not ideologically neutral and



should not be assumed to be such. This theoretical understanding of the use of deconstruction, in its simplest sense, has been used in this study to analyse key texts. Such texts are drawn from the following sources:

Published material

Books and academic journals (both medical and sociological) on tuberculosis – its control, treatment, history, and epidemiology – were the first point of reference. Moreover, I collected major documents published by the NTCP and the Department of Health on tuberculosis, since 1994. The pre-1994 Department of Health and Population Development's publication "Epidemiological Comments" (a journal type publication) was extremely useful in providing an historical context and timeline of important events, and for noting the overall changes in viewpoints in South Africa, towards tuberculosis. The key and most relevant documents published by the World Health Organisation on tuberculosis or other health care issues can be accessed via the WHO library or archives, which are available online. These documents were used to elucidate global changes in thinking regarding tuberculosis over the past seventy or so years.

Internet

Material published on the Internet was vital in gathering an understanding of tuberculosis discourses because as public virtual space it allows for public discourse to be expressed with very little constraint. It was useful therefore for example by opening up the opportunity to belong to online forums (such as the STOP-TB Forum), where issues about tuberculosis are openly discussed. Members participating in these e-forums are located all around the world – including South Africa. The comments made and issues raised in these forums allowed for the opportunity to see what dominant themes occurred within discussions. Additionally, many organisations that deal with tuberculosis issues, such as SANTA, also have websites which contain relevant data that gives insight into how tuberculosis disease and its control is perceived, from a non-governmental point of view.

Newspapers

Tuberculosis has become a hot topic in the South African media over the last few years and so articles on the disease, often quoting top officials, exist in abundance.



These articles were accessed using electronic databases housing the many popular South Africa's newspaper collections. In order to narrow the search, twenty popular South African newspapers were scanned for the 12-month time period from 1 April 2006 to 1 April 2007. This search revealed more than 300 articles dealing with tuberculosis. Newspaper articles presented a unique opportunity to uncover the public discourses of tuberculosis. They capture important information that may not necessarily be found in academic publications as well as publishing "opinions, remarks and statements given by [key] role players as historical events unfold" (Vandormael, 2005: 31). Documentary analysis and deconstruction therefore played a key part in the uncovering of tuberculosis discourses, both nationally and internationally.

Although discourses are embodied in all of the numerous documentary sources mentioned above, for the purpose of this study, and to create a manageable, workable sample, documents published by the South African Department of Health have been the primary sources of data. It is in the list of documents below that the dominant themes in tuberculosis discourse – from the 1970s onwards – can be found. This is not to suggest that other sources do not contain these themes or do not present other important themes. However, as these key publications are in most cases drawn-up in collaboration between the NTCP, the WHO, the Medical Research Council, the International Union Against Tuberculosis and Lung Disease, and the Centers for Disease Control they are publicly available and express the dominant issues in tuberculosis discourse. Further, all of these listed publications are available to the public and are drafted in conjunction with key parties in the tuberculosis field of interest. It is with conviction therefore that these documents are utilised because they best express the dominant themes in tuberculosis discourse in South Africa and are used as the primary sources of data for a discourse analysis. The Key Documents are alphabetically listed as follows:

- Community Health Workers Policy Framework (2004)
- Epidemiological Comments (all editions from 1973-2007)
- Mobilising Against Tuberculosis, Medium Term
 Development Plan 2002-2005 (2001)
- National Tuberculosis Crisis (2006)



- Practical Guidelines (1996, 2000 and 2004)
- The Management of Multidrug Resistant Tuberculosis in South Africa (1999)
- Tuberculosis, a Training Manual for Health Workers (1998)

Interviews

Structure of the Interview. The interview, as an instrument of research, is in this study regarded as a source of secondary data. This is because interviews often make known the private discourses of individuals and do not always bring out the public or dominant ones. However, the information shared during an interview can reflect or confirm the dominant discourse and has the potential to reveal marginalised issues and "subjugated knowledge", in Foucault's terminology. In this study, the primary type of interaction with participants was by conducting an "elite interview". An "elite interview" pertains to interviewing people in positions of authority, with regards to their expertise, who posses a comprehensive grasp of what is being researched and are "capable of giving answers with insight" (Gillham, 2000). Interviews used in this study had an open-ended format with a limited amount of structured questions asked in order to minimally direct the participants' responses. This results in the formation of further questions on the basis of the informant's responses, but still allows space for the participant to direct the flow of conversation somewhat.

Selection of Research Participants. Interviews were conducted with some of the key individuals involved in tuberculosis control, research and advocacy in South Africa. This included members of non-profit organisations involved in tuberculosis control, medical doctors, individuals associated with the Medical Research Council, academics, an ex-tuberculosis control program director, ex-Department of Health officials, a mining doctor and finally, top managers of the NTCP (located in Pretoria/Tshwane, South Africa). Interviews with these individuals served to make known the common themes of contemporary tuberculosis discourses. As experts in

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³ I am reluctant to use the word *informant* (as the accepted methodological term) because there is a current perception amongst the general population of South Africa that an *informant* implies someone who betrays a work colleague for their unethical behaviour or for workplace misconduct. This association of the word *informant* to an implied betrayal of information stems from the apartheid days when an *informant* was someone who leaked information to the South African Defence Force or Police about illegal anti-apartheid activities. It is therefore a sensitive word in the South Africa context and instead I will use participant, respondent or interviewee.



their field their discussions were nuanced and could serve to confirm or to explain or even to deny the trends uncovered from documentary analysis. In total, twenty-two "official" interviews were concluded during the course of 2006 up until August 2007.

Procedure of Interview. Participants were identified and contacted by telephone or email. If required, a brief outline of the study was provided and they were requested to participate in an interview. Upon approaching participants they were presented with a letter stating the research intent, procedure and use of research data. A copy of the letter can be found in Annexure 1. Participants were also made aware at the start of each interview that all attempts would be made to respect their character and dignity but that the information and opinions they provide would not necessarily remain confidential as their positions and the organisations they work for are well known in the public realm. Those who agreed to an interview consequently gave their consent to be part of this study. In some cases informal conversations and personal communications added to the "official" interviews. These were either face-to-face or via email and telephone.

As all of the participants were professionals, all the interviews were conducted in English, the primary business language in South Africa. Interview questions were orientated in such as way so as to discover the types of debates regarding tuberculosis that participants engaged in; the struggles they perceive health care workers, professionals and tuberculosis patient's experience; the contradictions of the debates they deal with, and the location of these debates within the changing dominant tuberculosis discourses. All interviews were one-on-one and usually (though not exclusively) conducted at the participants' place of work. Interviews were hand recorded by jotting down shorthand notes and quotes as the interview progressed. Each interview was then comprehensively fleshed out on paper directly afterwards and notes on the flow and themes of the conversations/interviews were made.

Ethical Issues. Guidelines used by the South African Medical Research Council's Ethics Committee (Du Toit, 2006) include respect for human dignity, autonomy, informed consent, confidentiality, maximum benefit, and justice. As this study involves human subjects it is based on a moral commitment to advancing human welfare, knowledge and understanding, and to exploring intricate social dynamics



relevant to the concepts of health and illness. Therefore, at the start of this study official permission to conduct this research was provided by the University of Pretoria's research ethics committee as well as by the Research Unit of the South African Department of Health (see Appendix 2). To be clear, this research concentrates primarily on public discourses, rather than private, individual ones. Thus, it is not any individual or institution per se that is under analysis. Finally, in the interests of protecting this study's integrity, all attempts are made to refraining from discrediting any individual characters or persons in this dissertation.

Research Difficulties. Those involved with the NTCP who were interviewed, are essentially "bureaucrats". As Becker and Meyers (1974) suggest "they do not constitute an 'elite' in the sense that Wall Street lawyers, elected politicians, or business executives are elites" but they are appointed government administrators nevertheless, and "they hold an advantageous position relative to the needed information, which serves to enhance their 'elitism'" (Becker and Meyers, 1974: 606). In essence, part of the job of these persons entails the daily accumulation and distribution of information. It is within their power to declare information "non-existent, not within the purview of their office, temporarily missing, lost, or confidential – all in order to prevent information from being released to those who are threatening, do not take an attractive approach, or are not liked for any number of other reason" (Becker and Meyers, 1974: 606).

Additionally, for those participants working for the NTCP, the Medical Research Council or any other publicly well-known institute, the nature of their work is such that they are often responsible to the existing power structure and highly visible. Becker and Meyers (1974) suggest that because of this type of position, especially those working for government, the respondents are often suspicious of persons who request information. "There is little guarantee of his [or her] anonymity because the information can only disseminate from a few sources". The person in this position "cannot be sure that information will not in some way be used against the agency, thereby getting him [or her] in trouble with his [or her] superiors for releasing it" (Becker and Meyers, 1974: 607). For this reason it was decided against using audio-recording equipment during interviews so as to avoid providing a further hindrance to the type of information shared by the respondents. Therefore although they are



acutely aware of their discretionary power and of the content of information they release this does make the job of a sociologist somewhat more difficult because it means that the participant may be withholding certain valuable insights and information.

A perfect example of this selective dissemination of information is illustrated by one particular occasion, when sitting in the office of an NTCP respondent. The respondent's office is located on the 18th floor of the Department of Health with a wonderful view over the Pretoria CBD and over the surrounding government buildings. The interview was a difficult one, with the respondent less than forthcoming while I had to use an array of interview techniques to prompt her into providing slightly more elaborative answers. During this tedious process her desk telephone rang and she answered. In pretending not to be interested in her one-sided telephone conversation I proceeded to shuffle industriously through my notes or occasionally turned to stare out of the window - I was getting used to being interrupted during my interviews with bureaucrats. I couldn't help but be curious though to what sounded like a fairly heated exchange between someone from the South African Defence Force and my respondent. The NTCP respondent was refusing to give the person on the other end of the line the latest statistics of drug-resistant tuberculosis in the country and she was angrily reminding him/her that the Defence Force was not co-operating with the NTCP in tuberculosis control efforts and as such she would not help "them" (the Defence Force) if they would not help "her" (meaning the NTCP in general). This exchange provides a wonderful example of how elite bureaucrats could feel it justifiably right to selectively divulge certain information towards certain parties. When my respondent put down the telephone and returned her attention to me she obviously felt as if I had "caught her out" and then proceeded to defend her actions to me.

The reluctance of bureaucrats to divulge information they do not deem necessary or the right of the interviewer to know can also present a level of bias in the research findings. When conducting interviews, I found that my social status as a young, female student sometimes played to my advantage in putting respondents at ease (as I was of a lower social position), but at other times proved a limitation because they felt the need to over-simplify information (for me as a younger person). I realised that I



could not exclude their bias and that it was best to adjust my interviewing technique in such a way that I best accomplished my desired goal. In order to do this I took advise from Becker and Meyers who suggest that the interviewer in this position doesn't focus on trying to *not* influence what the respondent says, but rather to focus on what the interviewer *can do* to meet his/her information goal (Becker and Meyers, 1974: 607). Therefore they encourage an interview style that is spontaneous and creative – a style where the information goal is not treated as a restriction. This means that all information possible should be gathered, and that nothing should be treated as superfluous or be disregarded (Becker and Meyers, 1974: 607).

The final difficulty involved government and NTCP officials who would not make time for an interview, gave little detail or only allowed short amounts of time in their schedules for the interview (sometimes only 15 minutes). This made interview data rather thin, yet nonetheless supported the claim that interviewing elites is a difficult business. Although the experience of interviewing elites was not easy and was even slightly intimidating, making use of the Becker and Meyers' (1974) advice was useful for identifying common themes, concerns, debates and issues that respondents brought up. As such, an imaginative, creative and flexible interview style proved most appropriate and usually served to complement the documentary analysis adequately.



CHAPTER TWO

A history of tuberculosis

"The LORD shall smite thee with a consumption, and with a fever"

Deuteronomy 28: 22 (KJV)

1. Introduction

Biomedical viewpoints define tuberculosis (*Mycobacterium tuberculosis*) as an infectious disease that is spread primarily by sputum droplets containing the tubercle bacilli (NTCP, 2004a: 11). The tubercle bacilli are minute rods that are readily engulfed by the white blood cells of the body (Dubos and Dubos, 1953: 111 – see figures 1 and 2). They have a low growth rate and little ability to break down complex organic molecules or to attack the substances that make up our bodies. It is their enormous numbers in the body, which cause the characteristic tubercles/ulcers. Their content is noxious to our bodies, causing irritation and toxic build up. The bacilli usually inhabit the lungs (pulmonary tuberculosis) but can also attack other organs of the body (extra-pulmonary tuberculosis). A person can harbour the dormant tubercle bacilli for many months or years before a lowering of the immune system triggers the advance of the bacilli into an active state, prompting the onset of disease. It is during this active stage that a person is termed ill or diseased and is able to infect other people by coughing up the virulent bacilli into the air.

Tuberculosis is an age-old disease. Documents dating from the early Greek and Roman empires describe cases resembling tuberculosis mortality, and mummies bearing signs of tuberculosis lesions have been found in Egyptian tombs dating from around 2 400 - 3 000 BC (Dubos and Dubos, 1953: 5). There is also much literature recounting the spread, treatment, perceptions and discourses of the disease in Europe and North America since the start of the Renaissance. Tracing the history of tuberculosis in places like Sub-Saharan Africa is more difficult partly because the epidemic occurrence of tuberculosis in this area is much more recent and partly because written documents of the disease are found only from the colonial period onwards. "Tuberculosis" as a word, first appeared in print around about 1840 but it has been recorded in documents under numerous other names: phthisis, scrofula,



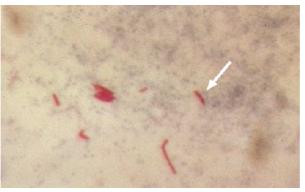
consumption, even bronchitis and asthma (Dubos and Dubos, 1953). So universal has the disease been that abundant theories about it have evolved over time. Some of them still influence contemporary thought and some have fallen by the wayside. From the late eighteenth to the early twentieth century tuberculosis was the number one cause of death in Europe and North America (Fourie, Townshend and Kleeberg, 1985) and it's social impact is recognised as often being "more influential than statesmen and soldiers in shaping the course of political history" and in colouring "the moods of civilizations" (Dubos and Dubos, 1953: 4).

Figure 1. Colonies of Mycobacterium tuberculosis on Lowenstein-Jensen medium



Source: Todar's online textbook of bacteriology. Picture courtesy of the US Centers for Disease Control. textbookofbacteriology.net/tuberculosis.html, Accessed, 24 August 2007

Figure 2. Mycobacterium tuberculosis. Acid-fast stain



Source: Todar's online textbook of bacteriology. Picture courtesy of the US Centers for Disease Control. textbookofbacteriology.net/tuberculosis.html, Accessed, 24 August 2007



2. Tuberculosis in Europe

In early seventeenth century Europe most debates about tuberculosis revolved around whether it was "catching" or was inherited from one's parents (Dubos and Dubos, 1953: 40). In Florence in 1648 the contagion theory was so dominant that laws decreed that people had to burn the furniture, clothing and linen of a diseased consumptive person. These were some of the first recorded state enforced regulations aimed at tuberculosis control. But the application of such laws was costly and opposition to the contagious theory of the disease had begun to develop in the Faculty of Paris around 1650. Unfortunately the "hereditary" theory only served to encourage the spread of the disease as suggested treatments dictated that the sick person remain indoors, without exposure to fresh air and live on a limited diet, including various folk remedies of the day — blood, breast milk, herbal teas etc. Opposing treatments encouraged isolation in sanatorium-type "cottages/homes", either in the mountains or at the seaside. Here alternatively, exercise and "vibrancy of life" were encouraged (Dubos and Dubos, 1953: 50).

Such views on tuberculosis even influenced social trends. For example, during the Romantic era tuberculosis is accredited as having contributed to the "graveyard school" of poetry (van Rensburg et al., 2005: 5). Melancholy meditations over the death of youth (due to *Consumption*), frailty and symbols of weeping willows became popular in 1750 Europe. Even the boisterous female type of the Revolutionary era was displaced by ideals of languishing beauties dressed in vaporous muslin, silk and thin linens. Much of this fashion was morbidly detrimental to the health of women of the era – keeping them cold and thin, thereby lowering their immune systems and their resistance to infection. Death by consuming disease was regarded as tragic but also poetic (Dubos and Dubos, 1953: 55).

The work of Susan Sontag (1978: 11) proposes that tuberculosis is an inherently polemic disease, one of contrasts and ambiguities – making it an interesting topic of study for a sociologist. Sontag poetically describes the active disease as manifesting itself in the individual in both a "white pallor" and a "red flush", stimulating "hyperactivity alternating with languidness" (Sontag, 1978: 11). Consequently, tuberculosis contains an ambivalent metaphor as being "both a scourge and an emblem of refinement" (Sontag, 1978: 61). The use of the word "consumption"



during the Romantic era reflects this ambiguity. Consumption implies "disintegration, febrilization, dematerialization" and as such tuberculosis was and still is regarded as a "disease of liquids – the body turning to phlegm and mucus and sputum and, finally, blood – and of air, of the need for better air" (Sontag, 1978: 13). At the same time the metaphor of consumption can suggest a divine "gift" that uncontrollably possesses and inspires individuals, through heated fevers – enough to drastically "sharpen their creative abilities and wit" (Dubos and Dubos, 1953).

By the end of the nineteenth century the harsh realities of the industrial revolution forced attitudes towards tuberculosis to change. Where before, tuberculosis had been associated with fateful hereditary transmission it now began to be associated with broader social concerns. The wealthy classes saw the miserable humanity, living in squalor, cold, starved, and diseased. Popular views of tuberculosis began to change and it was understood to breed suffering without romance (Dubos and Dubos, 1953: 65). At the same time, with the rise of germ theory, tuberculosis began to be associated with dirt, poverty and contagiousness. No longer was the great "white plague" associated with hereditary characteristics, but instead the theories suggesting the contagiousness of the disease proved correct. Tubercular infection was now known not to be a random act of God or nature, but instead it was the result of ones unfortunate social condition. Tuberculosis became associated with the working classes and with the city slums resulting from the industrial revolution, as such loosing its eighteenth century bourgeois association with literature, poetry, and classic elite society. It now became connected with urbanisation, the working class and with poverty.

For Sontag, tuberculosis has always been "imagined as a disease of poverty and deprivation. If not in the sense of poor nutrition, hygiene and unheated rooms, then poor in emotion, lack of stimulation or a deprived and broken spirit" (Sontag, 1978: 14). Her argument is that, what once made tuberculosis seem so interesting and romantic "also made it a curse and a source of special dread". Therefore tuberculosis was understood as a disease that required the individual to be isolated from the community (Sontag, 1978: 37). It was this belief that underpinned the creation of sanatoria in eighteenth century Europe. From the late seventeenth to the early nineteenth century perceptions of tuberculosis clearly reflect that the disease was



closely associated with poverty and its related characteristics (unsanitary living and working conditions, poor nutrition and immunity and so forth) (see Dubos, 1953). There was clearly therefore a dominance of issues of poverty in tuberculosis discourses in the late industrial period in Europe.

During this time, no longer was tuberculosis something to be feared, instead it was portrayed as a plague that could be conquered and eradicated once and for all from human society. Tuberculosis was suddenly a public issue that needed to be dealt with through communal effort. State sponsored public health campaigns focused on educating the masses about the cause and spread of disease. People were encouraged to foster a spirit of communal responsibility: to educate their children, to clean their homes and themselves, to look after the old and frail. Therefore personal hygiene was promoted in view of establishing greater general public hygiene (Dubos and Dubos, 1953).

Tuberculosis discourses were not only dominated by the theme of poverty but also by the theme of prevention. This discursive focus manifested itself in the improvement of sanitary infrastructure and the building of sanatoriums where patients were isolated for the period of their clinical treatment. Varying treatment regimes and the desire to find a cure may have also featured heavily in tuberculosis discourses but as a cure had not yet been found prevention was regarded as the best means of curbing the epidemic. This prevention centred on the protection of the individual (in the sense of protecting him/her from catching the disease) but also on the protection of society at large. For this reason, isolation in sanatoria was encouraged. In general, in Western Europe and North America the state became the dominant institution regulating disease control. Much of this control was based on a clinical biomedical paradigm, which grew in dominance during the industrial period as medicine became likened to a discipline of empirical, objective science (Dubos and Dubos, 1953). Nevertheless, social reform was costly and considered a long-term solution.

In the meantime a desperate hunt for cures to the many diseases plaguing the modern world was on. The search for a tuberculosis cure was propelled by the discovery of the tubercle bacilli in 1882 by Robert Koch. But while microbiologists and scientists searched for this cure the sanatorium movement, sparked by the eccentric English



Doctor, George Bodington grew rapidly. The most famous sanatoria in Europe were in Davos, Switzerland. Set high in the mountains, the fresh air, sunlight, rest and healthy diet often yielded dramatic results in tuberculosis patients. Although a scientific test of the effectiveness of sanatorium confinement was never carried out, Ryan suggests that other than their beneficial effects for the individual patients, their most important achievement was "the isolation of the infected person from other potential victims" (Ryan, 1992: 28). Other healing measures popular during the early 1900s included surgical treatment, such as artificial pneumothorax (inflation of the lungs) or thoraplasty (excision of whole portions of the ribcage). These treatments were however, reserved for the fortunate or for the wealthy. Most patients infected with tuberculosis were sent home to die in peace or to suffer in crowded hospital wards. "The typical sufferer spent most of his shortened life shuttling between rest at home and long queues at the clinics for medical attention" intermittently going back to the sanatorium until his or her eventual death (Ryan, 1992: 30).

Regardless of the numerous tuberculosis control efforts it is clear for the most part that tuberculosis waxed and waned throughout European history. The disease was most prevalent around 1650 and 1850 but a general great downward trend occurred in Europe at the start of the twentieth century. By the end of the twentieth century it was on the increase again. As Dubos and Dubos suggest, this could be attributed to the natural, biological rhythms of disease, i.e. "Tuberculosis began to decrease long before any specific measures had been instituted against the disease" (Dubos and Dubos, 1953: 185). Yet, Murray (2004: 170) gives three other possible reasons for the notable downward trends: improved socioeconomic conditions leading to better nutrition and living standards; primitive public health measures; and the establishment of sanatoriums. Although the role of public health campaigns was significant one also "cannot ignore the natural forces that altered the balance between man and the tubercle bacillus before the microbiological era" (Dubos and Dubos, 1953: 186).

Yet despite this general downward trend and despite the many efforts to improve sanitation, public health education and public nutrition, tuberculosis remained the number one killer in Europe and America in 1954. The search for a cure was still the most urgent medical problem facing the entire world, and optimism was dwindling.



As Corwin Hinshaw, a man pivotal in aiding the discovery of the miracle drug streptomycin, states:

At the midpoint of the 20th century, tuberculosis was recognised by all as the 'White Plague', undeniably the most dreaded enemy of the human race by any measure. Whether measured by prevalence, cost, social consequence, sheer misery or any yardstick, I believe that any observer of the time would consider the bacillus of tuberculosis as the enemy number one of the human race. None of us – myself included – believed that its control could be attained by medical means within this 20th century (Quoted in Ryan, 1992: 49).

3. A cure and a global "solution": The role of the WHO in tuberculosis control

Pasteur's discovery of attenuated bacilli in 1881 laid the foundation for the production of a vaccination for tuberculosis in 1921, the most widely used being BCG (Bacillus Calmette Guérin) (Murray, 2004: 173). The breakthroughs in a cure for tuberculosis came only in the 1940s and these were shrouded in controversy. During this time, tuberculosis discourses were dominated by this need to find a cure. The intense global efforts to find a cure led to the simultaneous discovery in the United States of America and in Europe of three different drugs deemed as "the cure". Streptomycin was discovered in 1944 by Albert Schatz, working under the guidance of Selman Waksman in the United States. Streptomycin was named the "miracle cure" by the American Media.

Another antibiotic was discovered simultaneously in the Bayer factory in Germany, however after the Second World War the Allies no longer acknowledged German patents and the drug could be made in any Allied country and sold at market driven prices to the highest bidder. At roughly the same time in 1943 PAS (para-aminosalicylic acid) was discovered by Jorgen Lenmann as well as possibly the most powerful anti-tuberculosis drug, isoniazid (isonicotinyl hydrazine); discovered in 1952 by German born Gerhard Domagk (Ryan, 1992). It was controversially though, only to Selman Waksman that the Nobel Prize in medicine was awarded in 1952, for his discovery of a cure for tuberculosis (Ryan, 1992: 370).



Unfortunately tuberculosis quickly showed resistance to each of these drugs and the miracle of the 1950s soon became a public health disaster, as patients who had been treated with wonderfully powerful drugs were presenting again with new strains of tuberculosis and rapidly declining in health until they died. It was not until a decade later, in 1960 though that John Crofton showed how he had effectively cured tuberculosis in every single patient of his Edinburgh test group through meticulous adherence to a drug regimen that consisted of a *combination* of streptomycin, isoniazid and PAS. Crofton proved that tuberculosis cannot be treated with one drug alone, it is only in combination that drug-resistance can be combated and a complete cure be assured (Ryan, 1992: 380). In order to ensure such treatment success patients were hospitalised or isolated in sanatoria for a long 12-18 month period. This was expensive to sustain, especially for low-income countries like South Africa. An ambulatory treatment regime was needed. This necessitated a dramatic shift in the thinking about tuberculosis control, one that was prompted on by the growing influence of the World Health Organisation.

In 1920, a conference on tuberculosis was convened in Paris in which thirty-one countries participated and the International Union Against Tuberculosis was established – it is now known as the International Union Against Tuberculosis and Lung Disease (Enarson and Rouillon, 2007). The conference ended in an impressive procession where "delegates one by one pledged 'to agree on the means to fight TB, to make a consensus on the strategy, to jointly apply the most effective weapons to combat this common enemy" (Enarson and Rouillon, 2007). Aside from routine reports of the conferences, a regular publication commenced in 1923. The Union and the Bulletin continued until their interruption by the start of the Second World War commenced.

The end of the Second World War was followed by the creation of certain global establishments that aimed to regulate global social action in order to avoid the recurrence of atrocities seen during the two World Wars. For example the League of Nations was re-formed into the United Nations (UN). On 7 April 1948 the World Health Organization was established as the United Nations specialised agency for health. As set out in its constitution, the WHO's objective is "the attainment by all



peoples of the highest possible level of health" (WHO, 1946). According to the WHO, health is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). The WHO became very influential in the establishment of health policies around the world. From its inception, the WHO "recognised the vital importance of a comprehensive approach to tuberculosis control, including treatment consistency and monitoring" (WHO, 2001: 11). A Tuberculosis Section was established within the WHO, which aimed to assist governments with control programmes that focused on BCG vaccination campaigns and effective case management. "Since then, case management has persisted as the central technical strategy for tuberculosis control" (Raviglione and Pio, 2002: 775). Amrith (2002: 2) suggests that the WHO's campaign against tuberculosis is marked by three successive stages.

The first stage was the worldwide preventive campaign of the 1950s, based on mass vaccination with BCG, 'case finding', and data collection. The second stage, beginning in the late 1950s, involved the trial and subsequent implementation of a strategy of treating tuberculosis using newly available anti-tuberculosis drugs, avoiding the need for hospitalisation but raising vexed questions of patient 'compliance' with a lengthy regimen of drugs. The third stage, which set in almost as soon as drug treatment became widespread, saw the disappearance of tuberculosis from the international health agenda during the 1970s, despite evidence that it remained a very significant public health problem in developing countries (Amrith, 2002: 2).

In 1947 the first report of the WHO Expert Committee on Tuberculosis adopted two important new policies. The first allowed for the sending of teams of tuberculosis experts to developing countries to demonstrate modern methods of tuberculosis control. The other policy advocated for mass BCG vaccination campaigns (WHO, 1965: 8). For first half of the twentieth century, tuberculosis clinics, dispensaries and sanatoria were the backbone of most anti-tuberculosis efforts. At the end of the Second World War, with the advent of miniature radiography and effective chemotherapeutic agents, it appeared as if the tuberculosis clinics and sanatoria were



the ideal places – when fully equipped – to deal with the disease. Therefore clinic and hospital/sanatoria-based treatment was encouraged as the standard location of treatment for tuberculosis. Experts suggested that these institutions and programmes used in tuberculosis control were extremely effective and should be used in the newly formed independent states, where the problem was considered to be far worse.

The International Union Against Tuberculosis was also very influential in addressing issues such as tuberculosis in Africa, strain variation in BCG, encouraging new clinical trials for new drugs, radiography for tuberculosis, and the role of voluntary and non-governmental agencies in helping in the fight against the disease (Enarson and Rouillon, 2007). The discovery of chemotherapeutic agents, which combated communicable disease, prompted the building of vertical control programmes, otherwise known as specialised programmes. A vertical programme has the characteristic of being single-purpose motivated, staffed with specialised personnel and being hierarchically structured from central to local level (Raviglione and Pio, 2002: 776). This vertical approach was backed by stable economic development and was therefore more easily implemented in high-income countries, but nonetheless the approach was imported to developing countries like South Africa.

By the early 1950s, in order to properly implement this new vertical system into tuberculosis control, a number of Tuberculosis Demonstration and Training Facilities had been opened in Asia, Africa and Europe. As the effectiveness of these centres soon became evident, they were flooded with new cases and simplified techniques for diagnosis and were then sought. The standardisation of such diagnostic procedures also meant that it was possible to simplify and accelerate the training of auxiliary health workers. Although diagnosis was now easily managed and required little specialised skill, treatment was still effected by qualified medical doctors (Raviglione and Pio, 2002).

Even with the discovery of PAS and a growing understanding of combination drug therapy, much treatment was still individualised according to patients' responses to medication. In the developing countries, specialised medical personnel were not in abundance. Therefore there was a growing rift in the diagnostic abilities and treatment capabilities of many tuberculosis programmes (WHO, 1965: 12). The role of these



diagnostic centres and the auxiliary health workers became vital at this point. The WHO recognised the effectiveness of the BCG vaccination and so encouraged mass vaccination programmes, conducted by mobile teams of doctors, nurses and auxiliary health workers. By 1951, "BCG campaigns became the largest field programme under the auspices of the WHO, in the world" (WHO, 1965: 13). As nurses and doctors were scarce in the developing countries a new type of auxiliary health worker was needed – the "BCG technician". The positive outcomes of using this type of semi-skilled worker "soon ended any doubts about entrusting non-professionals with refined techniques" (WHO, 1965: 13).

By 1959 there came another shift in the thinking about tuberculosis control. The WHO funded Tuberculosis Chemotherapy Centre in Madras, India, had shown that it was possible to treat tuberculosis using only a drug regimen and that nothing else was really needed. Wallace Fox had conceptualised the idea of supervised administration of medicines. This concept became the basis for the development of what is today known as directly observed therapy, or DOT (Raviglione and Pio, 2002: 756). Supervised treatment and encouraging results gained from the BCG vaccinations gave the WHO good reason to begin planning mass treatment programs based on chemical medication. Additionally there were encouraging results from the use of auxiliary health workers in developing countries, and also from growing research findings that revealed similar tuberculosis trends throughout the world (tuberculosis appeared in similar patterns in rural and urban areas and amongst the various age groups). These factors combined gave the WHO enough information to begin planning a model national tuberculosis programme (WHO, 1965: 15).

From the experience in Madras it became evident that it was more cost-effective to implement domiciliary diagnostic and treatment programmes rather than clinic or hospital based ones. This meant that patients could be treated on an outpatient basis, which reduced the costs needed to maintain beds in hospital tuberculosis wards. Additionally, "low-costs and standardization made it possible to conceive control programmes based on drugs" (WHO, 1965: 16). It was this idea, and not the discovery of drugs themselves, that was the changing force in tuberculosis control from the WHO perspective. Tuberculosis control was now cheap and easy to implement and could be managed with little risk by auxiliary health workers. The



implications of this style of treatment meant that patients could recuperate at home whilst only frequenting the nearest primary health care or specialised tuberculosis clinic or hospital in order to have someone observe them swallow their medication (Raviglione and Pio, 2002: 756). This idea was not initially accepted without hesitation.

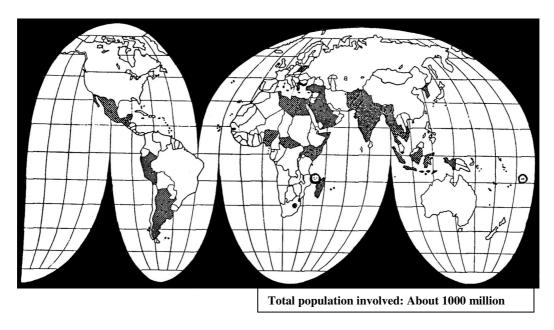
A report from the Seventh Expert Committee on Tuberculosis (WHO, 1960) suggested that the results from the Madras study were not conclusive and did not reveal a significant difference between patients treated in a clinic and those who opted for domiciliary treatment. Despite this hesitation the Committee agreed that "in countries with a large tuberculosis problem and with limited resources, it was advisable to use such resources initially to promote the community-wide tuberculosis control programmes through domiciliary use of anti-tuberculosis drugs rather than hospital construction" (WHO, 1960: 11). Yet, it was still agreed that as a model for national control, ambulatory chemotherapy based treatment was easy to implement and thus easily "transported".

Usually the WHO established a team of specialised doctors, nurses and x-ray technicians who remained in a country for approximately two years until a nationally applicable programme had been established and expansion had begun (WHO, 1965: 18). As a result, from the 1960s till the 1980s, many European and North American countries attempted to adopt this approach as well as creating a more integrated health service delivery plan (figure 3). This was not the case for "less developed" countries where the cost of medications was still too high and much treatment involved sanatorium confinement and hospice care up until the 1980s (Heunis, 2005: 225).

The WHO also recognised that a quantitative definition of tuberculosis was necessary in order to plan rational control programs (WHO, 1965: 3). Standardised treatment programmes had the advantage of being easily quantified and therefore capable of being comparatively measured. Thus the WHO could now begin statistically comparing and collating data collected from the various countries implementing such programmes. The advantage of this was that epidemiological trends could be easily created and predictions about the future path of the diseases could be made. If needed then, interventions could be readily applied and potential negative outcomes diverted.



Figure 3. Countries receiving WHO assistance in National Tuberculosis Programmes in 1965 (coloured in black)



Source: WHO. 1965. International Work in Tuberculosis, 1949-1964. Geneva: WHO.

The main lesson learnt during this period was that in less-developed countries mass campaigns could not produce a sustainable effect on tuberculosis epidemiology. Additionally, it was revealed that general health services were "essential in dealing with the continuous emergence of new cases and the maintenance of vaccination coverage" (Raviglione and Pio, 2002: 776). New policies to address these issues were spelt out in the eighth report of the WHO Expert Committee on Tuberculosis (WHO, 1964). The report emphasised the integration of service delivery and a need for the WHO to negotiate for lower costs of drugs in order to make them more widely accessible (Raviglione and Pio, 2002: 776). These policies were refined and reaffirmed in the ninth report of the WHO Expert Committee on Tuberculosis (WHO, 1974) and fitted well with the general trend within the WHO towards a primary health care approach.

The rationale behind a more integrated approach to tuberculosis control was that it would "make a more efficient use of human and financial resources, eliminate duplication of tasks, and provide more effective support to the units responsible for tuberculosis" (Raviglione and Pio, 2002: 777). A negative effect of the integration



policies was that there was a gradual loss of visibility of tuberculosis awareness and a gradual loss of expertise in organising effective control and case-management activities. As tuberculosis decreased in the developed countries and as its visibility waned the WHO saw a dramatic decline of tuberculosis on its agenda. No further meetings of the Expert Committee on Tuberculosis were convened after 1974 (Raviglione and Pio, 2002: 776). At the same time, tuberculosis control activities were administratively re-grouped, and by 1978 the WHO's expenditure on communicable disease control dropped to just 2.5% for all "bacterial and virus diseases" (of which tuberculosis was only one). In 1989, the WHO offices for tuberculosis control had dropped to only "2 full time professionals managing a tiny budget for operations" and no permanent consultants were posted in any countries (Raviglione and Pio, 2002: 777). Scientific publications decreased dramatically, and a number of influential tuberculosis institutions closed down (Amrith, 2002: 59).

4. The "re-emergence" of tuberculosis

Effective drug therapy may have provided a solution to the great "white plague" but by the mid 1980s a new plague was haunting the world, the Human Immunodeficiency Virus (HIV). Most developing countries like South Africa continued their ad hoc tuberculosis treatment programmes, many still using vertically orientated plans and semi-state charity organisations to effect some means of control over the disease. Tuberculosis had never really decreased in these countries; it was often only under-reported (like in the Bantustan homeland states in South Africa) or kept quiet under the isolation of the communist states. By the end of the 1980s, with the dissolution of the Soviet Union it became clear that tuberculosis was rife in Eastern Europe and the disease again became of concern to the Western European countries, who suddenly experienced an influx of immigrants from the former communist states. It also became clear that the high levels of socio-economic inequality in Africa and Latin America were fuelling the HIV/AIDS pandemic and as an associated disease, tuberculosis was once again on the rise in these areas. "In 1990, it was estimated that the global incidence of tuberculosis was 8 million new cases and resulted in around 3 million deaths" (Raviglione and Pio, 2002: 777).

The problem of the expanding tuberculosis crisis could no longer be ignored. In 1996 the WHO reported that in the previous year more people had died of tuberculosis than



in any other year in history and it was expected that at least thirty million people would die from tuberculosis in following ten years, if current trends continued (Amrith, 2002: 65). In 1993, the WHO declared tuberculosis to be a global public health emergency and by the following year had adopted the DOTS (directly observed therapy – short course) framework for effective tuberculosis control (WHO, 2001). According to the WHO, the DOTS strategy consists of five essential elements: political commitment, quality assured tuberculosis sputum microscopy for case detection, proper case-management reporting and standardised short-course therapy for all cases of tuberculosis, uninterrupted supply of quality-assured drugs and recording and reporting assessments of every tuberculosis patient. This strategy emphasises the need for standardised treatment and uninterrupted drug supply for the successful cure of a patient.

The WHO target, using DOTS, is to have a global case detection rate of 70% and a successful treatment rate of 85% (Dye, Geoffrey, Garnett, and Williams, 1998). DOTS involves a course of (usually) four very strong antibiotics, administered in a directly observed treatment program – i.e. people are observed swallowing their pills. If a person does not complete the course of treatment, or treatment is interrupted, he/she may develop drug resistant tuberculosis. This "implies resistance to at least Isioniazid and Rifampin, drugs used in DOTS programmes" and is termed multi drugresistant tuberculosis or MDR-TB⁴ (Farmer, 2003: 180). Acquired resistance is the term used for patients who have for some reason defaulted on their treatment and developed drug-resistance. "Primary MDR-TB occurs when others are infected and fall ill with MDR strains". So-called second line drugs, used to treat MDR-TB are very expensive and are often not available in resource poor settings (Farmer, 2003: 182). The DOTS program is based on passive case finding, which has hindered the success of many control programmes. Passive case finding entails patients being identified only when they present themselves to their local medical facility (doctor, clinic or hospital). The DOTS strategy helped many countries in the implementation of a workable tuberculosis control programme and has standardised tuberculosis treatment on a global scale.

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⁴ Drug-resistant strains of tuberculosis are numerous and their categorisation depends on their level of resistance to certain groupings of drugs/medications. Multi drug-resistance implies resistance to at least two of the first line drugs. Extremely drug-resistant tuberculosis implies resistance to at least two groups of second line drugs.



By 1999, at least 127 countries had adopted the DOTS strategy and global funding for tuberculosis control efforts had increased from 60 million US\$ in 1990 to 160 million US\$ in 1999 (Raviglione and Pio, 2002: 778). In November of 1998 the IUATLD joined with the WHO and other international partners to launch the Stop TB Initiative for global action in the hopes of extending the model to all countries of the world" (Enarson and Rouillon, 2007). "The Stop TB Partnership was established in 2000 to eliminate tuberculosis as a public health problem. It comprises a network of more than 500 international organizations, countries, donors from the public and private sectors, and nongovernmental and governmental organizations that have expressed an interest in working together to achieve this goal" (Stop TB, 2007).

In 1997 some estimates put the global burden of tuberculosis at 6.3 million new cases (Arnadottir, 2001: 563). In 2003 the WHO reported that 8.8 million new cases of tuberculosis had been diagnosed and that 22 countries were responsible for 80% of the global tuberculosis burden. These countries are found in Southeast Asia, sub-Saharan Africa and Eastern Europe (WHO, 2007b). Of most concern is the prevalence of drug-resistant strains of the disease. The WHO reports the disturbing pervasiveness of drug-resistant tuberculosis in all 109 countries surveyed, including South Africa (WHO, 2007b). However, the significant increase of cases of resistant strains of tuberculosis, in strategic places called "hot-spots" caused alarm for the supporters of the rigid DOTS programme.

As a result, in 1999 the WHO established the Working group on DOTS Plus for the management of resistant strains of tuberculosis. In 2006, this group was renamed the Stop TB Working Group on MDR-TB (Stop TB, 2007). DOTS Plus suggests a more active case finding approach along with an intersectoral strategy to dealing with tuberculosis and a commitment to ensuring the effective treatment of resistant strains. The treatment of drug-resistant tuberculosis is difficult, as it requires a complicated series of testing procedures for each individual case in order to identify which drugs can be effectively used. Because people showing symptoms of active tuberculosis are generally automatically treated with the standard six-month DOTS regimen this increases the risk of treating MDR-TB incorrectly.



Treating MDR-TB with poorly conceived treatment regiments or the incorrect drugs "amplifies" the resistance, causing what is known as super-strains – tuberculosis bacilli that are resistant to eight or more or two classes of second-line drugs (Farmer, 2003: 181,182). These strains are termed extremely drug-resistant tuberculosis or XDR-TB. Currently, the majority of patients with resistant strains of tuberculosis are only identified once they have failed with one or more courses of conventional DOTS therapy. This results in the continued transmission of resistant strains (Espinal, 2003). To date, a standard treatment of a tuberculosis case with the DOTS strategy costs roughly US\$12 per patient in a resource poor county, whilst individualised treatment of a resistant strain of tuberculosis can amount to US\$2 400 per case (Rigouts and Portaels, 2005: 73). At present the treatment of all types of tuberculosis in South Africa is free.

It is clear that in the last decade and a half, tuberculosis is once again at the forefront of medical and social development discourses. Yet, despite the renewed focus on tuberculosis due to its increased visibility and the intense prevalence of resistant strains I am inclined to agree with Amrith (2002: 70) when he suggests that it is not enough to assume that the WHO's previous neglect of the disease is because its priorities are simply guided by those "of clinicians and public health officials in the West". The WHO has consistently maintained a focus on diseases that were of negligible interest to the West –such as malaria, and diarrhoeal diseases (Amrith, 2002: 70). Instead, as Amrith suggests it was within the institutions of the advanced academies (such as the London School of Hygiene and the Johns Hopkins School of Public Health) in which tuberculosis virtually disappeared as a specialty, depriving the international medical community of resources and innovations in treating the disease (Amrith, 2002: 70). The same diagnostic methods and anti-tuberculosis drugs that were developed sixty years ago are the ones still being used today; no significantly new inventions have been made.

Thus, the decline of WHO interest in tuberculosis cannot only be the result of narrow "social control" or "economic interest" but is perhaps the result of the disease no longer being visible enough to those in influential policy arenas. Paul Farmer reminds us that such a realisation makes it "impossible not to regard the notion of 'tuberculosis resurgence' as something of a cruel joke – or yet another reminder of the invisibility



of the poor" (Farmer, 2001: 46). As the human immunodeficiency virus has increasingly spread throughout the developed world, the diseases of the poor (such as tuberculosis) which co-infect AIDS patients, are once again of concern to the people of these countries. The "resurgence" of interest in tuberculosis then should be contextualised within its association to the HIV/AIDS pandemic.

In light of this "re-visibility" of the poor and of their issues it is vitally important that in the developing nations we generate and foster capacity of academic research and reporting in a sound and convincing manner, so that their issues are not once again forgotten or silenced when it no longer affects those in the West. Today South Africa is again recognised as having one of the worst tuberculosis epidemics in the world. It is the leading infectious killer of youths and adults and it is estimated that it kills almost 1000 people every month (Fourie, 2006). The Medical Research Council estimates that in 1997 there were 180 507 cases of tuberculosis in the country. Recent estimates put that figure at around 500 000 infected people with a minimum of 37 people dying of the disease daily (TB Free, 2007). The tuberculosis problem in South Africa is steeped in an historical legacy of political and economic inequality in which treatment was marked by neglect, poor management of systems and located within fragmented health services. With the fall of apartheid, in 1996 tuberculosis was declared a top health priority by the Department of Health and a new control programme based on the DOTS strategy of the World Health Organisation was implemented.

5. Tuberculosis in South Africa

The history of tuberculosis in South Africa differs somewhat from the experience of Western Europe. This difference has to do with the unequal distribution of the disease between the white and non-white racial groups in South Africa. On the other hand there are also similarities in the aetiology of tuberculosis, between South Africa and Europe, which have to do with "the changing alignment of political and economic interests" of rapidly expanding capitalist industrial economies (Packard, 1989a: 5). Tuberculosis in South African literature emerges with the arrival of European colonial settlers in 1652. There is little evidence to suggest that tuberculosis was not present in the native African population before the arrival of the European colonists. However, it is generally accepted that most natives had not been routinely exposed to the disease



and therefore offered little biological resistance to it. As such, the native African population presented a somewhat "virgin soil" in which tuberculosis could spread uninhibited. It is also clear though that, despite this "virgin soil" theory, tuberculosis only emerged in epidemic proportions among the native populations with the advance of industrialization, in the latter half of the nineteenth century (Packard, 1989a: 22).

In the late eighteenth and early nineteenth century, tuberculosis peaked in Europe, initiating a movement of people away from the cities towards rural sanatoria or even to the favourable climates of the distant colonies. The arrival of hundreds of European consumptives in the late 1800s sparked the epidemic levels of the disease in South Africa (Heunis, 2005: 224). The disease was at first located along the coastal areas and in the port cities. As European settlers and explorers trekked towards the mineral rich highveld and the game rich lowveld they spread the disease to the interior. Initially, because of the selective immigration of tuberculotics, tuberculosis rates were high amongst the white population groups and lower amongst the black rural population. But it did not remain this way for long and unlike in Europe in the 1900s, tuberculosis in South Africa did not fall evenly on the population; it fell most predominantly on migrant working class Africans who spread the disease to the rural areas (Packard, 1989a: 3). According to Packard, this was not the result of their biological inferiority but was due instead, primarily to the role of politically and economically constructed inequality and to the forced migratory labour system encouraged by the mining capitalists of the day.

Industrialisation in South Africa was led by a boom in the mining industry, due to the discovery of diamonds near Kimberly in 1867 and of gold on the Witwatersrand in 1886 (Bulpin, 1983). The influx of fortune seeking prospectors expanded the need for fresh produce, basic infrastructure, land and cheap labour. Although the increase of trade in the budding mining towns stimulated a growth of the African peasantry (Bundy, 1979) it also drew vast numbers of black labourers from the rural areas, seeking to make money with which to pay the escalating taxes imposed upon them and to buy guns and ammunition to protect their tribes and to support the anti-colonial "frontier" wars. At the end of their contract period at a certain mine, black workers would return home to their families and tribal groups in the rural areas where they rested before going back to the mines to continue labouring. By the early 1900s many



such migrant labourers were housed in roughly built hostel-type compounds. These compounds were over-crowded and unsanitary, workers were poorly fed and clothed and expected to labour for very low wages, as competition amongst workers was high (Van Onselen, 1982).

Despite the fact that mine workers on the Witwatersrand were given meals of *miellie* pap (maize meal) "the 1912 Tuberculosis Commission estimated that an adequate diet would have used up one third of the average wage paid to black mines workers at the time" (Metcalf, 1992: 22 italics mine). This meant that mine labourers were often overworked, nutritionally deprived and gaining very little financial profit from their toil. Although this unsavoury environment often applied to all labourers on the mines, by the start of the 1900s white workers were able to legitimately voice their grievances and influence mining regulations in their favour, black workers could not. As such, their working and living conditions improved somewhat. On the other hand, the black African migrant workers were marginalised, un-unified and unable to legitimately unionise with enough political clout to force improvements of their conditions. Living and working in this environment provided the perfect breeding ground for a host of infectious diseases, one of them being tuberculosis.

Packard (1989a) suggests that the migrant labour system influenced the epidemiology of tuberculosis in the country in three ways: *Firstly*, it made possible the spread of tuberculosis from urban to rural areas. Unlike in Europe, the disease was uncontrolled in poorer rural areas (and still remains that way today) and was not necessarily associated with a disease of the cities. *Secondly*, the migrant system delayed black Africans' resistance to the bacilli, therefore prolonging the epidemic. Because whites were settled in the urban areas they had a more stable exposure to the disease and thus could develop resistance to the weaker tubercle bacilli. This is unlike black Africans who mostly lived in the rural areas and occasionally came to the urban centres for contract-based work, before returning home. *Thirdly*, black Africans weren't fully proletarianised and were thus limited in pushing for labour reforms and health reforms in the work place. These three factors make the epidemiology of tuberculosis in South Africa unique compared to that of Europe and North America (Packard, 1989a).



In the early twentieth century the developing urban, white, middle-class recognised the danger posed to them by the ill health of the poor, causing them to push for better health care and living conditions of black African workers in the mining districts. However, it did little to improve conditions in the rural areas (Packard, 1989a: 15). For the most part it improved tuberculosis treatment regimes for white South Africans. These treatment procedures followed the trends of the day in Europe and North America. This included sanatorium confinement, hospitalisation and, when discovered, the administration of chemotherapy (Heunis, 2005: 224). The sanatoria movement in South Africa coincided with the growing movement in Europe. Even though the mining industry played a key role in the dissemination of tuberculosis it was also influential – at the instigation of Cecil John Rhodes – in supplying the capital to build the first sanatorium in South Africa, just outside of Kimberly (Metcalf, 1992: 25).

It is at this point that the historical aetiology of tuberculosis in South Africa diverges from that of Europe. In general, tuberculosis control measures in South Africa "involved the application of exclusionary policies designed to keep disease out of the social and economic centres of white society" (Packard, 1989a: 299). Most policies aimed at decreasing tuberculosis incidence amongst black South Africans included half-hearted attempts to improve the living conditions in mining/labour compounds. The result was that tuberculosis was less and less a concern for the white urban/suburban population and more a problem of the non-white "Bantustans" and the "township" locations. Further, the disease was not mainly confined to the urban areas, as it was in Europe, but it became a concern in the rural districts as well. The result of such limited approaches was that tuberculosis amongst the rural South African population was never adequately addressed. This was not the case necessarily for example in Lesotho, where although tuberculosis was rife and workers migrated to South Africa – bringing the disease back to this country – a tuberculosis control program (however ineffective) was implemented early on to try and curb the spread of the disease (Tsikoane, 1998).

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⁵ "Bantustan" and "township" are specific South African apartheid terms used to describe the pseudo-homeland/independent states and the peri-urban settlements respectively, where the non-white population groups were obligated to live during the apartheid era.



After World War Two there was growing mobilisation of Africans in the country into workers associations and political interests, drawing concerns amongst the white electorate about the radicalisation of Africans. This created fear of labour competition and threatened the migrant labour system, further upsetting the mine owners and decreasing the chances of health reform for the black African workers. The start of apartheid in 1948 officially segregated South African society along racial lines, further excluding the non-white population groups from equal access to tuberculosis treatment (Packard, 1989a). Tuberculosis in South Africa must therefore be viewed as a product of the "pathological intersection of political, economic and biological processes" (Packard, 1989a: 19).

Apart from the epidemiology of the disease on the plateau, there is one section of the country that represents a unique epidemic within an epidemic, even today; that is the Western Cape (Health Systems Trust, 2004). The spread of tuberculosis in the Western Cape Province also reveals the political, economic and the racial divisions of the country. In the early part of the twentieth century the coloured population of Cape Town experienced very high mortality and morbidity rates. Decades before the height of the tuberculosis epidemic in South Africa as a whole, tuberculosis amongst the coloured and black population groups was in excess of one percent (Strebel and Seager, 1991: 67). Factors which contributed to this high prevalence included, rapid urbanisation with poor housing conditions, poor nutrition, overcrowding, unemployment and a short supply of nursing staff and clinics as well as numerous social issues like alcoholism, drug abuse and domestic instability. Until the turn of the millennium tuberculosis in the Western Cape remained the highest for any province in the country and continued to be a problem amongst the coloured population (Weyer, et al., 2003).

For the most part tuberculosis in South Africa was a disease of the economically poor and the politically marginalised. Treatment programs were mainly accessible to the rich and to the white population. But despite this tuberculosis was not yet curable and in many cases the disease was fatal. By the early 1900s the disease became a growing concern for many of the urban population in South Africa. This was due in part to an emergent worker activism and a convergence of white class interests over the need for improved worker's health (Packard, 1991: 43). Tuberculosis concerned both white



and black working class families and a call for improvements in working and living conditions forced government and private charities to begin more active tuberculosis control efforts. Therefore, tuberculosis was declared a notifiable disease – compulsory registration of all cases – in the Cape and in Natal in 1904 (Packard, 1991: 44). In 1919 tuberculosis was made a notifiable medical condition throughout the entire country (excluding Transkei, Bophuthatswana, Venda and Ciskei).

The sanatoria movement was for the most part the primary method of treating tuberculosis patients and controlling the spread of the disease during this time. The first public sanatorium was constructed in 1924 in Nelspoort but lack of accommodation for patients was common for whites and blacks during the early years of tuberculosis control. The discovery of streptomycin and other drugs for treating tuberculosis, malaria and typhus generally improved the health conditions of all South Africans somewhat but as these drugs were expensive, most treatment remained for the privileged few and included primarily hospital confinement.

During apartheid, tuberculosis control efforts by both government and private voluntary organisations were scaled up. Government expenditures for tuberculosis control "increased steadily since the Second World War and by the early 1980s amounted to R50 Million a year" (Packard, 1991: 47). In terms of their effectiveness, however, these efforts fell short of their goals. This is because health in general was subordinate to the overriding political and economic design of the Nationalist government. For example, although the introduction of effective anti-tuberculosis drugs saved many lives their availability was far below what was needed to control the rapid spread of the disease. Treatment was simply too little for the vast numbers of patients. Packard (1991) gives an example of the number of beds available to black and white patients during the year 1957:

...there were approximately 1 350 new white cases of TB. The accommodation available for these cases in the same year was 1 230 beds. By contrast there were approximately 40 000 new black cases, and the number of beds available nation-wide for all blacks in TB institutions in 1957 was 14 410. In effect there were nearly



three times as many black cases per available bed as there were white cases per bed (Packard, 1991: 49).

In order to combat this problem, black patients were sent "home" to their settlements/Homelands where charity organisations like South African National Tuberculosis Association (SANTA) had built numerous tuberculosis treatment centres and clinics. However, these centres only catered for those patients living in the specific Homeland and most of these were treated on an outpatient basis where follow up was difficult and patients often defaulted on their treatment regimen. The result is a continued spread of the disease in the Homelands, but also the creation of an ideal environment for the production of resistant strains of tuberculosis. Many patients, on the other hand, remained in the cities and urban areas in order to stay employed and to continue earning a wage. These infected individuals never received treatment; therefore continually spreading the disease in the urban centres as well (Packard, 1991).

One of the biggest negatives of apartheid policy in tuberculosis control was the fragmentation of treatment regimens used by the neighbouring Bantustan states. Antituberculosis drug regimens were not standardised for South African and homeland population groups. This meant that the relapse rate was very high as well as producing strains of tuberculosis that were resistant to Izoniazid. By 1980 "it was estimated that 38 per cent of all hospital TB patients represented relapse cases, which finding led the then head of SANTA to conclude that the treatment programme '...had to a considerable degree been a failure'" (Packard, 1991: 53). By the 1960s tuberculosis incidence rates peaked in South Africa, after which there was an apparent decline. "This decline is controversial though and most probably reflects the fact the notifications and statistics from the homeland states were not included in these figures" (Edginton, 2000: 12).

A national Tuberculosis Control Programme (TBCP) was created in 1979. Its policy aimed to accord tuberculosis health education first priority "followed by supervised therapy, active and passive case finding and BCG administration. Community involvement was required to assist with case-finding and supervised ambulatory care" (Lee and Buch, 1992: 290). This "community involvement" was usually provided by



voluntary welfare organisations such as SANTA and the Friends of the Sick Association. These organisations provided welfare services that the state was not capable of offering. In the case of tuberculosis control, this included the building of specialised tuberculosis clinics and sanatoria, meals on wheels programmes for the elderly or infirm, sheltered employment for tuberculosis patients and the provision of basic educational material (Ginwala and Collins, 1992). Welfare organisations played a significant role throughout the history of tuberculosis control in South Africa and their involvement will be discussed more in chapters five and six.

The role of welfare organisations, research institutes and international health organisations was influential in the changes that occurred within the health sector during the political transformation of South Africa. In 1994 with the election of a new government the restructuring of the health sector under a unified Department of Health produced significant changes for the management of disease and the control of tuberculosis across the Republic of South Africa. The changes during this period are of most interest for this dissertation as they mirror many of the changes in health and illness management that occurred throughout Africa, but in a rather condensed time frame. In a generalised manner we can regard the changes in health care in Africa since the 1980s as part of broader changes in the neo-liberal ideology of "development" and the associated role of the state in such development.

It is within the context of this overarching, hegemonic ideology in which current day tuberculosis discourse is located. For Foucault, discourse and ideology are closely linked but not essentially the same thing. At times the dominating ideology may dictate medical discourses and practices in such a way that it hinders the improvement of health in general. For example, Dubos and Dubos (1953) give evidence to suggest that tuberculosis waxed and waned throughout European history. The disease had been most prevalent around 1650 and again around 1850 but began a downward trend in the early twentieth century. They argue that "tuberculosis began to decrease long before any specific [biomedical] measures had been instituted against the disease" (Dubos and Dubos, 1953: 185). The reasons given for this decrease are that diseases naturally ebb and flow, but also that state-instituted public health measures and improved socioeconomic conditions during these times, led to better nutrition and to



better living standards, thereby increasing the overall health and immunity of individuals.

The suggestion is thus that although the role of public health campaigns was significant in decreasing the mortality rates of the disease, "one cannot ignore the natural forces that altered the balance between man and the tubercle bacillus before the microbiological era" (Dubos and Dubos, 1953: 186). As a result, tuberculosis cannot be viewed merely from a biomedical or clinical perspective, "for historical and social backgrounds loom large in the picture" (Dubos and Dubos, 1953: 219). This argument advocates for the use of historical evidence and proves that the complete elimination, or at least satisfactory control, of tuberculosis is impossible with biomedical factors alone. It consequently leads to a call for combined efforts to treat tuberculosis by using public health approaches, medical interventions, as well as increasing resistance by improving the quality of life of individuals.

This example reveals how a dominant ideology, which suggests a reductionist view of a medico-scientific solution to combating disease, can encumber the successful control of a specific disease if it ignores the social causes involved in that disease's aetiology. Understanding this reveals the importance of recognising how dominant ideologies (for example in the political and economic realms) influence the discourses of individual topics, like tuberculosis. In the same way global hegemonic discourses of the day influence local ones found in South Africa. The next chapter deals with some of these transformations in health discourses at an international level by framing them within the context of broader political and economic changes since the end of the Second World War. Chapter three therefore, begins by analysing the notion of citizenship and citizen rights within the context of social democracy, before looking at the internationalisation of health in the globalised era.



CHAPTER THREE

Social Welfare and Health in a Globalised World

"When it comes to global health, there is no 'them'... only 'us."

Global Health Council (2007)

1. Introduction

The issue of citizenship is key to the arguments presented in this study because contemporary tuberculosis discourses are framed within a broader context of development, welfare and human rights ideologies. The concept of human rights as a universal for all – and on which states should base their health policies – should be understood as the culmination of an historical process of unfolding state rationality since the mid-1970s, to minimise state welfare provisioning for citizens whilst maximising state control over the individual.

2. Citizenship, welfare and the state

Historically, the concept of "citizenship" – as something inherent to the *nation state* – is a fairly recent notion. But since early Greek society the idea of democracy in its infantile form encouraged a degree of "participation of *citizens* in the public and political institutions of the state, or more correctly, the *polis*" (Vandormael, 2005: 15 italics mine). In Ancient Greece therefore, the ability to freely interact with other individuals and to participate in the rule or government, denoted citizenship – this was only applicable to males though, not to woman, salves and foreigners (Vandormael, 2005: 16). The modern philosophy of citizenship has aspects similar to that of Ancient Greeks but leans more towards an individualistic view of "status" and "rights".

Early Greek thought on citizenship included the philosophy that an active citizen was a "true" citizen, and this activity was obligatory. Whereas the modern conceptualisation regards citizenship as more of a "right" than an obligation – despite the individual's level of participatory involvement. That is why a modern writer like Marshall, (1964) can define citizenship as a "*status* bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed" (Marshall, 1964: 92 italics mine).



Citizenship for him though, is also fundamentally about equality. But there is little consensus as to what this equality entails and how it is to be achieved.

For Marshall, equality does not simply imply entitlement to the same standards of living, but rather equal rights in which to pursue certain ends. For example, he proposes that property rights do not entitle every citizen to a piece of land, but rather the freedom to strive to own property, the freedom to protect it and the freedom to do their will with it. Essentially then, according to Marshall, equality is about *status* and not about income or class. In this viewpoint it is also about reducing general risk and insecurity (Marshall, 1964: 92). This view of equality is generally shared by contemporary human rights advocates, such as George Soros, Amartya Sen, Jeffery Sachs and Paul Farmer because it attempts to locate individual liberty or freedom within a broader social historical system and in doing so proposes that in order to gain more freedoms for individuals, numerous social factors need to be addressed – and not just one factor such as economics.

Further, for Marshall (1964), citizenship is political, not economic, and it is made up of three elements: civil, political and social. In this way, Marshall's ideas express a viewpoint similar to that of the Ancient Greeks. A major flaw in his argument is that he sees these elements developing and having been implemented progressively in a linear, fairly unchallenged manner. Marshall uses England as an example of how the developmental process of the concept of citizenship is tied to the growth of the capitalist system of production. For him, eighteenth century England saw the formation of civil rights, the nineteenth century was marked by the emergence of political rights and the twentieth century was the time in which social rights became important (Marshall, 1964).

Although Marshall clearly points out that these time periods do overlap he is also intent upon showing how the definition of citizenship entails the historical progressive inclusion of various categories of rights. Unfortunately in doing so he constructs citizenship as something "modern", an idea that expanded over time and slowly increased the freedoms of individuals; and as something exclusive to Western, developed countries. Aside from this, the argument is teleological and suggests a linear progression of ideology. In contrast, Foucault (1972) presents ideology as



something which progresses in a multitude of directions and that some ideas are elevated to the subjugation of others. At the same time Foucault (1972) suggests that ideas are not linear, but rather that they develop and form a conglomerate of "paths" that criss-cross and influence each other continuously. Yet, Marshall's conceptualisation of citizenship has some convincing points; it is to these that I would pay attention.

According to Marshall, at the end of the nineteenth century it became apparent that civil and political rights were legally sanctioned but not always capable of being attained by all persons equally. This lack of freedom to access certain rights was seen as due to the lack of social rights. For example,

the right to freedom of speech has little real substance if, from lack of education, you have nothing to say that is worth saying, and no means of making yourself heard if you say it...these blatant inequalities are not due to defects in civil rights, but to lack of social rights (Marshall, 1964: 97).

This awareness of "freedoms" and social rights appears to be a characteristic of the twentieth century and is evidenced in the growing concern for human rights.

At the same time as this growth in the issue of rights and of citizenship, the eighteenth century also saw the birth of the modern national consciousness, and an awakening of public opinion and awareness. However, for the most part during this time, citizenship – in meaning or effective outcome – did little to undermine inequality. Citizenship, based on civil, political and social rights tends to legitimise social inequality, such as class difference (Marshall, 1964: 77). Inequality in this view is part of the social structure and fabric of society, a necessary evil. For the most part then, poverty was addressed by only the morally kind hearted or the religiously convinced. Consequently, volunteerism and charity was merely useful in its attempt to "abate the nuisance of poverty without disturbing the pattern of inequality" (Marshall, 1964: 105).



The most discernable aspect of citizenship rights in the mid-twentieth century was the growth of state administered and state funded social services. The revolutionary aspect of state-funded services rests on the presumed "ability of those who do not own property to influence the distribution of resources through electoral mechanisms" (Fierlbeck, 1991: 582). This "novel" approach to governance became a core feature of the welfare state. The rise of the welfare state may have begun in the nineteenth century but is definitely more a feature of the mid twentieth century Western Europe, especially the social democratic state. The key attributes of the initial ideology of welfarism are illustrated in the English example of its early welfare states. Firstly, welfare was seen as a political rationality "structured by the wish to encourage national growth and well being through the promotion of social responsibility and the mutuality of social risk" (Rose and Miller, 1992: 192). In this view, welfare of citizens is regarded as a contractual relationship between the citizen and the public powers. As such the state would be responsible, as the English state was, to "attack the 'five giants of Want, Disease, Idleness, Ignorance and Squalor'. In return, the citizen would respect his or her obligations to be thrifty, industrious, and socially responsible" (Rose and Miller, 1992: 192). The second characteristic of welfarism lies in its "attempts to link the fiscal, calculative and bureaucratic capacities of the apparatus of the state to the government of social life. As such, it relies on bureaucracy as a central tenant of maintaining order and efficacy" (Rose and Miller, 1992: 194).

Welfarism is therefore regarded as the rational organisation of a system of networks, "assembled from diverse and often antagonistic components" – one that attempts to "link the aspirations of authorities with the lives of individuals" in a way that improves/betters the existence of the state and the individuals (Rose and Miller, 1992: 194). But Neocosmos (2006) questions whether the granting of social rights was ever intended to encourage such an active, participatory style of citizenship as Rose and Miller suggest. He argues rather, that the social democratic style of government could not provide welfare to its citizens without strong economic development. "The granting of social citizenship rights was itself contingent on economic growth which itself was dependent on market competition" (Neocosmos, 2006: 10). This perspective suggests that although welfarism may have been framed within the vocabulary of social rights and may have been intended to promote the freedom of individuals and



encourage active citizenship, it had the result of making the provision of welfare services the obligation of the government led state. The result was that individuals became passive in their acceptance of the state's provision of services, and active participation in governance diminished.

Marshall's (1964: 258) suggestion that the welfare state places an intense emphasis on individualism, tends to support this view that welfarism inadvertently creates a passive citizenship. His assumption is that for an individual, welfare is an irrefutable right but that it is the welfare state that is regarded as "the responsible promoter and guardian of the whole community", and this is something "more complex than the sum total of the welfare of all its individual members arrived at by simple addition" (Marshall, 1964: 259). Inherent in the idea of welfarism then, is a tension between access to rights and political participation, the rights of the individual and the rights of the political community at large; a tension between the state and the individual. Seeking the wellbeing for one may lie in contrast to the wellbeing of the other.

Although Britain is often used as an example to show the development of welfare policies, similar ideas had also infiltrated North America and had taken root by the early twentieth century. But in the United States welfare policies differed with that of Western European welfare states in two fundamental ways. Firstly, they never promised U.S. citizens social security from the cradle to the grave and secondly, they were always intended to be short-term relief strategies in order to avoid producing dependency (Barbour and Wright, 2003: 636). It is these fundamental differences that reveal ideological rifts between liberal and conservative views in the United States of America. Without dwelling too long on the differences between liberal and conservative views of government in the United States it is important to highlight some necessary points. In general, classic liberals seek a distributive society and so advocate for the continuation of a welfare style state and for stronger state control in order to curb negative effects of the market forces.

Conservatives on the other hand, may in general not be averse to the spirit of welfare but are more concerned with how its implications could lead to the state's increasing interference and control over the individual's ability to freely participate in the market. Especially, they are concerned that the state would tighten its control over



market competition and thus the ability of capitalists to increase their profits. Thus conservatives advocate for less state control over market forces, thereby giving each individual the opportunity to realise his/her own success – in effect, to allow capitalist competition to prevail unchecked. Although this is an extremely simple division of the two groups, what needs to be pointed out is that essentially, both liberal and conservative viewpoints have as their central ideology, the presumption that the answer to human development lies in economic growth. Time has yet to reveal whether this ideology is useful or not and this is not the space to explore this discussion. Nevertheless it is this presumption that lies as the foundation of a contemporary dominating global ideology called neo-liberalism.

The "political mentality of neo-liberalism breaks with welfarism at the level of moralities, explanations and vocabularies" (Rose and Miller, 1992: 198). Neoliberalism advocates for less state interference in competitive, open markets and places more emphasis on the role of markets to replace planning and to regulate economic activity. Neo-liberals criticise the authority and ability of political authorities to govern anything for general good. They are sceptical of state power and control and of interference in realms of business and finance (both public and private). As a result, "those aspects of government that welfare construed as political responsibilities are, as far as possible, to be transformed into commodified forms and regulated according to market principles" (Rose and Miller, 1992: 199). In order to foster growth and social development this implies that, "active entrepreneurship should replace the passivity and dependency of responsible solidarity as individuals are encouraged to strive to optimise their own quality of life and that of their families" (Rose and Miller, 1992: 199). The outcome of this ideology has been a growth in privatisation and the outsourcing of services that traditionally fell under the responsibility of the state. As such, neo-liberal policies generally emphasise market liberalisation and economic growth rather than distributive policies.

Neo-liberal ideologies are generally associated with modern states that embody free market principles. Development is regarded as being directly related to economic liberalisation, embodied in the concepts of free market exchange and de-regulation. The economy is believed to be the liberator of humanity and the state is the trusty steed, leading forth to economic progress and freedom for all. These neo-liberal ideals



stand in contrast to those that were articulated by former American President, Roosevelt in the first half of the previous century. Between 1933-1938, Roosevelt initiated a series of programs entitled the New Deal (Barbour and Wright, 2003). After the devastation caused by the collapse of the stock exchange and by the Great Depression, Roosevelt's government aimed to begin a relief, recovery and reform of the United States economy. Essentially the New Deal focused more on economic liberalisation and less on welfare, but eventually it evolved to focus largely on civil and political rights (Barkan, 2006). Roosevelt's New Deal policies reflected a general social welfare consensus amongst the citizens of North American and Western European countries whereby social problems were regarded as being best addressed via politically driven economic and social change, resulting in communal and individual development. It is for this reason that social commitment to development was encouraged and charity organisations grew rapidly.

Charity organisations and networks of charities are most definitely a feature of industrialisation. This is not to negate the role played by religious organisations in many cultures prior to industrialisation, only to mention instead that as a social movement – in sociological definitions – it is a feature associated with the high levels of inequality resulting from rapid industrialisation (Bartlett, 1928: 336). Nevertheless, in England and France, laws allowing persons or organisations the right to hold property for the benefit of others were already formally sanctioned in the sixteenth century (Anonymous author, 1968: 440). The colonial period was marked by a growth in charities as Europeans became exposed to the perceived "primitiveness" of the natives. This coincided with the rapid movement of Protestants into the colonies. At the time their Christianity called strongly for having a benevolent, compassionate and caring attitude towards ones neighbours - fostering the growth of charities in the colonies. The organisation of charities into larger collections or groups only developed in nineteenth century England. Bartlett points out that the first Charity Organisation Society was started in London in the late 1800s. Many charities existing before the 1800s faced much criticism and little legal protection. Critics (notably the elite and the threatened European aristocracies) were concerned with the potential for fraud and misappropriation of funds that charities posed (Anonymous author, 1968: 440).



Despite these criticisms, charity organisations grew swiftly in numbers and their arrangement under umbrella organisations reveals the level of civil involvement by "ordinary" citizens in the care and welfare of the less fortunate. Many of these organisations supported causes that found international support in the globalising world of the 1900s – so much so that some of them evolved into fully-fledged social movements, such as the environmental movement. These organisations also found a role in influencing policy makers and in holding their elected leaders accountable. In this way charity organisations were a vessel for enacting democracy and therefore regarded as a part of citizenship. For example, in the "early 1800s, U.S. and European bodies such as the British and Foreign Anti-Slavery Society were driving forces behind government action on the slave trade" and eventually helped to end the gruesome practice (Simmons, 1998: 84). The influence of charities can also be seen when in 1948 the United Nations listed 41 consultative groups (mostly charities) as able to "cooperate and consult with the UN economic and Social Council" (Simmons, 1998: 83). The growth of these citizen/civil organisations is a reflection of classic liberal thinking about citizenship. As the foundation for neo-liberal thought, this perspective "tends to define civil society as a body of private actors freely pursuing their interests and goals, without interference from the state, on the one hand, and in the expectation that the state ensures the conditions necessary for the former to exercise these civil, social and political rights, on the other hand" (Vandormael, 2005: 20).

It is evident then that up until about the mid-1970s in Britain and other "Western" countries there was a social agreement that welfare was part of citizenship and that if this welfare was not or could not be provided by the state then charitable organisations should be *legally* entitled to do so. The consensus was however that the state should be the primary provider of welfare in order to foster growth and development. Additionally, there was a hegemonic belief that the best way to realise such development was through the implementation of a social democratic state. The concept of social democracy, as propositioned by the Western countries, was well received by many newly formed ex-colonial states (as of course was the socialist style of government advocated by the communist countries in the USSR). Clearly, social democracy was the characteristic feature of the Western world and its counterparts during the 1960s and 70s.



The mini collapse of the stock market in 1981 and the growing debt of many developing nations initiated a move towards more lenient state controls on the market in order to encourage the growth of capital through free trade and increased competition. In Britain, it was Margaret Thatcher who expressed her aim to reduce state control of the market in order to attempt to address the economic decline of the day. In the United States the adoption of the Washington Consensus revealed its desire for decreased state involvement on the expanding market forces. The Washington Consensus – usually considered a model set of neo-liberal policies – was a phrase coined by John Williamson in 1987. It outlined a macroeconomic framework based on a specific set of ten economic policy prescriptions. With the help of large institutions like the World Bank, the International Monetary Fund, and the U.S. Treasury Department, these ten recommended policies are considered to constitute a standard reform package promoted for crisis-stricken countries (Cypher, 1998: 47).

The main rational behind frameworks like the Washington consensus is that social growth and *development* is to be attained by economic change driven by an open market, and that it is the state's responsibility to encourage and provide the conditions for such change. Many of these ideas about economic liberalisation were imported to the newly independent African states along with large amounts of financial loans from the "developed" world. However they came with conditions that required various government-led structural adjustments that required minimal state interference in market competition and capitalist growth. The effects of structural adjustment policies on the health care system in Africa will be discussed in the next chapter.

This new thinking about development has taken on a radical ideology and is located at the core of current state welfare planning in many of the world's developed nations. But it is in fact disempowering and not empowering for citizens. It has the secondary effect of undermining the efforts of those governments, like the ANC, which have slightly more socialist mandates and want to build a welfare style state. Naturally, "development" is a complex term. In discussing development, Ferguson argues that it is politically naive to simply begin by asking if aid programs really help poor people. (Ferguson, 1990: 12). His reasoning is that when discussing development one should not resort to a focus on the development industry. A focus on individual aid programs



or on the industry distracts from an understanding of what "development" means in certain contexts. Therefore, examining projects such as building dams or water schemes may highlight how such projects have served the interests of a few yet have marginalised the already poor, but this level of examination leads only to a continued focus on the "development" industry and does little to further an understanding of the ideology behind the concept of "development".

Rather, Ferguson advises that one must examine the term "development" itself. In doing so he deconstructs "development" in a Derridan manner by uncovering the numerous meanings associated with the term. These meanings are not necessarily linguistic in nature but are rather social constructions (as all language is) that are located in historical context particular to the modern era. Thus, the social meanings of "development" are ideological and as such can have real consequences when used to justify certain actions. As Ferguson (1990: xv) points out, social scientists must ask, "what do these ideas do, what real social effects do they have?" According to him, "development" has two popular connotations. On the one hand it is used to refer to the "process of transition or transformation towards a modern, capitalist, industrial economy": a form of Modernisation Theory. On the other hand the term is used, in growing popularity from the 1970s onwards, to define the desire for a "better quality of life" or "standard of living", and refers to "the reduction or amelioration of poverty and material want" (Ferguson, 1990: 15). As he puts it, "the directionality implied" in the latter usage of the word development "is no longer historical, but moral. 'Development' is no longer a movement in history, but an activity, a social program, a war on poverty on a global scale" (Ferguson, 1990: 15 italics mine).

In combination with a neo-liberal ideology, this latter way of thinking about "development" leaves developing states with little real financial capacity to implement such projects in any meaningful manner. The gap is then filled by private business (hoping to solicit tax deductions) or well-meaning aid organisations. The outcome of this is that the state is seemingly absolved of its responsibility to *actively* contribute towards the "bettering" of people's lives. The state is consequently tasked with merely making sure that the facilities (physical infrastructure), governance structures (legal and political) and necessary mechanisms are in place to facilitate the implementation of development projects/programs by private industry and non-



governmental organisations. The enormous growth in the aid industry since the 1980s pays testament to this phenomenon.

The justification behind this thinking is that developing states do not have the capacity to improve the lives of their citizens on their own and therefore need help (framed by the word "partnership") from private industry and non-governmental organisations. The existence of these "partnerships" obscures the knowledge of who is providing what services. Citizens loose their ability to hold the responsible parties accountable simply because they are not sure who exactly is responsible. This "partnership" thus has the latent effect of leaving the citizens, especially the poor, disempowered.

In South Africa, the mounting frustration around who is to be held responsible for certain services (traditionally regarded as the state's task) can be seen in the growing number of civil protests against poor service delivery (Smidt, 2005: 15). Communities that have been left without water and electricity for years are beginning to protest and demand to know why what they have been promised has not yet been provided. But they are at a lost as to whom to direct their frustrations. Should it be towards the contracted civil engineering companies, towards the locally elected ward councillors, or towards the provincial Department' responsible for the particular service? As their petitions and requests get shuffled from one party to the next, the buck passing and lack of answers fuels the anger of disgruntled residents and protests often turn violent. Sometimes communities have managed to form lobby-style groups such as the Anti-Privatisation Forum or the Anti-Eviction Campaign, and so are able to direct their complaints to these groups. But even these groups have difficulty making their voices heard (see Smidt, 2005: 15).

Internationally the movement from a social democratic consensus in the first half of the twentieth century to a neo-liberal consensus towards the end of the century reveals a shift in the perception of how freedom, equality and justice are to be gained and maintained. In a neo-liberal paradigm, no longer are these fundamentals of citizenship to be gained from political action or from social transformation, instead they are believed to be the latent but positive outcomes of market driven, economic reforms. The underlying conclusion therefore is that citizenship rights — civil, political and



social – will only be ensured through progressive economic processes. In this neoliberal view then, "development" is achieved when the state makes conditions for capitalist growth available by opening up markets, allowing for competition and decreasing taxes. The result is lowered income for the state, increased privatisation and less social welfare for citizens. In this environment it is the poor who suffer the most because their opportunity to fairly access the free market is weaker, and their access to social support in the form of grants, pensions and so forth is also minimised.

The contemporary articulation of this development ideology is to be found in discourses of human rights. The signing of the Universal Declaration of Human Rights in the 1940s was something new for a world becoming increasingly more interconnected. For the first time in history the rights of individuals were regarded as universal norms and as a framework for social living. No longer were citizenship rights something to be sought for individuals of nation states, but now universal human rights were also desired for global populations. This rights discourse is embedded in the framework of the United Nations and in projects such as the Millennium Project. This project focuses on campaigning for the eight Millennium Development Goals (MDGs). According to the official UN Millennium Project website, the MDGs are the "world's time-bound and quantified targets for addressing extreme poverty in its many dimensions - income poverty, hunger, disease, lack of adequate shelter, and exclusion - while promoting gender equality, education, and environmental sustainability. They are also basic human rights, the rights of each person on the planet to health, education, shelter, and security" (Millennium Project, 2007).

Human rights discourse permeates much of today's development ideology, but it is important to remember that it is historically contextualised within a complex relationship between individuals and the state, and the struggle to balance power between the two. It is also framed within the context of a modern neo-liberal paradigm. Harper (2003: 16) suggests that there is an intricate interaction of global discourses and the state. He makes use of Foucault's (1997) arguments about governmentality and issues around the public health of a global "super-state" and its control, to suggest that neo-liberal thought "starts not from the existence of the state, seeing in the government the means for attaining that end it would be for itself, but



rather from society, which is in a complex relation of exteriority and interiority with respect to the state" (Foucault, 1997: 75).

By the end of the Second World War, issues of health became the concern of more than merely individual states and countries. The increasingly global interconnectedness facilitated the growth of international health organisations. As the formation of such institutions grew a consensus of ideas about health and illness developed around certain issues. Leslie Butt (2002) cautions though that a "normative consensus" of health care that is based on the limited human rights model (as is prevalent today), should be careful in defining its terms because otherwise it runs the risk of "being tied to global historical transformations and the hegemony of capital" – just as has been the roots of other movements that aimed to improve the welfare of the needy (Butt, 2002: 32).

3. The internationalisation of health

The World Health Organisation as we know it today, was not the first international health organisation. Many attempts had been made in the late 1800s and early 1900s to form a body or formalised organisation that would be concerned with international health and illness issues. Amongst others there was The Pan American Sanitary Board (now known as PAHO - Pan American Health Organisation), founded in 1903. Before the formation of the WHO as we know it today, the International Office of Public Health created in 1909, was probably the closest successful institution of its kind. At the suggestions of the League of Nations, it was later amalgamated into the Health Organisation, which was established in 1920 (Amrith, 2001: 6 and Allen, 1950: 28). The International Office of Public Health served initially only as a platform where member nations could exchange information about the presence and spread of disease. Most disease control strategies at the time involved quarantine procedures but this became increasingly difficult to maintain in a world where nations were more and more inter-dependent on one another and upon open borders. Later the functional responsibilities of the International Office of Public Health increased as it became a useful medium for formulating recommendations in health policies and for the study of many health factors, but essentially it still had little authority, and little financial or political clout (Allen, 1950: 29).



Despite this, by the end of the 1920s, the League's Health Organisation and the International Office of Public Health were able to persuade and influence governments concerning matters of public health and policy formation. The Health Organisation developed a permanent and effective epidemiological intelligence system that covered a large portion of the world's populations and finally it "pioneered the application of preventive health measures to such related matters as nutrition, housing and even health insurance" (Allen, 1950: 29). The authority of this organisation to recommend policy and public health procedures was often questioned though. Allen gives the examples of how in 1933 Britain criticised the Health Organisation's studies on the most suitable methods for safeguarding public health in particular countries during the depression because British representatives considered such matters to be the responsibility of each nation alone. Japan complained that the League's health assistance to China after 1937 exceeded the proper jurisdiction of that organisation (Allen, 1950: 30). The disagreement about the authority and responsibilities of the Health Organisation continued for almost a decade. It is also worthy to note that for the most part it was European and North American countries that were involved in the activities of the League's Health Organisation.

It was only in post-war 1946 that, culminating from the first International Health Conference, the WHO was established under the directorship of Dr. B Chrisholm (WHO, 2007c). This was the first conference to be called by the United Nations and the WHO was the first specialised agency of the United Nations to which every member of the United Nations subscribed (Shimkin, 1946). Its constitution came into force a few years later on the 7th April 1948 – a date we now celebrate every year as World Health Day. Within the framework of expanding trade relations, international health collaboration became necessary as the volume, range and speed of trade and travel increased (Allen, 1950: 27). Amrith therefore suggests that "the establishment of the World Health Organization after the Second World War was part of a much wider internationalisation of responsibility for security and welfare, and a period of energetic institution-building, giving birth to the Bretton Woods Institutions" – the International Bank for Reconstruction and Development, and the International Monetary Fund (Amrith, 2001: 6).

The WHO now also incorporated countries from Asia, South America and Africa into



its structures. The WHO was partitioned into 6 regional offices, each with a large degree of autonomy (Amrith, 2001: 6)⁶. This partitioning allowed for the incorporation of existing health organisations, such as the Pan American Health Organisation, into the structure of the newly formed WHO. As mentioned previously, the WHO's objective, since its inception, is "the attainment by all peoples of the highest possible level of health" (WHO, 2007d). The WHO redefined the concept of health to entail "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). The final wording of this definition of health was formalised by Dr. Harry Gear of South Africa and assumes that health is the right of all people and that it entails addressing both the biological as well as the social aspects of disease. From the wording of the Constitution it is clear that the WHO regarded the provisioning of the conditions conducive to health to be the responsibility of the state. The Constitution was constructed during a time when a social democratic consensus of welfare was forming and therefore its wording suggests the state take responsibility for the well being of its citizens by not only providing health care, but also by ensuring that issues such as poverty, unemployment or discrimination for instance, are addressed. For example, the pre-amble of the Constitution states:

Parties to this Constitution declare, in conformity with the Charter of the United Nations, that the following principles are basic to the happiness, harmonious relations and security of all peoples:

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
- The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

⁶ The regional offices include: South-east Asia (SEARO); Western Pacific (WPRO); Africa (AFRO); Europe (EURO); the Americas (PASO/PAHO), and the Eastern Mediterranean (EMRO) (Amrith, 2001: 6).



- The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest cooperation of individuals and *States*.
- The achievement of any State in the promotion and protection of health is of value to all.
- Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.
- Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.
 - The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.
 - Informed opinion and active cooperation on the part of the public are of the utmost importance in the improvement of the health of the people.
 - Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures (WHO, 1946 italics mine)

The parts emphasised in italics reflect the assumption on the part of the WHO that states should provide health care directly and not encourage the private sector to do so. These also explicitly highlight that the state is required to make the conditions of health and well being possible by providing both technological interventions to combat disease, and social interventions, such as poverty alleviation and sanitary infrastructure.

The WHO initially focused its efforts on epidemic diseases (usually infectious), nutrition and maternal and infant health. It approached the control of infectious diseases by implementing strategies that usually entailed the formulation of vertical controls. These addressed a particular disease and revolved around the use of technological and scientific advances of disease control. They focused very little on community health or overall wellbeing – going against much of what was stated in the



WHO Constitution – and rather took a curative approach. For these specific diseases, preventative measures entailed primarily mass vaccination campaigns without addressing behavioural issues or social inequalities such as poverty or political upheaval. Vertical control programmes were rationalised within a context of "development" (Amrith, 2001: 9).

From the 1950s onwards the term "development" in WHO documents usually referred to the "third world" or developing countries and implied that a move towards a desired modernised, developed state would be required if health for all was to be achieved (Amrith, 2001: 9). The prevailing discourse of the WHO at the time was therefore that poverty was the cause of ill health and disease and that the best method of eliminating poverty would be through socio-economic reforms. These discourses are therefore not unrelated to broader ideologies of development that were prevalent in the United Nation at the time. However, as can be seen there was a growing reliance on the use of technological methods of disease elimination and an increasing dependence on biomedical interventions.

By the late 1960s there was a crisis of vertical control programs for infectious diseases, due to the failure of the global eradication of Malaria (Garrett, 1994). Alternative methods were sought. New studies of community health and integrated strategies were conducted in many developing areas and hospital based care for primary illness was questioned (Cueto, 2007). The WHO was having difficulties promoting successful vertical control programs in countries where the health systems were in their embryonic phases (Litsios, ⁷ 2007: 2). In Africa, colonisation did little to promote public health as a central theme. For the most part, during the colonial era, primary health care was non-existent. Most health initiatives focused on immunisation campaigns to control epidemic diseases, or aimed to "civilise" the perceived uncontrolled sexuality of the African native. Medical interventions were also usually based in urban areas, with a focus on the city slum locations, leaving the rural areas devoid of large scale or effective health systems (Musisi, 2007). Merely transplanting

⁷ Socrates Litsios headed up the team that presented the concept of Primary Health Care to the WHO governing bodies in January 1975 in a paper entitled "Promotion of National Health Services." Culminating from this he was made Programme Area Leader of the new unit of Primary Health Care in the Division of Strengthening of Health Services, under the directorship of Dr Kenneth Newell.



European hospital-based health care systems into the newly developing African states proved ineffective, and so while Europe was experiencing a decline in disease and mortality, in developing nations diseases were rampant, and diseases control ineffective.

At the same time many Christian mission organisations working in the developing nations, such as the Lutheran Christian Medical Council and the Society of the Red Cross, had experienced success in providing basic health care at the local level. They did so by making use of community members trained as health workers to supply basic health care (Cueto, 2007). These "community-level" health care initiatives presented alternatives to vertical control methods and also fitted well with the growing belief that a basic standard of health was necessary. Primary health care therefore became a central theme within the WHO, advocated by the then Director General of the WHO, Dr. Halfdan Mahler – in position for 15 years from 1973-1988 (WHO, 2007e). His background lay in an interest of tuberculosis in Ecuador and India. Dr. Mahler was an extremely charismatic leader who provided continuity of leadership and ideas to the WHO – something the organisation had been criticised for (Cueto, 2007). In the words of Dr. Mahler "without health, life has little quality, for even if health is not everything, without it, the rest is nothing" (quoted in Rafei, 1997).

The year 1978 saw the first International Conference on Primary Health Care in Alma-Ata. This was a watershed event attended by representatives from 134 governments numerous academics and members from 67 international organisations (WHO, 1978). For the first time the USSR also embraced a commitment to move towards a primary health care approach. There was a sense that health could be achieved through international cooperation of nations. Amrith suggests that the Alma-Ata Conference with its slogan *Health for all by the year 2000* reveals a significant paradigm shift that "occurred in the early 1970s, under the directorship of Dr Halfdan Mahler, towards a more broadly-based strategy of cheap, equitably distributed, low-technology health care" (Amrith, 2001: 13).

The slogan *Health for All* was based on the philosophy of social equity and justice and on the principle that resources and services should be distributed in a way that



minimises inequities and pursues "health as an integral component of social and economic development" (Rafei, 1997). Three main ideas about primary health care emanated from this conference (WHO, 1978). Firstly the negative role of "disease technology" was identified. The aim was to address this using appropriate technology that is scientifically sound and culturally acceptable. The second idea identified was a criticism against Elitism. Instead of medical overspecialisation and top-down health campaigns, community participation was encouraged. Thirdly, a development approach was sought, whereby primary health care would be the centre of the public health system. This included a partnership approach to dealing with issues of health and disease, so as to create a social and political context for development (Cueto, 2007).

The primary health care approach suggested alternatives to vertical control programmes and to the ideology, which recommended that copying and implementing strategies and policies that had worked well in the "first-world" nations could achieve the development of under-developed nations. As such the concept of primary health care departed from the provider-receiver approach of the basic health services (Rafei, 1997). It was intended to be a people-focused approach based on flexible organisation and provision of health care in a way that is known to yield maximum gains in health for the particular setting. Health, in this outlook was pursued as an integral component of socioeconomic development.

But the primary health care approach took a general downward turn by the end of the 1980s due to adverse economic and political factors on a global level. Primary health care was criticised for being too holistic, too general and for not being a realistic tool for addressing the major diseases in developing countries in a cost-effective manner. It was suggested instead that a more "selective primary health care (SPHC) was introduced. The term meant a package of low-cost technical interventions to tackle the main disease problems of poor countries" (Cueto, 2004: 9). Although the primary health care model had been revolutionary for international health, as an idea it became an icon of top-down "developmentalism" and Western imperialism and therefore lacked the support of many developing countries – especially those in Latin America. As such there was a lack of real commitment at policy and legislative level. In principle many countries agreed to the fundamentals of primary health care but did



little to practically implement them.

Studies on primary health care development even revealed serious weaknesses in the strategy and large discrepancies between government commitment and real effective implementation amongst the European nations. This can be seen in a WHO report of the achievements of primary health care in European countries "ten years after the Alma-Ata" declaration was signed (Ramic, 1989: 30). This document states: "Inequalities in socioeconomic conditions, in health status of the population and in levels of health care are considerably high among European countries" and that the "understanding of primary health care is different not only in practice but also according to national documents" (Ramic, 1989: 30). In 1984, WHO European member states had set twelve health targets to achieve the goal of Health for All. These targets were to be reached primarily by implementing a primary health care approach. The first two targets aimed to bring equity in health, improved quality of life and overall better health to the people of Europe (WHO, 1993). According to Ramic (1989: 30) each country produced enough evidence to prove that "ten years after Alma-Ata" the first two of these targets were still far from being reached. As such, this marked the end of the emphasis by the WHO on primary health care.

In 1988 Japanese physician Dr. Hiroshi Nakajima was elected as the new Director General (WHO, 2007e). By this stage HIV and AIDS became the new focus for the WHO. Although ideas about primary health care did not disappear, they were certainly no longer at the forefront of WHO discourses. Rather more immediate concerns presented by the Human Immunodeficiency Virus were looming large in the picture and *Health for All* was relegated to the status of a utopian dream, unattainable in the foreseeable future. The major challenge for the WHO during the twentieth century was how to combat ill health in developing countries, in light of HIV and AIDS.

Cueto suggests that by looking at WHO policies, two assumptions regarding international health in the twentieth century can be made: "First, a recognition that diseases in less developed nations are socially and economically-sustained and need a political response. Secondly, an assumption that the main diseases in poor countries were a natural reality that needed adequate technological solutions" (Cueto, 2004:



14). For Cueto these two assumptions occurred contiguously and imply that poverty and ill health were often regarded as going hand in hand and that both issues should be addressed through technological solutions, driven by political processes. For example, tuberculosis control in Africa in the era of HIV and AIDS is considered to be curable only if government sanctioned medical interventions can be made. There is a discourse which ignores the historical colonial importation of tuberculosis to the African continent and suggests that the disease is only curable using bio-medically driven strategies. This approach implies a technological style "solution" to the "problem" whilst ignoring the fact that tuberculosis in Africa – especially in South Africa – is historically not equally spread across the population. As such standardised/universal mechanisms of disease control may not necessarily be the best solution, as not all people are standardised or universally the same.

During the 1980s and early 1990s many developed countries had successfully combated most infectious diseases and instead chronic diseases, such as cancer, heart diseases, high blood pressure or high cholesterol, and diabetes became their concern. Other issues such as drug and alcohol abuse and smoking became serious concerns for the Western world. However, as the global movement of people increased and the Internet advanced the flow of information, knowledge of and concern for diseases of the poor began to spread. In fact, the large scale migration that marks this era reintroduced diseases such as tuberculosis back to epidemic proportions in certain parts of the developed world. For example, in 1990 New York City saw a dramatic increase in reported cases of tuberculosis. The disease was most prevalent amongst the poorer immigrant populations of the inner city slums. Ryan (1993: 390) reveals that in New York, the reported new cases of tuberculosis jumped from as low as 4% increase per year to a staggering 9.4% increase between the years 1990 and 1991.

In the United Kingdom, tuberculosis showed a similar dramatic increase after 1992, and elsewhere in the developing nations infectious diseases were also showing signs of upward trends. Rightly so, the association between the increase of certain infectious diseases could be correlated with conditions of deprived inner city poverty that often geographically marked such outbreaks, and for the early part of these new outbreaks this was the accepted theory (Ryan, 1993: 390).



After the WHO convened a special meeting in October of 1990, it was established that in the previous five years tuberculosis had presented a veritable explosion in Sub-Saharan Africa and it was estimated that "tuberculosis caused 2.9 million deaths in 1990, making this diseases the largest cause of death from a single pathogen in the world" (quoted in Ryan, 1993: 396). The growth of resistant strains of tuberculosis also presented a major concern for the WHO. But after much speculation doctors within the WHO finally arrived at the shocking realisation that although issues such as poverty, homelessness and social deprivation certainly spurred on the increase of tuberculosis, the "most important trigger for this new global threat was now obvious: it was the AIDS virus" (Ryan, 1993: 397). This realisation marked an important shift in WHO discourses regarding infectious diseases. In a very subtle way the epidemiology of certain diseases were re-cast to become directly associated with AIDS. No longer did the WHO primarily associate, for example, tuberculosis with poverty and social deprivation; instead it now became associated foremost with AIDS and then secondarily with poverty. This issue will be discussed in greater detail in chapter six.

The emergence of HIV and AIDS did not only have negative influence. The enormity of its impact most certainly generated a shared, global, public interest in health and illness issues unlike the world has ever witnessed before. In part this global awareness and interest of the macro influences in the spread of disease has been facilitated by the development of information technology such as cellular phones, wireless satellite communication and the Internet. Partly in response to this growing interest the WHO launched The World Health Report in 1995. This was intended to be the first in a new series of annual health surveys. As Kickbusch states: "Unlike any previous report in content or style, it goes far beyond the conventional boundaries of health reports, and takes up in the strongest terms issues such as poverty, inequality, marginalisation, sex discrimination, and gross inequities on health and health care" (Kickbusch, 1995: 1518). In this period the WHO fervently promoted the cause of the marginalised populations of the world (migrants, females, the poor) and placed significant emphasis on addressing issues of poverty.

Cueto's (2004: 14) suggestion that WHO policies in the twentieth century recognised disease as socially and economically-sustained is therefore supported. Simply put,



many diseases like tuberculosis were linked to issues of poverty. Such a correlation was not only discursive but also translated into policy. Despite this, by the end of the twentieth century, some diseases were being associated more with HIV and AIDS than with poverty and issues of economic or social depravation. What is clear then is that issues of poverty had began to be shifted to the margins of health discourse. This can be regarded as the *first* of three significant shifts that have occurred within the WHO during the transition to the new millennium.

The *second* shift has to do with the organisation's authority on a global scale. By the mid 1990s the WHO had developed into a formidable and reputable institution whose influence extended beyond that of a research and awareness organisation, or a body that merely provided a platform for international debate on health and illness issues. It now became the foremost authority on disease control and could persuade influential proportions of the world's governments to conform their policies to meet certain public health standards set by the institution itself. This is evident in the language used to describe its publications. For example the WHO website declares that the main purpose of the World Health Report is to "give countries, donor agencies, international organizations and others the information they need to help them make policy and funding decisions" (WHO, 2007d italics mine).

When Dr. Gro Harlem Brundthand succeeded Nakajima as Director General in May of 1998 the WHO influence over policy decisions at country level could be strongly felt (WHO, 2007e). For example, Under Dr. Brundthand's directorship two major initiatives were made WHO priorities. One was the DOTS campaign to control the spread of tuberculosis and the other was the formal launching of the Framework Convention on Tobacco Control. Tobacco is the world's second biggest killer and encouraging countries to sign a framework for tobacco control became a major priority of the WHO at this time (WHO, 2007f). Dr. Brundthand also spearheaded a focus on violence as an important public health issue, but her most significant contribution to the WHO, as director, came with the establishment of the Commission on Macroeconomics and Health, chaired by Jeffery Sachs (then director of the Centre for International Development at Harvard University). "The Commission on Macroeconomics and Health (CMH), was made up of 18 of the world's leading economists, public health experts, development professionals and policy-makers"



(WHO, 2007g).

The CMH was designed with the objective of analysing the impact of health on development – over a two year period – and then of "producing a set of measures designed to maximise the poverty reduction and economic development benefits of health sector investment" (Arhin-Tenkorang, 2001). According to the Commission on Macroeconomics and Health (WHO, 2007g) its chief task was to act as a "source of advice and analyses for WHO and the broader development community on how health relates to macroeconomic and development issues". Its aim was to help disseminate key aspects of WHO policy to the Finance and other Ministers throughout the world (WHO, 2007g). The mission of the CMH presents a good example of how WHO policies began to frame health and illness alongside economic ones. This constitutes the third shift within the WHO during the end of the previous century. From 2000 onward the WHO assumed as part of its responsibility the need to address issues of illness in relation to market economic forces. This ideology, it's argued here, is tied to a broader development ideology, which sees the alleviation of poverty and inequality as resulting from economic structural adjustments first, and socio-political ones second – in essence a neo-liberal approach to development.

Standing (2002: 22) however, suggests that despite the growth of neo-liberal policies, from the late 1990s till the present day there has also arisen a more "sober assessment of developmental failures" and of neo-liberal policies. She argues that the issue of poverty has re-emerged as a concern for G-8 countries and that once again health is a topic in international aid agendas. In her view, the WHO Commission on Macroeconomics and Health, set up in 2001, is a positive move towards addressing the realities of developing nations. Standing points out that debates about poverty have shifted "from using a predominantly income-focused concept towards concepts of poverty which focus on risk, vulnerability and exclusion" (Standing, 2002: 24). As a result she feels that ill health is once again regarded as both an outcome and a cause of poverty. On her later point this study disagrees somewhat. Although, poverty as a cause and effect of illness has never really left WHO discourse, it has certainly been relocated to the periphery. In its place solutions to global problems of health are to be found by implementing cost-effective, focused, well-managed programs designed around the benefits of the biomedical paradigm. This elucidates a growing focus and



reliance on technological solutions to humanities problems – a sense that all negative producing factors, such as disease, can be controlled using external forces, such as medication.

At the Fifty-eighth World Health Assembly in 2005, resolution 58.33 on "sustainable health financing, universal coverage and social health insurance" was adopted (WHO, 2005a). In this resolution, WHO member states were urged, "to ensure that health financing systems include prepayment and risk sharing mechanisms, to avoid catastrophic health-care expenditure, and to work towards universal coverage. Following this mandate, WHO provides technical support, information and tools as well as capacity strengthening for the development of health-financing systems" (WHO, 2005a). Therefore the WHO now provides governments not only with advice on how to control diseases and promote health but also on How much countries should spend on health and on The establishment and use of dedicated taxes for health⁸ in order to combat those diseases. Such a significant new responsibility, shouldered by the WHO, reveals that essentially it views poverty (and its associated ill health) as best being eradicated by implementing economic reforms. At the same time these reforms should be the responsibility of governments. The organisation as such encourages governments to adopt principles that are aligned with WHO policies, which are considered as "best practice" - not only in health care but also in governance.

A primary example can be seen in this study's focus on tuberculosis control in South Africa. South Africa is able to access cheap drugs used in tuberculosis treatment as long as it adopts the WHO policy on primary health care and DOTS. This South Africa has done in the 1990s with full commitment and support from the ANC led government. In doing so it has adhered to the internationally accepted "best practice" for tuberculosis control. The latent implication is that now the country should see an improvement in tuberculosis control – as will be discussed in chapters five and six, this has not been the case. In the meantime the following chapter moves from the

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⁸ These are the titles of two documents found on the WHO Health Financing website, written by William Savedoff (Discussion paper 2/03) and by Addy Carol (for the WHO Regional Office for the Western Pacific, Manila, 2004) respectively. Available at http://www.who.int/health_financing/functions/en/ Accessed, 2 July 2007



above discussion on the internationalization of health and the formation of the WHO, to a look at health care on the African continent. Chapter four therefore examines the negative effects of structural adjustment policies on the budding health systems of Africa. This sets a context – historically, economically and politically – within which to further discuss tuberculosis discourses in South Africa.



CHAPTER FOUR

Health care and democracy in post-independence Africa

"Healing is a matter of time, but sometimes it is also a matter of opportunity"

Hippocrates

1. Introduction

From the 1960s – when many African countries gained independence – until the 1980s, the newly formed African governments often actively promoted health care in a similar vein as that of the social democratic states in Western Europe. When examining how health care systems in Africa have changed over the second half of the twentieth century it becomes evident that many African countries were initially influenced by the strong post-Second World War social welfare consensus that encouraged complete state provisioning for health care. However, towards the end of the century the efforts of many countries – such as Zimbabwe, Tanzania, and Botswana for example – in building successful health care systems, were undermined by growing neo-liberal structural adjustment policies that forced their governments to cut state spending for health care. This chapter reveals how many African countries have ended up following the trend of the Western world, whereby provisioning for health care is no longer a core function of the state, but rather becomes a peripheral obligation caught up in tension between the need for economic growth and ideas of basic human rights.

At the risk of sounding overly cynical though, health care for the newly forming African states was often secondary to the political issues of the day and often providing health care – or seeming to do so – was a good political strategy. In Kenya for example, its first decade of independence saw rapid economic growth, averaging just below 6% a year (Amrith, 2001: 5). The Kenya African National Union made free basic medical services one of the platforms of their campaign in the 1963 election, and proceeded to introduce free outpatient treatment in 1965. According to Amrith:

President Kenyatta spearheaded the construction of numerous rural health centres and training hospitals". But by 1970 Kenya's public



health services began to be "undermined by a lack of resources and the unsustainable demand for medical care generated by the highest rate of population growth known to history. A recent study has shown that by the late 1970s, Kenyatta National Hospital had no ambulances, and minimal access to running water; in 1980, the operating theatre closed for a week because of a complete lack of supplies. The impact of this deterioration can be seen in the slowdown in the decline of under-five mortality after 1980. The situation was exacerbated in the 1980s by economic stagnation, cuts in public spending and state authoritarianism under Daniel Arap Moi" (Amrith, 2001: 5).

When the WHO promoted the primary health care approach (discussed in the previous chapter) it was quickly adopted by some of the new African states. This can be seen in the example of Tanzania's 1967 *Arusha* Socialist Declaration, which called for an equitable distribution of health services aimed at providing equal and free access to health (Musisi, 2007 and Kopoka, 2000: 5). Primary health care in Tanzania was regarded as part of an overall process of social development, emphasising *ujamaa-collectivised* villages. In Tanzania, by 1980 76% of the total population had access to health services – defined as within one-hour access by public transport (UNICEF, 1990).

Some African countries often took a Keynesian approach to development, which was prevalent from about the 1950s-1980s. Development in this light was regarded as the responsibility of the state towards its citizens and involved rational state planning. Consequently the state is considered to be the driving force behind development and growth. However the state also had to allow for the growth of social capital and not just financial capital. This method for example, made nutritional programs part of the health care approach (Matshalaga, 2000). The results in the health care sector were so effective in countries like Botswana and Zimbabwe that basic health indicators, such as under-five child mortality and general life expectancy at birth, show significantly positive improvements from the 1970 until the early 1990s (United Nations, 1992: 25).

For example in Botswana, the figures for 1991 show an average life expectancy of 67



years at birth, an increase from the 1981 figures by eight years. However, by 2005 the average life expectancy for males and females was reduced to 42 and 41 years respectively (WHO, 2007h). The under-five child mortality in Botswana "fell from about 180 per thousand around 1976 to 30 per thousand around 1990 – an incredible fall of, on average, 10 per thousand (absolute) per year" (Noymer, 1998: 8). But by 2000 this had again increased to 100 child deaths (under five years of age) per thousand of the population (WHO, 2007h). Under-five mortality rates in Tanzania show a similar downward trend during the 1970s and 1980s (UNICEF, 2007). Figure 4 is a map revealing the dramatic improvement in child mortality in countries across the world, from 1960 to 1990 (World Bank, 1993: 22). Note the significant improvement in Botswana, Zimbabwe and Tanzania. The state's emphasis on health care in these countries clearly had a positive influence on the wellbeing and overall health of their people.

Primary health care in Africa was especially marked by the training and mobilisation of auxiliary health care providers called *Village Health Workers* (sometimes known as Community Health Workers) (Musisi, 2007). Several countries instituted programs that utilized the services of these Village Health Workers: Ghana began in 1969, Botswana in 1969 and Lesotho, Benin and Zimbabwe in 1978 (Musisi, 2007). Due to the growing influence of the WHO and a coinciding growth of newly independent African states, there was a general tendency in Africa to incorporate a "horizontal style" approach to treating certain diseases. This included using local systems and authorities, volunteers and medical interventions such as mass immunization campaigns alongside nutrition programmes (Musisi, 2007).

But the 1980s saw a time of economic crisis in low-income countries. A decline in commodity prices and collapsing fiscal regimes took their toll on public investment and expenditure (Standing, 2002: 20). This had severe effects on the public health care services and the public health facilities soon fell into chronic disrepair, especially in sub-Saharan Africa (Standing, 2002: 20). The previously growing public health services deteriorated and there was a rush towards the private sector by those who could afford it. For those too impoverished to do so, health care was simply a luxury that could no longer be afforded and alternative sources of health care were sought (such as traditional healers or self-medication).



1960 Under-five mortality rate Less than 25 175 or more 125-174 75-124 50-74 1990

Figure 4. Child mortality by country, 1960 and 1990

Source: World Development Report. (World Bank, 1993: 22).



2. Structural adjustment policies and health care in Africa

As the debt of developing countries increased, they approached institutions like the World Bank and the International Monetary Fund (IMF) for more loans. These loans were provided on condition that certain standard economic reform strategies were implemented (Crisp and Kelly, 1999: 534). These structural adjustment policies, as they were called, began to be implemented in some countries nearing the end of the 1980s but mostly took place in Africa in the early 1990s. In 1991 Zimbabwe was one country that implemented these policies as a result of it acquiring loans from the IMF and the World Bank. The strategic changes included a reduction in the "budget deficit through a combination of cuts in public enterprise deficits and rationalisation of public decontrol, and regulation of foreign trade, investment and production; phased removal of subsidies; devaluation of the local currency; and enforcement/introduction of cost recovery in the health and education" (Bijlmakers, Bassett and Sanders, 1996: 11). Structural adjustment policies forced the Zimbabwean government to cut back on spending for health care or to implement cost-recovery procedures. In 1993 the government abolished all fees at rural health centres in order to alleviate the effects of a severe drought, but by the end of 1994 it surprisingly reversed its policy and began implementing huge charges for all health services (Bijlmakers et al., 1996: 15).

In order to offset the negative effects of structural adjustment policies on certain populations groups – especially those already marginalised or in dire poverty – some countries attempted to create some form of social security net that maximised benefits for disadvantaged groups, but at minimal cost to the state. The rationale behind this was no different to that seen in post-World War Two Europe, when a strong social welfare consensus was popular. As discussed in chapter three, this welfare approach was considered by all to be a core responsibility of the state. Zimbabwe created the Social Development Fund, intending to provide a safety net to protect the vulnerable. But from the start the scheme was grossly under funded and in 1994 it is reported that only 1.5 million Zimbabwean Dollars were spent on assistance for health fees (Bijlmakers et al., 1996: 17). Instead Bijlmakers et al. found that most of the burden resulting from changing policies, was placed upon the individuals themselves. Thus, individuals now had to find new and diverse ways of supplementing a diminished household income. They often put off visiting a doctor, they self-medicated/treated, or they pooled money together to visit private practitioners. Interestingly the



underreporting of diseases can be seen mostly amongst children. Bijlmakers et al. (1996) suggest that this is not the result of decreased level of disease amongst children but rather indicates that it is the weakest who are often the most negatively affected by economically conservative policy changes in health care.

Structural adjustment policies are often regarded as neo-liberal attempts to maintain the current Western hegemony and global dominance because they promote financial and trade liberalisation, and state deregulation of the market (Crisp and Kelly, 1999). In Sengupta's (2003) opinion, the tension between the premises of public health and neo-liberal economic theory is that the former posits that public health is *public* good. This means that public health "benefits cannot be individually appropriated or computed, but have to be seen in the context of benefits that accrue to the public. Thus public health outcomes are shared, and their accumulation leads to better living conditions" (Sengupta, 2003: 63). On the other hand neo-liberal policies view health as a *private* good that is accessed by the medium of the market (Sengupta, 2003: 64). Both these assumptions are based on the idea that health can be measured and can therefore represent the well being of either the group or the individual. But measuring health is complex, for two reasons.

Firstly: Measuring health usually entails the stipulation of certain health indicators by which to compare findings. It is easier however, to quantify the number of people infected with active tuberculosis, for example, than it is to calculate how many people are "healthy" – because health is not as easily defined, observed or perceived. In reality what is most easily quantified is disease, not health (Bijlmakers et al., 1996: 18). In other words, measuring the general quality of health for a population is a difficult task and more likely to be completed using qualitative techniques rather than statistical methods or formulae. Qualitative data unfortunately tend to be less valued in policy-making circles than quantitative data.

Secondly: Studies that examine health outcomes, i.e. gains made in the progress towards health improvements, often focus on the growth of GNP/GDP and health spending. This is the more common approach when dealing with the effects of structural adjustment programs on health. In general, because structural adjustment policies involve the reduction of the public sector and a devaluation of the local



currency – leading to higher prices for imported essentials – this often increases the proportion of unemployed while at the same time increasing the cost of basic living (Riddell, 1992: 57). As such, these policies are often blamed for exacerbating poverty and inequality. Poverty and poor health often go hand in hand. According to the World Bank, most studies of the effects of structural adjustment programs on health "have found that central government expenditure on health in countries with adjustment lending programs [implemented in the 1980s] did not suffer more than elsewhere" (World Bank, 1993: 46). But the Bank admits that this result "is not definitive because state and local governments are often responsible for a substantial share of public spending on health" (World Bank, 1993: 46).

Bijlmakers et al. argue that the effects of structural adjustment policies on health care and the correlation between health and GDP per capita are rather complex (Bijlmakers et al., 1996: 17). In general, economic growth leads to improved health and nutritional status but there is little evidence to assume that the reverse is true. This is because increased GNP does not reflect the increase in inequality nor does it reflect the distribution of wealth in a country. Income is probably the most important extrinsic factor that can increase an individual's level of health (Bijlmakers et al., 1996: 17). Reflecting this complexity, the World Development Report (World Bank, 1993) highlights positive data revealing that between 1985–1990 health spending increased somewhat in countries with adjustment programs but as it concludes that "unfortunately, the data are not good enough to allow any judgment on whether adjustment programs directly helped to ensure that public spending on health was efficient (World Bank, 1993: 47). Therefore as Crisp and Kelly suggest, no clear correlation between structural adjustment policies in Africa and increased levels of poverty can be made because evidence linking the two is "sketchy and unreliable" (Crisp and Kelly, 1999: 543).

Understanding therefore that measuring health (of a social group) is a complex task and that the relationship between economic growth and health status is difficult to assess makes it easier to explain why it is not simply a matter of arguing that increased GNP will lead to better health for all. As can be seen in many African and Latin American countries, despite a growth in GNP, due to new structural adjustment programmes, there is a negative increase in the income difference between the rich



and the poor (Sachs, 2006). Worldwide, but especially in African and Latin America, the gini-coefficient has not really been reduced, and economic inequality is worsening. This is reflected in a rise of diseases typically associated with poverty – such as tuberculosis (Farmer, 2003 and Garrett, 1994).

At the same time it is also tricky to assume that there is a *simple* causal relationship between the economic structural adjustment policies set in place and the worsening health situation of many of the developing countries mentioned here. Other factors such as HIV and AIDS, environmental degradation, ecological disasters (drought or flooding) and volatile political situations have also taxed the resources of these countries and hindered the success of health reforms (Bijlmakers et al., 1996: 20). Yet despite the difficulty of measuring the effects of structural adjustment programs on health, the World Development Report concedes that "cuts in government spending are usually central to an adjustment program" and that therefore "health spending is likely to be reduced" (World Bank, 1993: 45). It takes cognisance of the fact that in many countries these cuts were "indiscriminate and failed to preserve those elements of the health system with the strongest long-term benefits for health" (World Bank, 1993: 45).

One of the ways in which structural adjustment programs undermined elements in newly democratised African health care systems, was that it undercut the role of the state in the provision of health care. As adjustment strategies forced welfare services to became peripheral, and as African governments adopted market-centred forms of governance, this left sections of health care provisioning open to the private sector – both for profit and not-for profit – in what is termed "partnerships" with the state. The overburdened states gladly welcomed the role of civil society in sharing its health provisioning responsibility. This is an important issue, one which will be elaborated upon in chapter six.

Although South Africa did not implement structural adjustment programs, as conditions of World Bank or IMF grants, it did implement neo-liberal economic policies in the 1990s that mirrored some of the changes these other African countries had undergone in the 1980s. But the new democratic state of South Africa came about at a time when neo-liberalism was already hegemonic. It is within this dominating



framework that the ANC has attempted to build a health care system that models aspects of the social democratic welfare approach. The ideologies underpinning neoliberal and welfarism are juxtaposed and this is reflected in the South African health care context.

3. South African heath care at a time of transition

The early health and welfare system in South Africa was marked by inherent contradictions and was designed around racial and economic privilege. It was developed in the late 19th century to address the poverty and poor health of whites (van Niekerk, 2003b: 363). "Welfare" was a term used exclusively for the white population and the health care system was designed to meet the needs particularly of mining capital by sustaining a cheap and healthy indigenous African labour force. In 1942 the Gluckmann Commission was established to report on the health provisioning by the state and to advise for possible change. At that time, health services were becoming racially and geographically fragmented and "government health services were carried out by four provincial administrations, which absorbed the bulk of state health spending mainly to support academic hospitals" (van Niekerk, 2003b: 364). Patients were also expected to pay for services and although a proliferation of private medical schemes existed, they were accessible only to whites in stable employment and able to afford medical insurance premiums (van Niekerk, 2003b: 363).

Sidney and Emily Kark and their colleagues at the Pholela Health Center in the then Natal Province are well known for their pre-1948 community-orientated primary care approach (Tollman and Pick, 2002: 1725). "Community-orientated primary care is a continuous process by which primary care is provided to a defined community on the basis of its assessed health needs through the planned integration of public health practice with the delivery of primary care services" (Mullan and Epstein, 2002: 1748). This approach recognised the Gluckman Commission's vision of a national health service based on a network of health centres providing community level health care for all (Kark and Cassel, 2002: 1743). The Kark's work spearheaded the formation of the Institute for Family and Community Health during the late 1940s at Natal University. This Institute became key to "providing the training and research necessary to support the rapid growth in health centres being planned" (Tollman and



Pick, 2002: 1725). Despite these efforts by certain individuals and groups to develop a workable system of community-orientated primary health care in the country their work was severely undermined by the strength of the apartheid state.

The National Party government implemented a health care system that consisted of fourteen separate departments, established to look after the health of the different racial groups. "Administration of health care was fragmented, with four homelands, and six 'self governing' territories" (Yach and Kistnasamy, 2007: 4). The Department of Health and Population Development's overall objectives were to spread knowledge of health services, to promote the concept of healthy living, to stimulate personal awareness of good health and to generate active community involvement in health matters (Küstner, 1979: 2).

According to Yach and Kistnasamy, different health care programmes were vertically fragmented through "service differentiation (preventive and curative services) amongst the federal government, the provinces and local authorities" (Yach and Kistnasamy, 2007: 4). Expenditure on tertiary health services (hospital level) was prioritised above those of primary health care services. In 1978 the National Welfare Council was formed to provide service delivery and social welfare grants to the needy population but in reality their distribution to non-white population groups was usually poor, if not non-existent (van Niekerk, 2003b: 366). South African health care policies were so unjust towards those living in the country that a resolution adopted by the seventeenth World Health Assembly in 1964 considered apartheid to have failed to "adhere to the humanitarian principles governing the WHO". As a result, South Africa officially lost its voting privileges within the WHO (United Nations, 1994).

By the mid 1970s the National Party government was struggling financially – due to global economic insecurities – and in order to minimise welfare expenditure it implemented the "last resort" strategy, whereby those seeking welfare grants or welfare services were required to prove that they had first exhausted all other means of finding provision (such as charitable organisations and family aid) (van Niekerk, 2003b: 366). The state dramatically decreased its financial responsibility towards the country's social welfare services and the privatisation of health care was promoted.



This had little effect on the wealthier white population, 80 percent of whom, by this time "had access to private medical care and thus no need to use or invest in the public health care system on which nearly all Africans and most Coloureds and Indians depended" (van Niekerk, 2003b: 366).

After the Alma Ata conference of 1978 the South African government agreed to adopt some of the primary health care recommendations but the few changes implemented did little to reallocate health resources and had a miniscule effect on the health of the majority of people in the country (Marks and Andersson, 1987: 178). In fact, in 1979 the WHO endorsed the Lagos Declaration, effectively denouncing the negative health effects of apartheid for South Africans (Cueto, 2007). The government did allow for the formation of the National Progressive Primary Health Care Network (NPPHCN), initially funded by the Henry J. Kaiser Family Foundation in the early 1980s. "Led as much by activists as by health professionals, and explicitly aligned with the political opposition, the NPPHCN gave weight to previously atomized efforts" (Tollman and Pick, 2002: 1726). Unfortunately it often found itself challenging the apartheid regime and effectively producing little in the way of bettering primary health care.

In 1983 the new Constitution's "Presidential Council" effectively brought about a restructuring of the system of "institutionalized segregation and required Coloureds, Indians, and whites to have separate administrations for their 'own health affairs'" (van Niekerk, 2003b: 365). Health care for whites fell under the "general affairs" of government and although controlled by the central government, was managed locally by racially refined administrations. The concept of primary/community-orientated health care was sidelined and little noted.

Solomon, Benatar and van Rensburg (1995: 16) suggest that during the 1970s and 1980s the health care system in South Africa was "mainly influenced by forces reflecting the core of (predominantly Western and increasingly economic) values common to the subculture of medicine worldwide". They argue that this period was marked by a drive towards a marketplace model of health care, fostered by the self-interest of a privileged minority (white and black) and that this has allowed private medicine to flourish at the expense of public medicine. For example, "academic medicine during this time period came under increasing strain as teaching hospitals



faced the demands of a growing and more urbanized population, the private sector recruited medical and nursing staff into more lucrative positions" (Solomon and Benatar, 1997: 891). In some senses then the National Party government's policies regarding health reflected the ambiguous nature of the country's governance. On the one hand it was implementing policies that followed global trends towards a neoliberal economy. But on the other hand welfare and good basic health care was freely available for the few white "citizens". It was therefore showing signs of neo-liberal tendencies as well as some "welfarist" tendencies for the few privileged (whites) who were regarded as legitimate citizens.

In 1990 the Ministry released the National Policy for Health, Act 116 (van Niekerk, 2003b: 368). The principles underpinning this new policy were to continue the residualism of the 1970s and 1980s by making the physical, mental and social wellbeing the responsibility of each individual South Africa citizen (Department of Health, 1990: 4). Further reflecting the ambiguity of National Party policies, "citizen" in this case would imply a person born and living with appropriate documentation, in the boarders of the South African Republic - this included people of all races. Emphasis was also on the "recovery of costs incurred in medical treatment from the inhabitants themselves" and the "encouragement of the private sector to provide health services, with the qualification that it should be in the public interest" (Department of Health, 1990: 4). At the same time though, Health Minister, Dr Rina Venter encouraged the shifting of funds from hospitals towards primary health care facilities at a local level. In order to do this, legislature demanded that at least 5% of all provincial funds allocated for health care were to go to the local district authorities. There was clearly a tension therefore between the desire to move towards a primary health care approach and the need to cut state financial expenditure and embrace the global trend towards a neo-liberal framework.

Primary health care as a system, requires community-based implementation and involvement, "ambulatory facilities", drag follow-up and other methods that minimise hospital care expenses (Coughlan, 1995: 6). In a country where health services were already so fragmented, this primary health care approach was not easily implemented without an overhaul of the entire socio-structural makeup. In 1990 this would not happen for another 5 years or so. The obvious advantage to a primary health care



system is that it is accessible, appropriate and cheaper for both the state and the individual patient but it does involve high start-up costs (Coughlan, 1995). This was the stumbling block for the South African state, which had limited resources and showed lack of political commitment towards change. The National Party government may have claimed to be dedicated to a primary health care approach but it was selective in its implementation and it took few measures to address the issues of clean water and sanitation for all – as basic to the premises of primary health care (SAIRR, 1992: 127).

However, the releasing of Nelson Mandela and the un-banning of the ANC in 1990 led to the political transformation that the country had been waiting for and desperately needed. On 2 May 1994, the World Health Organisation restored South Africa's full membership with immediate effect (United Nations, 1994). When the ANC came into power in 1994 one of its major objectives was the nationalising of health care services. This raised daunting questions about how the ANC government would be able to "replace the revenue lost by physicians and other health care workers through the nationalisation of the private-sector health care industry. More than half of the physicians worked in the private sector. This also raised the question of whether they could be attracted or compelled into the public sector at levels of remuneration equivalent to that of the private sector" (van Niekerk, 2003b: 371).

Additionally the public sector health-care system in South Africa was highly fragmented. At the central level there were four departments of health, one for each racial group, and almost 800 local authorities. In 1993, with rationalisation, these departments were combined into one. There was also a strong but fragmented private sector including health professionals in private practice, private hospitals, pharmaceutical manufacturers and distributors, medical aid schemes, and others (ANC, 1994).

As Bloom and McIntyre (1998) suggest, in developing countries where there is significant socio-economic inequality, the ministries of health "have a difficult role in balancing the demands of various stake holders. The very nature of such divided societies leads to them having to "find strategies to ensure that the needs of the poor and politically week are given priority, in spite of pressures by powerful interest



groups" (Bloom and McIntyre, 1998: 1531). The new government's approach was to promote the primary health care system. The ANC 1994 National Health Plan stated that the state would be "responsible for creating the framework within which health is promoted and health care is delivered" (ANC, 1994). This Health Plan made it clear that the government would be the major provider of health services to all the population by creating a "single comprehensive, equitable and integrated National Health System. This required bureaucratic rationalisation and the centralisation of both public and private health care delivery. Health care provision was to occur via a hierarchical coordinated structure from local, to district, to provincial, through to national authority levels.

Transformation of the health system necessitated the formation of District Health Systems throughout the country (ANC, 1994). However, demarcating these health district boundaries posed a problem because they "had to be coterminous with local government boundaries and contiguous. By early 1999 there were 39 health regions, 174 health districts and 843 local municipalities nationally" (Department of Health, 2001). Further, the difficulty of finding funds to build and staff the primary care clinics, especially in poor areas, was a source of much contestation. As resources were limited they were usually withdrawn from academic medical centers. "Almost 100 new primary care clinics were opened in the country by the end of 1996, funded by a cut of about 7 percent in the budget for teaching hospitals...Such restructuring offers many potential benefits, but clearly at the cost of hospital-based services, particularly in the academic centers" (Solomon and Benatar, 1997: 891). This caused severe ill feelings within the academic environment creating a push factor driving highly skilled medical professionals into the private sector or even out of the country – leading to a "brain drain" in the 1990s. Although this involves mainly medical doctors, it also includes physio-, occupational-, speech and audio-therapists, and even nurses. For example, currently, 12% of foreign nurses in the United Kingdom are South Africans (Hassim, Heywood and Berger, 2007: 130).

Overall, the department of health was centralised in a hierarchical manner with the Minister and Deputy Minister of Health located at the top of the ladder of command The Minister and Deputy are appointed by the president and the selection of the Director General is subject to cabinet approval (Hassim, Haywood, Berger, 2007:



108). Figure 5 depicts an organogram for the Department of Health. Four separate divisions were formed, each headed by a deputy director general. However, the responsibility of national health care provision is also the responsibility of each provincial department of health. There are nine provinces in post-apartheid South Africa (Hassim, Haywood, Berger, 2007: 110). Funding of the health department currently flows from the central treasury. Usually, funds are sourced from general tax revenue but the authority, responsibility, and control over funds is decentralised to the lowest district level. Therefore each province and district has the authority to allocate funds in the direction they choose.

"In the late 1970s, overall funding for health services in South Africa (both public and private sectors) was about 5 percent of the gross national product" and remained at that level for about 10 years (Solomon and Benatar, 1997: 891). From the late 1980s to the mid 1990s health care expenditures increased to about 8 percent and it currently stands at about 13 percent of the gross national product. Total health expenditure as a percentage of the gross domestic product in 2005 was about 8.1% (Health Systems Trust, 2007). Looking at table 1 this percentage is what the World Bank considers to be an adequate expenditure for a developing country. The private sector accounts for the largest portion of this expenditure providing excellent care to only about 20 percent of the country's population. In 1996 the ANC made health care freely available to the public sector for children under the age of six, pregnant and nursing mothers, the elderly, the disabled and certain categories of the chronically ill. However, in order to ensure some cost recovery, user fees for insured patients using public hospitals were increased (ANC, 1994: 1).

Regardless of the ANC's commitment to providing basic, good quality health care for the citizens of its new democracy, a more immediate concern was how to develop a redistributive growth strategy, whereby the state would "perform a prominent interventionist role with substantially increased expenditures in the social sectors to meet equity imperatives" (van Niekerk, 2003b: 371). This led to the formulation of the Reconstruction and Development Programme (RDP) in 1994. Many of the proposals made for RDP policies were strongly influenced by policy advisors from the World Bank and private business in South Africa. South Africa's interim government, established in 1994, was formed as a result of a compromise regarding



the level of state control of the markets and its hold on capital, and thus private business still held a fair amount of weight in policy decision-making.

Minister of Health Dr ME Tshabalala-Msimang Deputy Minister of Health Ms N Madiala-Routledge Director General Mr TD Mseleku Cluster: Strategic Planning Dr MP Mahlathi Ms MK Matsau Dr KS Chetty Legal Services Health Information Research Communicable Deseases **Human Resourses** & Evaluation Ms D Pearmain Dr L Makubalo Ms CGL Gumede International Health Liaison **Bargaining Council** HIV & AIDS and STI's PHC, Districts and & Employment Relations Development Mr. Mak Kau Dr Nomonde Xundu Communications Gender Focal Point Non-Communicable Diseases Pharmaceutical Policy and Sub-Directorate: Human Planning Ms M Hela (Acting) Ms C Kotzenberg Ms E Maluleke Directorate: Information Medicines Regulatory Aythority Office of Standards Comliance Communication Technology Dr SH Khotu Directorate: Support Services Maternal, Child & Woman's Hospital Services Health and Nutrition Dr A Amos Dr T Sibeko Health Economics

Figure 5. Organogram of the South African Department of Health

Source: Website of the South African Department of Health

http://www.doh.gov.za/department/index.html Accessed, 5 July 2007



Table 1. Data on health care expenditure and health status in South Africa and countries that have comprehensive health expenditure data

| | Health expenditure as % of GDP ^a | Infant mortality rate ^b (per 1000) | Life expectancy at birth 1991 (yr) | Annual incidence of tuberculosis 1990 (per 100,000) |
|---------------------------------|--|--|---------------------------------------|---|
| | | Middle-income countries | | |
| South Africa | 8.5 | >49 | < 63 | 250 |
| Colombia | 7.3 | 23 | 69 | 67 |
| Mexico | 4.8 | 36 | 70 | 110 |
| Philippines | 2.4 | 41 | 65 | 280 |
| Established market economies | 9.2 | 8 | 77 | 20 |

Sources: Expenditure data derived from McIntyre et al. (1995) and Berman (1997); Health indicator data derived from McIntyre et al. (1995) and World Bank (1993), Tables 1, 28, A.7 and A.9.

Source: Bloom and McIntyre, 1998: 1530

After the mini-crash of the Johannesburg Stock Exchange (JSE) in the early 1970s the International Monetary Fund (IMF) had become involved in South African economic affairs and encouraged the country's financiers to enter the international money markets (Bond, 2000: 24). After this the JSE kicked off spectacularly but the "capital stock of corporate South Africa stagnated and a deep recession commenced" (Bond, 2000: 24). For Bond, neo-liberal frameworks for policy making were already adopted in South Africa as early as the 1980s and are not merely a "new" government characteristic. Bond argues that with globalisation a crisis of overcapitalisation occurred due to the rise of financial markets and this amplified the processes of uneven development across the world and within South Africa. He also emphasises the pernicious role played by the IMF and the World Bank in driving economic policy change during the 1980s and 1990s with the change of government.

But, South Africa struggled to enter an unfair global market with heightened competition and the protectionist barriers imposed by large economies and so during the 1990s new strategies for global market involvement evolved. "The most obvious was intensified concentration within the financial sector" (Bond, 2000: 26). According to Bond, the RDP was a realistic and feasible strategy for the ANC to adopt, given the local and international forces. However he is clear to point out that in

These middle income countries were selected as they have conducted similarly comprehensive health expenditure surveys. Data for South Africa are for 199219/93, 1993 for Colombia, 1992 for Mexico, 1991 for Philippines, and 1990/1991 for established market economies.

^bData on the infant mortality rate are for 1992 in South Africa and 1991 in the other countries.



reality the RDP builds upon a myth that a social welfare state can be developed within the sphere of a neo-liberal economic structure. For Bond the unfortunate result is merely an ignoring of the "Meeting Basic Needs" goal of the RDP and an amplification of the "Building the Economy" goal (Bond, 2000: 54). Some of Bond's cynicism is justified because as Adalzadeh (1996) points out, the RDP failed to deliver on its social development mandate and instead the government adopted a move towards a "trickle-down approach to economic development" (Adalzadeh, 1996: 4).

In keeping with their neo-liberal economic strategy for development, in June of 1996 the Department of Finance unveiled their new macroeconomic scheme called the Growth, Employment and Re-distribution Strategy (GEAR) (Adelzadeh, 1996: 1). It had two main objectives. The first was to maintain internal fiscal restraint to rapidly eliminate the state deficit while, simultaneously, reprioritising the existing national budget to meet social needs. Secondly, it aimed to implement economic reforms, such as lifting exchange controls, restructuring state assets, and developing a flexible labour market to facilitate a globally competitive, export-led growth path that would enable the economy to expand by 6% and create 400 000 jobs annually (van Niekerk, 2003b: 371). Both Bond and van Niekerk are persuaded that these features of GEAR reflect neo-liberal underpinnings to the ANC government's development approach and deflect from the more welfarist and socialist approach presented by the ANC's freedom charter. Rather these features subscribe to a style similar to that of the Washington Consensus (van Niekerk, 2003b and Bond, 2000).

In light of these economic strategies, the ANC elected to forgo in part, its somewhat socialist and welfare style persuasions and instead to pursue an economic growth strategy that would eventually lead to social development. Although the South African economy is growing, unemployment has increased and the gap between the poor and the rich has grown wider. The difficulties faced by the new government are expressed in the following example. The new constitution recognises that health is a basic human right and "that the state must 'take reasonable and legislative and other measures, within its available resources, to achieve the progressive realisation' of access to health care services" (Hassim, Haywood, Berger, 2007: 19). At the same time it must also allow the state to rationalise health spending in a way that benefits



the majority of citizens. It cannot therefore always justify the cost of one heart transplant for one patient, when that financial expense could be used to provide measles vaccinations or tuberculosis treatment for 100 other people (Hassim, Haywood, Berger, 2007: 19). As this example highlights, balancing the costs of health care expenditure and outcomes in an environment dominated by neo-liberal economic policies, is complex when juxtaposed by a constitution and government mandate that expresses, in a language of human rights, a more welfarist ideology.

The South African experience mirrors a reality similar to that faced by other African countries towards the end of the 1990s. Welfare campaigns were undermined by neoliberal economic polices that discourage state "over-spending" in areas such as health care. The result has been not only a decline in state funding of the health care sector but also a marginalisation of certain welfare services, traditionally thought to be the responsibility of the state. The state is thus in a contradictory position whereby it is expected to deliver in its provision of welfare and elementary services, but is expected to do so within the framework of an economic system that discourages state spending in these areas. In the South African case, what the state professes to be able to do stands in contradiction to what it actually can do. In examining tuberculosis discourses this contradiction is further revealed.



CHAPTER FIVE

TB or not TB?

"Tuberculosis is a social disease, and presents problems that transcend the conventional medical approach.... Its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body"

(Dubos and Dubos, 1953: vii).

1. Introduction

This chapter deals with tuberculosis discourse in South Africa, with a focus on the recent period during the political transition to democracy. Characteristic of contemporary tuberculosis discourse is the dominance of a biomedical focus and of the issue of HIV/AIDS. These characteristics are set against the backdrop of a hegemonic neo-liberal ideology, which directs the state away from investing in social health-care interventions. As a result, tuberculosis discourse is peppered with issues that reflect a tension between a social welfare mentality of the ANC government and the neo-liberal economic policies in which it operates. Because of the dominance of biomedicine these issues are not expressed in the language of politics but rather in the language of medicine and science.

The *first* characteristic of tuberculosis discourse today concerns the dominance of biomedicine, in its reductionist medico-scientific form. With the discovery of chemotherapeutic drugs in the 1940s the thinking, debates and treatment of tuberculosis have become dominantly medically orientated, cure centred and individual-directed. It will be argued that the result is a detachment from the social environment of the individual medical condition and de-contextualisation of illness. For example, in tuberculosis discourse there has been a noticeable increase in emphasis over the past seven years given to so-called *drug-resistant* strains of tuberculosis. This increased attention has challenged leading views on tuberculosis treatment using standard chemotherapy and has raised concerns regarding public safety. What is evident nevertheless is that tuberculosis discourse in South Africa is first and foremost characterised by a reductionist biomedical ideology. This first characteristic is discussed in this chapter; the second characteristic will be addressed



in chapter six.

This *second* dominant characteristic of tuberculosis discourse in South Africa today is that since the 1990s tuberculosis has become linked – epidemiologically, conceptually and discursively – primarily to HIV/AIDS, and ultimately less directly to issues of poverty and inequality. It will be argued that because HIV/AIDS discourse in the country has become dominantly biomedical and removed from the public realm of debate, tuberculosis discourse has suffered a similar fate. Emphasis is thus placed on the state's WHO recommended DOTS intervention program, which is purely biomedical. As the state is compelled to invest in this strategy it tends to ignore other issues surrounding tuberculosis, such as the social factors of poverty, inequality, migration etc. In this manner the state withdraws from its responsibility to provide the basic conditions for health and this responsibility is left to the community or taken up by non-governmental organisations.

This chapter will begin by addressing some of the less common issues in contemporary tuberculosis discourse. These issues include the linking of tuberculosis and prisons, migration, the mining industry, and gender. Some of the "silencing" or in Foucault's terms, subjugation, of these themes has to do with a neglect of the historical factors involved in the spread of the disease in South Africa. What is most evident is that their silence/subjugation is paralleled by a growth in neo-liberalism, a growth in medico-scientific dominance on tuberculosis control and a growth in HIV/AIDS.

2. Silencing social relations

Some of the issues that in the past were considered important to understanding the spread of tuberculosis and its control in South Africa have with the introduction of the new DOTS strategy been increasingly silenced. For example, the 2002-2005 Plan for TB Control, published in 2001, expresses a strong focus on the need to "improve communication" between the mining sector, prisons and the NTCP in order to "interrupt the chain of transmission in these settings" (NTCP, 2001: 60). In this document it is suggested that because the "situation is not uniform" the approach towards tuberculosis control in these settings must be carefully researched and designed according to the specific needs of these unique institutions. Yet, the 2004



Practical Guidelines, a document detailing the implementation of the suggestions set out in the *Plan for TB Control*, and published nearly three years later, contains no reference to the mining sector, to migration or to the treatment of tuberculosis in prisons.

Prisons represent a unique arena in which tuberculosis is to be controlled. Even though prisoners are given chemotherapeutic drugs there is a high turnover of inmates who, when they leave, often do not report to local clinics to complete their treatment; and in most cases, awaiting trial prisoners are not treated for tuberculosis. Overcrowded prisons present intense breeding grounds for disease and the airborne tubercle bacilli spread quickly in these environments. A study in the United States of inmates who were released before the completion of tuberculosis therapy indicated that only 43% were able to make it to the required doctor's appointment after release (CDC, 2006). In South Africa a study on multi drug-resistant tuberculosis revealed that spending time in prison has significant impact on treatment defaulting (MRC and CDC, 2005: 12). Despite the importance of addressing tuberculosis in prisons the NTCP has not produced any publicly available documents suggesting treatment of the disease in prison settings.

A second issue that is becoming increasingly less prominent in tuberculosis discourse has to do with the topic of migration. Packard's (1989a) pioneering work, highlighted in chapter two, points out the past role of the migratory labour system in South Africa in spreading tuberculosis from urban to rural areas. Following Packard's research it can be concluded that the South African mining industry of the 1900s and early twentieth century expressed a tuberculosis discourse dominated by the topics of silicosis, *migration* and poor working and living conditions. Today the situation is different, even though migrancy continues, and the issue of integrating tuberculosis and HIV care is far more prevalent. For example, in April 1999 a specialised clinic was opened in the Free State with the

primary aim of delivering preventive therapy such as isoniazid to those at high risk of tuberculosis (individuals with HIV infection or silicosis), and cotrimoxazole to those at highest risk for opportunistic infections. The clinic's design has taken regard of the



importance of minimising stigma, protecting confidentiality, monitoring potential side effects, supporting adherence and identification of prophylaxis failure (Charalambous, et. al, 2004: 49).

This clinic was replicated across the country within the mining industry but it clearly has a biomedical mandate and not a social one. Even though migration was and still is an important issue to consider in tuberculosis control, tuberculosis discourse found within the mining sector is now predominantly focused on the issue of HIV/AIDS. As a result it is increasingly difficult to find mining sector or Department of Health documents on this topic.

Van Rensburg et al. reflect that "HIV/AIDS has in recent years come to overwhelm the healthcare scene [in South Africa] to the extent that it seriously distracts attention and diverts resources from other diseases. TB may serve as a prime example of such a 'loser' disease" (Van Rensburg et al., 2005). For example, the NCTP does not take responsibility for tuberculosis control amongst mine workers. Instead, the mining industry itself handles the treatment of tuberculosis in its private clinics. For the most part the industry has implemented a strategy based on the DOTS system. This includes a six-month course of chemotherapeutic drugs and directly observed therapy. Nevertheless, despite the mining sector's well-implemented tuberculosis control programmes (in many cases these are exemplary) tuberculosis rates amongst gold and platinum mine workers in South Africa have continued to rise from the 1990s into the new millennium. The Safety In Mines Research Advisory Committee (Churchyard et al., 2003) concluded that this was primarily due to HIV infection and that treatment for and identification of HIV should be scaled up.

It was suggested therefore that better case finding mechanisms be used and that Isoniazid prophylactic treatment be given to all HIV positive mineworkers. Case finding techniques should include "a combination of radiological screening and symptoms detection" (weight loss, night sweats, fever), and increasing detection rates to 60% (Churchyard et al., 2003: 1). At the same time though, as Calverley and Murray point out, high silica levels were also found in many mines, despite



legislation. They argue that tuberculosis could – and did – develop months or even years after silica exposure ceased. They also found that tuberculosis prevalence was highest for those mineworkers who smoked (Calverley and Murray, 2005: 111). This later evidence, whereby tuberculosis amongst mine workers is said to be conditional to social conditions (such as smoking addictions) appears to be largely ignored within the context of HIV/AIDS. Instead in order to combat increasing tuberculosis the mine Safety Research Advisory Committee suggests the implementation of biomedical, clinical strategies "to ensure improved *clinical practice* with regard to the diagnosis [and treatment] of TB" (Murray et al., 2004 italics mine). Therefore the mining sector is clearly taking a bio-medical approach to the treatment and management of tuberculosis and in doing so is ignoring the social factors such as migration, stress, and substance addiction that increase the risk of developing the disease.

A third noticeable "silence" in tuberculosis discourse is the lack of gender related issues. Gender disparities in tuberculosis aetiology and treatment seem to fill only a marginal space in this discourse. In conducting interviews for this study three respondents briefly discussed the issue of gender in tuberculosis control. They mentioned that most tuberculosis supporters and nurses at clinics are female, whilst the majority of patients are male and that this apparently causes conflict. If this is the case it is surprising that there is seemingly no effort to recruit male nurses or male volunteers as tuberculosis supporters or community health workers. Further, the issue of gender does not once appear in any of the key document used in this study. Because of an existing misconception that public health discourse is gender neutral and therefore does not need to address issues of power relations between the genders, it is important to briefly consider this issue some more.

In our globalised world, liberal notions of human rights are being extended to include gender rights. In doing so there is a growing awareness that public health, as a discipline and practice, is not gender neutral and should not be assumed to be so. For this reason Seidel (1990: 477) contends that "the official rights' culture and rights' discourse has stimulated a broader conceptualisation of risk" – as it relates to health influencing behaviour (Seidel, 1990: 477). Understanding this level of behaviour entails a comprehension of the different gender's positions of status and power, and this understanding comes from qualitative studies which take a gender sensitive



approach. For example, studies on transactional sexual relationships in South Africa reveal to a far greater extent than do public health statistics the position many poor woman find themselves in with regards to relational power struggles. These positions of "power" have direct impact on their health behaviour (such as defining when and how and under what circumstances one can demand the use of a condom during sexual intercourse)⁹.

According to the UNDP (1995), "women account for a disproportionate 70% of all poor individuals. They may, as such, be considered as a marginalized population" (Hanson, 2002: 8). But globally 1.7 times more cases of pulmonary tuberculosis in males are reported as compared to females. This could merely imply however that physiological responses to tuberculosis differ between the sexes rather than accurately reflect the socio-economic differences between access and availability to health care between men and woman (Hanson, 2002: 8). As HIV/AIDS disproportionately affects women in Sub-Saharan Africa, and HIV positive persons are at greater risk of developing active tuberculosis, then woman in the region are clearly at greater risk of developing tuberculosis disease. Yet the statistics do not reflect this. The answers must therefore lie beyond mere epidemiological statistics and be found in sociological and anthropological studies that entail deep ethnographic fieldwork as well as comprehensive analysis of the variety of social factors that influence the prevalence of tuberculosis between the sexes. This is a topic that should potentially be opened to further research and exploration. With this knowledge in mind, it is therefore surprising that gender is not more of an issue in South African tuberculosis control.

The final issue that appears to fill a rather less prominent place in tuberculosis discourse concerns the issue of tuberculosis elimination. When the cures for tuberculosis were discovered in the mid 1940s there was an existing common belief that tuberculosis would soon be done away with due to the "success" of the wonders of medical biological science. Ryan (1992) provides examples of how in the 1950s newspapers all over the world, such as the *Stadt Anzeiger* in Germany and the *New York Times* in the U.S.A reported that the disease which had plagued humanity would soon be conquered. But this is no longer the belief. Now the disease is only regarded

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⁹ For more on transactional sexual relations in South Africa read Hunter, 2002 and Wojcicki, 2002



as one to be managed and controlled – even the name, Tuberculosis *Control* Programme attests to this. For example, the words of the United Nation's Millennium Development Goals plainly state that Goal Six's aim is to *combat* HIV/AIDS, Malaria and other diseases, like tuberculosis by *halting* and *reversing* their incidence by 2015 (Millennium Project, 2007). At no point does the word "eradicate" feature.

This viewpoint that tuberculosis is to be maintained, controlled or managed is not dissimilar to that held in the late 1800s and early 1900s, before the discovery of a cure. It must be pointed out however, that this issue of eradication is not completely silenced and it still appears every-now-and-then. One such example can be found in the South African 2002-2005 Plan for TB Control's preface by the Minister of Health, where she writes "I believe, with this plan, we can effectively manage, and eventually eliminate TB" (NTCP, 2001: 1). In contrast to the Minister's optimism however, most respondents interviewed in this study stated that tuberculosis would or could not be eradicated, at least not until a cure for HIV was found. Here tuberculosis is again directly linked to the issue of HIV/AIDS and its maintenance is regarded as being inextricably tied to HIV from now on.

These four issues mentioned above are still found in South African tuberculosis discourse but are gradually growing less important. Their relevance is being drowned out by the dominant focus on medicinal/chemotherapeutic treatment and on HIV/AIDS. Three of the issues mentioned above (migration, poor mine workers and gender) refer to the sociological "fault lines" in which tuberculosis occurs. They are issues that address the social causes of tuberculosis. Slowly silencing them allows for the history and social context of this age-old disease to be neglected. As these issues grow less important they are replaced by a dominating and scientifically "convincing" rationality that favours biomedical-technical solutions to treating the disease. Thus the prevailing discourse along with its less important topics convey a sense of disregard for the historical factors involved in the spread of the disease in South Africa. In effect this decontextualises tuberculosis, detaching it from its social context and reformulating it into a modern context of neo-liberal, free-market based economies, one in which health care becomes commodified and its ethic of serving the sick gets undermined.



3. Medicalising tuberculosis in South Africa

In recounting the history of tuberculosis treatment in South Africa it is possible to identify the common characteristics and themes that have dominated over the past sixty odd years. The focus of this study is on the recent history and on the themes that dominate the tuberculosis discourse today, but looking back a little does allow for a comparative analysis of how some of the dominating themes have changed over time. For the most part, before the late 1970s, South African tuberculosis control remained unchanged from that of the sanatoria or hospital-based care routine, with the added chemotherapeutic advantage. During this time the tuberculosis discourse in South Africa was dominated by the issue of prevention and was similar to late industrial European discourse regarding disease and conditions of poverty. It was considered the state's responsibility to provide comprehensive health coverage as well as to produce the conditions for social development to occur. For the most part, the National Party government could provide this to its white citizens by adopting colonial style exploitative practices, which undermined the welfare of the non-white racial groups.

But by the latter half of the twentieth century health and illness discourse globally became dominated by scientific medical ideology. From the 1970s onwards tuberculosis discourse emphasised the control and management of tuberculosis using scientific treatment and curative outcomes far more than social interventions and disease prevention that would address elimination of the disease. Government documents, newspaper articles, research reports and even academic articles are now often dominated by statistical and medical terminology. For example, an article published in *The Star* in 2006 discusses the South African government's strategy to intensify its "fight against TB". The article begins by mentioning the statistical figures of the tuberculosis burden: "little more than half of all tuberculosis patients in South Africa are cured...185 000 new TB cases were diagnosed...cure rate of 54 percent..." (The Star, 2006: 19). It is also peppered with the opinions of expert medical doctors and NTCP control managers, who make comments about the fact that tuberculosis "can be treated and cured", that people must "report to clinics at an earlier stage of their TB infection", and that "TB is misdiagnosed late in people who are HIVpositive" (The Star, 2006: 19). Even though tuberculosis is spread by conditions of poverty and even though numerous social factors are involved in preventing some



patients from completing their chemotherapeutic treatment, this article makes no mention of what these social factors are or what the NTCP is doing to counteract them. Instead it focuses on the medical treatment and management of the disease in individual patients.

This example not only reveals how tuberculosis is regarded as a disease to be *managed*, not *eliminated*, it also reflects a prevailing dichotomy between the role of science and of the social on the conditions of illness and health. When science and biomedical technology are reasoned as being the primary solutions to ill health it is often to the suppression of ideas about social interventions. For this reason, in the dominating biomedical paradigm treatment strategies (for tuberculosis) are generally medical/medicine based, ignoring the role of social interventions (such as poverty alleviation, better sanitary conditions, better nutrition, stable employment creation and so forth) that can play a role in improving health. The development of this biomedical, technical reasoning in the 1980s fitted well with the emerging neo-liberal paradigm – which suggested minimal state investment in health welfare – and the two ideologies evolved into dominance simultaneously.

The expansion of modern medicine is closely tied to the development of the biological sciences and the sub-disciplines of biology (Puustinen, Leiman and Viljanen, 2003: 77). With the advance of cellular theory, biochemical explanations "displaced the physical and humeral approaches" to human health and illness, which had defined medical science prior, and new "theoretical demarcation lines were formed in medicine between reductionism and holism" (Puustinen, Leiman and Viljanen, 2003: 77). The reductionist approach in medicine "attempts to explain human illness through biological concepts, whereas the advocates of holism have tried to incorporate social and cultural issues as well as personal experience into medical theory" (Puustinen, Leiman and Viljanen, 2003: 77). Yet despite these different medical theories they have one common aim, to advance the biological basis of medicine. Foucault would argue that this leads to the advance of one form of "knowledge" – in this case the biomedical model.

The biomedical model in general stresses the application of the principles of natural science, (especially biology and physiology) to clinical medicine. In Western Europe



during the seventeenth century the escalation of professional clinical medicine, based primarily on the reductionist medical approach, weakened the plurality of healing systems that existed before. This development was also marked by the rise of an elite class of wealthy males who dominated the scientific medical profession as doctors, physicians and surgeons (Stacey, 1998). As this class of doctors held considerable power the production of medico-scientific knowledge tended to be predominantly reductionist. In Foucault's terms, this involved the subjugation of other forms of medical knowledge (holism) and hence an increase in the medicalisation of many areas of life (such as deviancy or pregnancy) and their removal from cultural and social contexts. In this regard, conceptualisations of "normal" and "pathological" are often constructed within the language of scientific rationality (Foucault, 2003: 37).

This scientific rationality attempts to make sense of health and illness in a rational and calculated way. In South Africa, the emergence in dominance of this ideology is evident in the influence of epidemiology as a discipline in state tuberculosis control in the 1970s. The South African Tuberculosis Control Programme, officially created in 1979 was classified under the Epidemiology Directorate¹⁰ and fell under authority of the larger Department of Health and Population Development¹¹ (Lee and Buch, 1992: 290). In an effort to curb the increase in tuberculosis the Department of Health and Population Development defined its priorities with regards to the disease by including the following focuses for tuberculosis control: health education, intensified casefinding, effective treatment and lastly primary protection (Küstner, 1982). At this time epidemiology – as a discipline that studies epidemic diseases – was becoming popular worldwide. Epidemiological surveys can reveal risk groups, risk factors,

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¹⁰The Epidemiological Directorate published a monthly communication called *Epidemiological Comments*, which disseminated information to a diversity of health care personnel on different levels. *Epidemiological Comments* was not a journal but rather a communication tool that enabled the Directorate, researchers, academics and policy makers to disseminate information about diseases that pose epidemic threats to every level of the health care sector. These diseases were legally classified in the Health Act as being notifiable. This meant that when a patient was diagnosed as positive for any of the disease on the list, by law the case would have had to be notified to the proper authorities. *Epidemiological Comments* was published monthly, every year from 1973 to 1995. Thereafter there was a period when it was no longer published regularly until in 2000 when it began to be reproduced quarterly by the Department of Health Systems Research. In effect, the publication was a collection of information (reports, policy, research findings, advertisements, and commentaries) submitted by not only the Epidemiological Directorate but also by any interested parties.

¹¹ Sometimes the South African Department of Health and Population Development is referred to as the Department of Health and Welfare in official documents. It was termed the Department of Health, Welfare and Pensions up until the early 1980s.



trends/patterns in disease aetiology and distribution (Helman, 2000: 218). "Epidemiology is primarily a quantitative discipline that portrays the occurrence of disease and ascertains susceptibility to risk, viewed in the context of cultural and social processes, environmental attributes, and historical sequence" (True, 1996: 326). Epidemiologists generally define *rate* as the probability or chance of an event occurring. *Incidence* refers to the sum of all newly diagnosed cases of a disease (Helman, 2000: 218). In order to measure the incidence of a disease it is therefore imperative to have a good case reporting and data collection system in place as it relies on the figures of all reported cases of a disease. The *prevalence* of a disease on the other hand refers to the "measure of the pool from which overt disease arises" (Küstner, 1979: 5). No comprehensive prevalence study of tuberculosis in South Africa has ever been conducted.

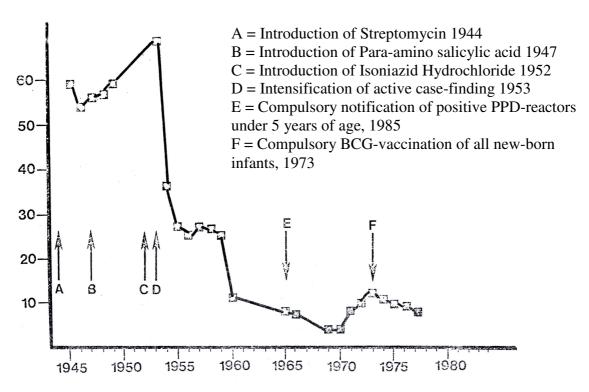
At this time Dr. Horst Küstner was employed by the Epidemiology Directorate and brought with him the epidemiological expertise to "measure" tuberculosis. The first National Tuberculosis Health Conference was organised by the Department of Health and Population Development and the South African Medical Research Council from 6-8 June 1979, in Pretoria. At this conference he recommended that what was needed to control tuberculosis, was a "standardised *yardstick* for measurement" and basic scientific parameters. Küstner argued that South Africa desperately needed "tools" put in place to begin measuring the incidence of tuberculosis so that trends and patterns in the disease's epidemiology could be traced and effective measures to curb negative disease trends could be formulated. For example, he showed that despite the introduction of anti-tuberculosis drugs and new measures of control, the incidence of tuberculosis in South Africa had been on the rise from the 1920s and that epidemiological calculations would be able to track this increase as well as suggesting reasons for it.

In response to Küstner's recommendations, the Tuberculosis Control Programme adopted a suggested standardised treatment regimen comprising a combination of any of the following four drugs – isoniazid, pyrazinamide, streptomycin, thioacetaone, rifampicin and ethembutol. These drugs had been introduced at varying intervals and their effects on mortality can be dramatically seen in Figure 6, which maps the influence of anti-tuberculosis drugs on tuberculosis mortality from 1945 to 1975. The



new policies also recommended that tuberculosis diagnosis be made using primarily bacteriological sputum smear testing and not radiographic means, as had been the norm of the past. These policies were formally laid down, and although adherence to them was emphasised, monitoring their implementation was poor and often inefficient. As a result of poor adherence to the new guidelines, their importance for effective control of tuberculosis became a central point of discussion and began to dominate the discourse in South Africa – for example it was a focal topic at the Robert Koch Commemorative Conference on Tuberculosis held in 1982 (Küstner, 1982).

Figure 6. The Mortality rate from tuberculosis per 100 000 population – South Africa, 1945-1977



Source: Epidemiological Comments of the Department of Health, 15 June 1979.

In support of the new epidemiological methods of monitoring disease the National Tuberculosis Control Programme introduced a new set of forms (GW 20/9.1, GW 20/9.2, GW 20/10) in 1983 (Department of Health and Welfare, 1986a: 1). These forms aimed at more effective patient data capture, believed to be relevant for understanding the epidemiology of the disease. Capturing patient data is considered essential because the greatest problem in administering chemotherapeutic drugs is



patients who do not adhere to their treatment regimens. These patients are termed "absconders" or "defaulters". According to this viewpoint, it is therefore necessary to capture patient's residential and other contact details to facilitate follow-up in the event that they stop their drug treatment. The new forms allowed for medical personnel to record these details and also to track a patient's treatment progress. Additionally, it enabled the recording of a patient's medical history so that he/she could be treated "holistically"; i.e. all clinical illnesses addressed simultaneously. Importantly "holistically' here does not refer to addressing the social conditions affecting the patient's ability to complete treatment and hence be cured, but refers instead to the treatment of all the patient's other clinical diseases.

Further, by implementing a standard system of case registration and patient information it was possible to begin analysing the data to produce epidemiological conclusions. The first analysis of this data was done in 1986 (Department of Health and Welfare, 1986b). At the time the National Tuberculosis Control Programme had been under criticism because of its rising expenditure and poor results. In the financial year of 1985/1986 the programme had spent over 76,4 million Rand, yet it appeared as if tuberculosis was on the increase. Table 2 shows the increasing expenditure on tuberculosis for 1985, 1986 and 1987 and the increase in annual caseload.

This could have indicated that increased expenditure implied more resources for awareness campaigns and for infrastructure development and hence improved case finding, but the findings of the 1986 data analysis revealed and argued convincingly that the new system of patient data collection was significantly problematic in diagnosis and that more needed to be done to effectively finance and manage the actual *diagnosis* of tuberculosis. Therefore, it should not necessarily be assumed that the increase in funds led to better case finding and diagnosis, but instead that the increase in the caseload of tuberculosis patients was perhaps due to an overall increase in tuberculosis incidence in the country. The final suggestion of the research report was that a bacteriological register was desperately needed for the tuberculosis control programme to be managed effectively, both with regards to disease control, but also with regards to cost (Department of Health and Welfare, 1986b: 29). What becomes evident at this point is that tuberculosis discourse was increasingly filled with issues on how best to record patient data, how to ensure patients take their pills,



and how to improve cost-effectiveness. Increasingly, the management of the disease in an efficient bureaucratic sense became a priority. Yet, despite the restrictions on South African participation in global forums, conferences and organisations of health and illness, many of these newly recommended policies for tuberculosis control were inline with current trends internationally. Clearly South Africa was following the global tendency to address tuberculosis using primarily epidemiological techniques of analysis and biomedical methods of control.

Table 2. Selected variables of the Tuberculosis Control Programme – seven health regions of South Africa, 1985-1990.

| | 1985 | 1986 | 1987 | 1988 | 1990 |
|--|--------|--------|---------|--------|---------|
| Total annual case load | 88 268 | 93 020 | 95 669 | 99 251 | 124 635 |
| Percentage distribution of patients with | | | | | |
| known outcomes: | | | | | |
| Cured and discharged | 78 | 77 | 75 | 74 | 76 |
| Absconded | 16 | 17 | 20 | 21 | 10 |
| Demised | 6 | 6 | 5 | 5 | 4 |
| Direct Departmental expenditure on TB- | | | | | |
| control programme (Million) | R 75 | R 91 | R 114 | * | * |
| Average annual cost per patient | | | | | |
| (Denominator = case load) | R 850 | R 978 | R 1 192 | * | * |

^{*} Since the devolution on 1 April 1988, the department has limited information on the expenditure on the Tuberculosis Control Programme

Source: Adapted from *Epidemiological Comments* of the Department of Health. Vol. 18 (8), August 1991.

The epidemiological discipline reflects the "enlightenment" perspective that humans can control the world they live in using scientific and technological advancements. The result is a search for rational, calculable and manageable strategies of controlling the problems that plague humanity, such as tuberculosis. For Illich, medical practice and epidemiology, are really *engineering* endeavours – ones that intervene in order to improve health for individuals who are sick, who might become sick, or who are exposed to "supposedly disease-making aspects" in their environments (Illich, 1975a: 78). The conclusion then is that medicine is technical in its very nature and this technical characteristic arose to prominence in the second half of the twentieth century. In the discourse of illness and health this is known as medicalisation. The intrusion of medical practice into everyday private realms of being is known as "medicalisation of life".



According to Sharp (Sharp, 2002: 370), the "medicalisation of life" implies a "process characterised by the depersonalization and objectification of human subjects". The human body becomes denatured or dehumanised – as in the case of storehouses of organs or tissues used for genetic study or transplants (Sharp, 2002: 370). Further, for Andrews and Nelkin (1998) bodies are often described in scientific discourses as though they were earthly terrains, that can be "mined", and their by-products "extracted" (Sharp, 2002: 370). In effect, human bodies have become "deterritorialized" and dislocated from the context in which they are embodied. Pálsson and Hardardóttir (2002) explain how in Greenland, where Icelanders find cultural collective history in an obsession with mapping their genealogy, recent genetic "mapping" or coding projects have challenged traditional forms of Icelanders' understanding of their bodies and their history. As a result, the intense scientific "gaze" and use of biotechnology to map and code the body has blurred the local understanding of location and sense of belonging (Pálsson and Hardardóttir, 2002).

In this way the history and territorial realities of Icelanders has been undermined, "deterritorializing" their everyday lived reality and the conceptualisation of their bodies (Sharp, 2002: 371). In simple terms, the interference of medical science in everyday forms of life decontextualises the body's physiology. In the case of disease, such as tuberculosis, the illness experienced by the individual is "removed" from the social and environmental (or for some, even cultural and spiritual) factors that led to the acquisition of the disease.

The medicalisation of everyday life also implies an extension of medical practice into the realm of the home. This is the most notable feature of the twentieth century – a practice whereby doctors and nurses can perform home-based care, forcing the realm of the private into the "publicity" of medical science. This casts individuals as victims of the medical "gaze" and of the technological interventions imposed upon them in the form of medications and operations. Individuals are left passively to receive treatment, under the pretence that "doctor knows best". Regardless of a growing understanding since the 1980s that health is more than mere medical intervention the authority of medicine in everyday life is still prevalent. As Illich points out:



People have learnt that health depends on the environment, on food and on working conditions, and that these, with economic development, easily turn into dangers to health, especially for the poor. But people also still believe that health levels will improve with the amount spent on medical services, that more medical interventions would be better, and that doctors know best what these services should be. People still trust the doctor with the key to the cabinet and still value its contents (Illich, 1975b: 73).

The dominance of the reductionist biomedical discipline and its characteristic of scientific and technological involvement in illness is further evidenced by the formation of a single standardised medical strategy for certain diseases. This is particularly evident in the case of tuberculosis control. In the late 1950s the WHO and the Indian Government established a series of projects to investigate the medical implications of anti-tuberculosis drugs on poor patients in India's rural areas. The results of the Indian trials culminated in the formation of a standardised global policy that focused exclusively on the use and distribution of anti-tuberculosis drugs, especially to resource poor areas (Amrith, 2004). According to Amrith, this was the outcome "of the confluence of two discourses borne out of the experiences in South India: the first was the individualisation of tuberculosis as a public health problem.

The second was a discourse of cost-effectiveness" (Amrith, 2004: 115). The combination of these discourses enabled the limiting of tuberculosis treatment policy to a drug-centred approach. The development of the DOTS strategy made seemingly possible a "copy-and-paste" solution to the difficulties of lengthy chemotherapeutic treatment regimes. Countries around the world could implement the same DOTS programme and similar measurement techniques could be used to compare their progress. Although the so called DOTS strategy was officially only "launched" in the 1990s many countries had by the 1980s already adopted standardised approaches and supervised medication similar to DOTS. For Amrith, this global policy movement was based on a "generalization of the results" and on the "imagination of a singular 'third world', united in its epidemiological and social characteristics" (Amrith, 2004: 123).



Because tuberculosis is inextricably linked to social practices and behaviour, its "control" calls for a degree of medical management and surveillance that low-income, underdeveloped states can rarely provide. In apartheid South Africa, this could be managed only for the white population, and results show that tuberculosis amongst whites in the country was almost non-existent (Lee and Buch, 1992). But replicating this level of management throughout the rest of the non-white population was far beyond the means of the National Party government. According to Amrith the most "cost-effective" solution developed for resource-poor countries was a control plan based on drug-regimented treatments, which shifted care towards a more "domestic form of hospitalisation" (Amrith, 2004: 128).

In other words, a strategy was created whereby patients could take their medication at home, thereby relieving the state from having to cover the expense of hospitalisation. However as Foucault suggests, this type of arrangement may be able to offer such treatment for free, and relatively cheaply, but it is also one that requires a "medical corps dispersed throughout the social body" (Foucault, 1984: 285 quoted in Amrtih, 2004: 129). Such a "medical corps" was encouraged by the movement towards primary health, which as mentioned before, was actively promoted by the WHO in the 1980s. But the apartheid government only had the resources and manpower to provide such a "medical corps" for the white population; the rest of the country was forced to make do with meagre services and minimal tuberculosis control.

It is for these reasons that the adoption of the DOTS-like strategy was not quickly accepted in apartheid South Africa. Doing so would have required an overhaul of the entire Department of Health structures and the National Party government was not yet ready for such a move. A call for a unified national health service in South Africa and an improvement in the socio-economic status of individuals was however widely expressed, especially by the Medical Research Council (MRC), because despite the numerous measuring systems put in place and the suggested treatment regimens, the tuberculosis situation had not improved, case finding had not been upped and strains of resistant tuberculosis were growing¹². In the 1980s the Department of Health and

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¹² Explicit mention of this call for a unified national health service can bee seen in *Epidemiological Comments* of the Department of Health, January 1990. Vol. 17, No. 1 and in the editorial of *the South*



Population Development was still disjointed and racially divided into seven health regions. These regions did not include the independent homelands. From the start of officially instituted apartheid policies in the 1940s until the implementation of a national tuberculosis control programme in 1979, tuberculosis treatment in South Africa was fragmented, inefficient, and unequally available for the majority of the country's population (Ginwala and Collins, 1991: 272).

Up until the mid 1990s, tuberculosis care in South Africa took place only at clinics and in hospitals. Many of these hospitals were exclusively designated for tuberculosis patients and were usually run by South African National Tuberculosis Association (SANTA). Tuberculosis was not considered to be a priority of the state, because it mostly affected non-white population groups and thus not legitimate "citizens", and so it deferred its responsibility onto SANTA. Even though the National Party government was SANTA's primary donor the state had little influence over how SANTA conducted its business. The ability of SANTA to conduct its tuberculosis services usually unhindered by state interference was brought to a head in the early 2000s when SANTA was accused of mismanagement of state funds and its funding was cut. Additionally, by the end of 2006 the twenty-two SANTA hospitals were taken under state control and many of its community outreach activities were closed down due to a dramatic decrease in funding (SANTA, 2006).

In many areas SANTA hospitals had developed strategies for dealing with patients that catered to the needs of the local community. For instance, patients could spend their entire treatment period in hospital in one area whereas in another area a more outpatient-based approach was practiced. However SANTA's autonomy in how its hospitals were run, as well as its expenditure on "non-medical" services (such as food parcels) was not compatible with the current DOTS program, which is purely biomedical in focus and demands a standardised treatment approach delivered in the most cost-effective manner. The introduction of the DOTS strategy into the country consequently created significant tension between the NTCP¹³ and SANTA –

African Medical Journal. Vol. 70, issue 30 August 1986, entitled "Failure of tuberculosis control in South Africa – the need for a unitary national health service".

¹³ The relationship between SANTA and the NTCP is very sour at present. When asking managers at the NTCP to discuss this relationship, they were very reluctant and often said "it's confidential" or even "SANTA does not exist anymore". SANTA *does* still exist but its status as an umbrella body is



decreasing its activities and involvement in tuberculosis control dramatically. This new approach to tuberculosis control therefore fundamentally changed the nature of many tuberculosis charities, whereby they became centres for the recruiting and training of tuberculosis/DOTS supporters. The changing nature of tuberculosis charities is an issue that will be discussed in greater detail in chapter six and entails examining the influence of the primary health care model and the effect of HIV/AIDS on the operation of these organisations.

SANTA was formed already in 1947, prompted by an awareness of the uneven distribution of tuberculosis in South Africa (SANTA, 2007). The foundation members consisted of 18 welfare/charity organisations concerned with the tuberculosis problem affecting the poor in the country. The founding organisations resolved, under the chairmanship of Mr. Charles James, to form a national umbrella association aimed at combating tuberculosis (SANTA, 2007). The establishment of SANTA coincided with the introduction of the Welfare Organisations Act, number 40 of 1947, to national legislature. This Act allowed for the establishment of welfare/charity organisations to be involved in traditional state responsibilities, such as health care. Welfare organisations could receive provision (full or partial) from the state but could not be maintained or *controlled* by the state or by a hospital board (among others). This Act enabled organisations like SANTA to be actively involved in tuberculosis care (Ginwala and Collins, 1991: 272).

The charities involved in tuberculosis control often provided social services other than health care to the communities and families of patients ill with tuberculosis. This was in recognition of the fact that improvements in health are conditional not only on biomedical interventions but on social ones as well. These services included providing educational material, support groups, initiating awareness campaigns offerings of food parcels, meals on wheals, temporary housing, counselling and so forth. These organisations were run primarily by volunteers and usually focused around offering assistance to those people whom the state was not supporting. In apartheid South Africa, this included primarily the non-white racial groups. During this time the state

marginal and because it no longer receives large grants from the state it no longer manages any hospitals. The organisation is currently being "forced to reassess its mandate and functions" (Interview with John Heindrich, CEO of SANTA).



was ill equipped to provide welfare services to the majority of the poor. For the most part the National Party government maintained welfare and health care support to only the white population group, whom it considered to be legitimate citizens. For white people the state had a responsibility to provide welfare to its citizens. This viewpoint is similar to the welfare consensus adopted by the Western European countries post World War Two – as discussed in chapter three. Further, this viewpoint acknowledges the importance of social factors in health and illness. Yet, despite this understanding the treatment of tuberculosis in South Africa was becoming more and more based on a reductionist biomedical paradigm.

"SANTA pioneered the provision of low-cost TB bed accommodation, combined with adequate nutrition and high quality medical and nursing care (SANTA, 2007). It was also able to initiate its own treatment programmes that differed according to the health needs of various areas. But during the 1980s it attempted to create standardised chemotherapeutic treatment in its hospitals, congruent with those based on the Madras formulae mentioned previously. Soon SANTA hospitals became sites for the testing of "new" standardised, directly observed treatment programmes. At this time hospital care for racial groups other than the whites, became too expensive for the struggling National Party government, and so called "outpatient" treatment for tuberculosis was investigated. Hospital-based treatment was also considered too costly for the patient, as it often required him/her to take unpaid leave from work. For many poorer residents of the country unpaid leave or the potential of loosing ones job in order to receive hospital treatment spelt disaster for their families, especially if the patient was the primary bread winner. Studies were therefore conducted to determine the cost-effectiveness of outpatient based tuberculosis treatment.

In 1986 a study published in *Epidemiological Comments* revealed that one-month of hospital care for one tuberculosis patient was eleven times more expensive than one-month outpatient treatment at a clinic (Department of Health and Welfare, 1986b). The same study reported that the volume of anti-tuberculosis treatment administered at clinics was roughly two and a half times as much as administered at hospitals and concluded therefore, that "the clinic service is more efficient" and funds to this service should be expanded (Department of Health and Welfare, 1986b: 24). A plan was therefore initiated whereby patients were treated in hospital for a suggested two



months and thereafter treated on an outpatient basis. According to a report produced in *Epidemiological Comments* by 1990, 81% of tuberculosis patients were treated in clinics compared to 76% in 1988 (Swanevelder, 1990).

Although limited to only two years, table 3 shows the annual tuberculosis caseload for hospitals and clinics. It reveals a growing tendency in the late 1980s to move initial tuberculosis care to the clinic environment. It also shows a certain level of efficacy of the implementation of primary health care, and implies that transition of diagnosis and treatment for tuberculosis was successfully taking place at the clinics. This short period gives only a limited view, and data for more recent time periods is not available because the Department of Health does not collect aggregate data on percentage of treatment at various health care facilities. Therefore it is impossible to confirm that over time the percentage of tuberculosis patients treated primarily in hospitals decreased. However, data for the Hlabisa district in KwaZulu-Natal reveals that from 1991-1996 "the proportion of patients treated in hospital decreased from 19% to 13%" primarily because the number of treatment points in the community had increased from "37 in 1991 to 147 in 1996" (Tanser and Wilkinson, 1999: 4). This example emphasises that even though national aggregates are not available, in some areas tuberculosis treatment became less hospital centred.

Table 3. The annual tuberculosis caseload treated by clinics and hospitals. Tuberculosis Control Programme of South Africa 1990

| | Percentages | Total Number of Cases | | | | |
|------------|-------------|-----------------------------|--|--|--|--|
| 1990 Total | | | | | | |
| Clinics | 81 | 100349 | | | | |
| Hospitals | 19 | 24286 | | | | |
| 1988 Total | | | | | | |
| Clinics | 76 | * | | | | |
| Hospitals | 24 | * | | | | |

^{*} Data not available

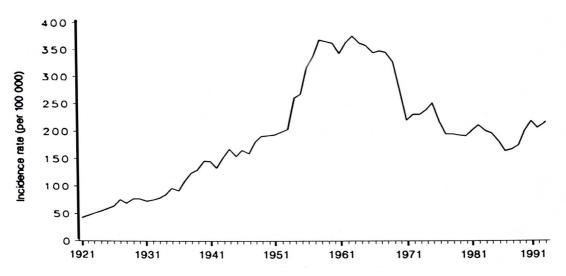
Source: Adapted from *Epidemiological Comments* of the Department of Health. Vol. 18 (8), August 1991



These editions of Epidemiological Comments reveal that during the late 1980s, the primary theme in tuberculosis discourse was one of "cost and effect" and hospital-based care was being reconsidered in order to find a more cost-effective treatment strategy.

In 1990 a national study of tuberculosis revealed that tuberculosis was once again on the increase amongst all racial groups and age groups of South Africa (Swanevelder, 1990). Figures 7 shows the increase of tuberculosis incidence from 1921 to 1993 and figure 8 reveals a slow upward trend around the mid 1980s with a significantly sharper increase of tuberculosis cases after 1995. According to figure 7, the incidence rate in 1981 was roughly 200 per 100 000 of the population but it steadily increased to 314 in 1997 (Dye et al., 1998: 682) and by 2005 that number was up to over 600 per 100 000 of the population – showing that the increasing trend noted in the late 1980s continued into the new millennium (WHO, 2007a).

Figure 7. The incidence rate of tuberculosis per 100 000 population, South Africa 1921-1993



Source: Epidemiological Comments of the Department of Health. Vol. 22 (1), January 1995



Figure 8: South African tuberculosis notification rate per 100 000 population

Triangles = ss+ cases, squares = all cases (227,320 in 2003) Year

ss+ = sputum smear positive cases. Sputum smear positive cases reflect data from individuals testing positive for mycobacterium tubercle bacilli on two sputum tests. This test is generally regarded as being most accurate and thus data from these tests are deemed more precise.

Source: Tuberculosis Epidemiological Profile. Global TB Control, WHO Report (WHO, 2004)

It is important to note though, that comparing incidence rates before and after 1996 (with the implementation of the new NTCP and DOTS) is problematic because the data collection methods used were not necessarily the same. Additionally, data collected during the 1980s and early 1990s should be regarded with caution, because the unstable political conditions in the country at the time made it impossible for many people (usually non-whites) to attend hospitals and clinics and so underreporting is a possibility. As such figures may actually be higher than recorded. Figure 9 reveals slightly more accurate data collected after 1994 up until 2005 and identifies the actual number of reported tuberculosis cases, also revealing a growing trend in case reporting and detection.

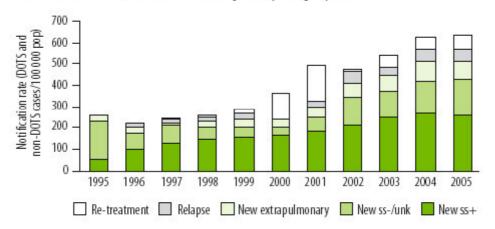
Packard and Coetzee argue that the sharp increase of tuberculosis at the end of the 1980s was due to significant political and economic factors at the time as well as to biological ones (Packard and Coetzee, 1995). For instance they suggest that the intense political turmoil between the Inkatha Freedom Party and the ANC at the time racked the townships, displacing people and creating the conditions in which tuberculosis spreads. Additionally, the scrapping of influx control laws in 1987



coincided with a serious drought and economic recession, causing many rural dwellers to flee to the cities, often to live in crowded slum conditions that were conducive to the spread of tuberculosis (Packard and Coetzee, 1995: 105). On the other hand the sharp rise in tuberculosis incidence after 1995 can be attributed in part to the formulation of a centralised National Tuberculosis Control Programme and hence the use of better case finding methods but importantly also to the increase of HIV/AIDS (Pitchenik, 1992: 77). The growing influence of HIV/AIDS on tuberculosis has been so dramatic that by 2005 South Africa had at 19%, the largest global proportion of HIV/AIDS positive individuals infected with tuberculosis. Figure 10 shows this percentage. At the same time 58% of all tuberculosis cases were also HIV positive (WHO, 2007a).

Figure 9: Case Notifications for South Africa, 1995-2005





ss-= Sputum Smear negative

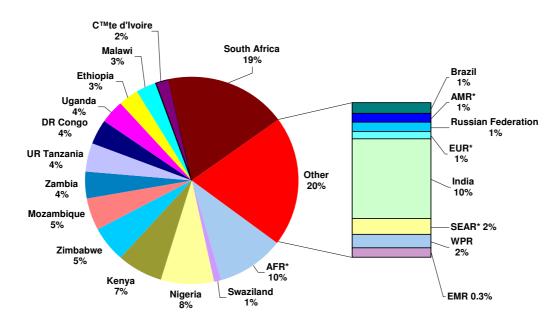
unk = unknown

ss+ = sputum smear positive

Source: Global tuberculosis control - surveillance, planning, financing. (WHO, 2007a)



Figure 10. Global geographical distribution of HIV-positive TB cases, 2005.



For each country or region, the number of incident TB cases arising in people with HIV is shown as a percentage of the global total of such cases. AFR* is all countries in the WHO African Region except those shown separately; AMR* excludes Brazil; EUR* excludes the Russian Federation; SEAR* excludes India.

Source: Global tuberculosis control - surveillance, planning, financing. (WHO, 2007a)

Due to the sudden tuberculosis increase, South Africa employed a full time tuberculosis advisor from the TB Advisory Group (Glatthaar, 1992: 84) and enlisted expert help from Dr. Karel Styblo, ex-director of scientific activities of the IUATLD (Edginton, 2000: 17). Dr. Styblo performed a rapid appraisal of the tuberculosis situation and found that the national policy was not clearly laid out, clearly communicated or clearly implemented. Additionally, he reported a lack of focus on infectious (smear positive) cases, that the information system was inadequate and that there was misdistribution of hospital beds and laboratory services. All these factors were argued to undermine the effective control of tuberculosis in the country (Edginton, 2000). With the technical assistance of the WHO a DOTS "pilot" was implemented in Mpumalanga province in 1994 and the implementation of a new "recording and reporting system based on the recommended international system" began (Edginton, 2000).



4. National tuberculosis control in post-apartheid South Africa

The restructuring of the state health department after the 1994 election allowed for the complete overhaul of the National Tuberculosis Control Programme. The new focus became the implementation of the WHO adopted DOTS strategy. The 1996 Practical Guidelines stated that "South Africa urgently needs this more focused and standardised approach" (NTCP, 1996: ii). Tuberculosis was thus given priority and the NTCP was placed under the Directorship of Dr Refiloe Matji, appointed in 1996. The former Epidemiology Unit was dismantled in 1997 and the NTCP was slotted into the "Communicable Diseases" cluster/division, which lies under authority of the Deputy Director-General of Strategic Health Programmes. This deputy reports directly to the Deputy-Minister and Minister of Health. The NTCP staff at head office management level should always include "a manager, a person responsible for provincial support, a trainer, an advocacy officer and a financial administrator" (NTCP, 1998: 11). Although the NTCP is managed by a central office and is hierarchically structured, actual implementation of the control programme occurs at local area and district health service in an integrated manner. This implies that treatment for tuberculosis is integrated at clinic and hospital facilities with treatment for other illnesses and diseases. The result is that nurses, doctors and other health care workers do not work with tuberculosis patients exclusively but instead rotate duties regularly.

A joint review on *Tuberculosis Control in South Africa*, conducted in June of 1996 by the WHO and the NTCP, determined that South Africa had one of the highest tuberculosis burdens in the world and was ranked twelfth out of twenty-two high burden countries (WHO, 1996: 37). The review suggested that "full nation-wide implementation of the revised TBCP", involving the WHO recommended DOTS strategy, would "result over the next 10 years in the prevention of 1.7 million new tuberculosis cases, the saving of over R2 billion.... and the prevention of spread of multi-drug resistance" (WHO, 1996: 2). Consequentially a "five-year strategic plan was developed to implement DOTS in phases" throughout the country (WHO, 1998a: 37). Aside from a strong WHO contingent, probably the most influential South Africans driving tuberculosis policy change during the 1990s were Dr. Neil Cameron from the Communicable Disease Control Directorate, Dr. Lombard and Dr. Bernard



Fourie from the Medical Research Council, and Director of Epidemiology, Dr. Horst Küstner. The new control strategy was extended after its five-year trial period and is still the current system in place. It is based on the WHO recommended DOTS strategy and was initially outlined in the 1996 *Practical Guidelines* published by the NTCP.

As part of the WHO recommended strategy all health workers had to be trained in the DOTS approach. From interviews with managers at the NTCP, it appears as if much of this training has still not occurred – especially for older and higher-level medical personnel, such as doctors. This leaves the system managed by medical staff who are not always clear on tuberculosis diagnostic, testing and treatment procedures. Nevertheless a *Training Manual for Health Workers* in South Africa was published with the aim of assisting "health workers in the successful control of tuberculosis –to ensure a high smear conversion rate of at least 85% at the end of the intensive phase and ultimately to cure at least 85% of all new smear positive cases" (NTCP, 1998: 1).

The newly adopted tuberculosis control strategy in South Africa is congruent with the WHO recommended policy for tuberculosis treatment as outlined in their publications, *Global Tuberculosis Control* (WHO, 1997: 5) and the 1998 *Tuberculosis Handbook* (WHO, 1998b). These documents are specifically "intended primarily for use in those low-and middle-income countries" and explicitly mention that "TB control and primary health care (PHC) are interdependent" and as such adopting the WHO strategy entails adoption of the primary health care system (WHO, 1998b: 7 and 19). Additionally, according to the WHO, key features that the South African NCTP had to express in its new approach, consisted of the following: Strong political commitment, a reliable and constant supply of the correct anti-tuberculosis drugs, reliable microscopy services, complete recording, reporting and case finding and appropriately trained health workers. Additionally these are all pre-requisites for a successful national tuberculosis control programme.

By adopting the WHO recommended strategy for treating tuberculosis South Africa has followed a purely reductionist biomedical approach. This strategy takes very little (if none at all) cognisance of the social factors involved in the aetiology of this disease. A quote from the 2004 *Practical Guidelines*, addressing the goals and targets of the NTCP confirms this.



The overall objectives of the NTCP are to:

- reduce mortality and morbidity attributable to TB;
- prevent the development of drug resistance; and
- ensure accurate measurement and evaluation of programme performance (NTCP, 2004a: 7).

None of these objectives address any social causes in tuberculosis control. The official state policy is therefore simply reductionist and ignores issues of poverty, migration, gender, substance addiction - all issues which have been proven to increase the risk of developing tuberculosis disease. The result of reducing the treatment of such a social disease to mere biomedical interventions is that treatment becomes decontextualised. Scientifically formulated treatment is therefore dispensed to patients regardless of their varied social environments. In such a context, individual patients, despite their living and working environments, are required to take responsibility for the "success" of their treatment and the responsibility of treatment outcomes is removed from the medical scientific community and also from the state. Regardless of the patient's circumstances he/she is expected to adhere to a strict sixmonth chemotherapeutic regimen in order to achieve a smear-positive conversion and be declared cured. For the most part, his/her social reality is non-consequential. In order to "help" the patient do this, DOTS treatment supports are mobilised. These are volunteers from the patient's community who are required to literally watch the patient swallow his/her pills. The responsibility for treatment success is thus thrust upon the community and the individual.

The outcome of such a simplified treatment programme is not encouraging. Tuberculosis incidence in South Africa has continued to increase since the 1990s and in 2005 it stood at 550 cases/100 000 of the population (NTCP, 2006). Globally, South Africa is currently ranked seventh amongst the twenty-two high burden countries and it no longer even boasts 100% treatment coverage for its population. In 2004 Mpumalanga province had its "DOTS status" revoked because the DOTS strategy was not being adequately implemented in the province. Table 4 reveals how DOTS treatment coverage in South Africa has actually decreased since 2003. An



external review of the NTCP in October 2005 found that despite the new strategy for tuberculosis control having been in place since 1996, ten years later tuberculosis incidence had still not declined, instead it had increased (Balt et al., 2005). Most noticeably, cure rates hovered at only around 50%, far short of the WHO target of 80% (Balt et al., 2005). In fact, cure rates in 1994 were 54% and had only improved marginally in 2005 to 56% (Policy Unit of The Presidency, 2007: 39). Consequently, in 2006 the Minister of Health declared a crisis of tuberculosis in the country. In the era of HIV/AIDS, tuberculosis certainly does present a possible crisis and its treatment with a simple, reductionist biomedical model needs to be reconsidered. The need to address alternative forms of tuberculosis treatment, ones that are not purely based on chemotherapeutic medication, is no more evident than in the topic of drugresistant strains of tuberculosis.

Table 4. DOTS expansion and enhancement

| DOTS expansion and enhancement | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 |
|--|------|------|------|------|------|------|------|------|------|------|------|
| DOTS coverage (%) | 0.0 | 0.0 | 13 | 22 | 66 | 77 | 77 | 98 | 100 | 93 | 94 |
| DOTS notification rate (new & relapse/100 000 pop) | - | - | 15 | 50 | 201 | 193 | 262 | 457 | 484 | 546 | 549 |
| DOTS notification rate (new ss+/100 000 pop) | - | - | 10 | 37 | 121 | 137 | 155 | 210 | 248 | 256 | 253 |
| DOTS case detection rate (all new cases, %) | - | - | 2.9 | 9.4 | 35 | 36 | 44 | 70 | 75 | 82 | 82 |
| DOTS case detection rate (new ss+, %) | - | - | 5.0 | 18 | 57 | 62 | 67 | 88 | 101 | 104 | 103 |
| Case detection rate within DOTS areas (new ss+, %) h | - | - | 38 | 83 | 87 | 81 | 88 | 89 | 101 | 112 | 110 |
| DOTS treatment success (new ss+, %) | - | 69 | 73 | 74 | 60 | 66 | 65 | 68 | 67 | 70 | - |
| DOTS re-treatment success (ss+, %) | - | 67 | 68 | 71 | 47 | 52 | 53 | 53 | 52 | 56 | - |

Source: Country Profile Fact Sheet, South Africa (WHO, 2007b).

5. Drug-resistant tuberculosis

In the past few years there has been a marked increase in emphasis on drug-resistant strains of tuberculosis, both globally and locally in South Africa. This topic has sparked a rethinking of tuberculosis treatment using standardised therapy and has raised concerns about issues of individual human rights and safety. In part, there is a greater general awareness of the disease. In most sub-Saharan Africa countries, the annual tuberculosis incidence rates have increased two to threefold since 1990 (WHO, 2005b: 349), indicating that public knowledge about the disease has grown and that more people are going for testing. Additionally, on the 26 August of 2005, the WHO regional committee for Africa declared the tuberculosis epidemic to be an African emergency, drawing more attention to the disease (WHO, 2005b: 349). However, it



was a controversial article by Neel Gandhi and associates (2006), published in the *Lancet* and presented at the XVI International AIDS Conference in Toronto in 2006 that attracted much of the South African media's attention. Dramatic newspaper headlines read as follows: "TB now a bigger monster than ever" (Saturday Star, 2006: 5), "Dangerous Disease" (The Mercury, 2006), "New Deadly TB-cases in PE" (Independent Online, 2007) and "Health official tackle drug-resistant TB" (Verwey, 2006: 4). Gandhi et al. (2006) suggested that the emergence of extremely drug-resistant tuberculosis (XDR-TB) in South Africa proved virtually fatal to those dually infected with the human immunodeficiency virus and that therefore more integrated tuberculosis and HIV programs need to be established. Further, the article criticised the South African National Tuberculosis Control Programme's effectiveness and the usefulness of the World Health Organisation endorsed standardised treatment regimen (DOTS) in resource-poor settings.

The development of drug-resistance is an important consideration in the chemotherapeutic control of tuberculosis. Unless chemotherapeutic regimes are carefully calculated and effectively administered the development of various strains of resistant tuberculosis could spell disaster for a country's control efforts. Even though Gandhi and his colleague's article about *extremely* drug-resistant tuberculosis strains caused a frenzy in 2006 these resistant strains of tuberculosis are not unfamiliar to specialists in this field. The MRC of South Africa has been involved in studying drug-resistant tuberculosis since 1965, with specific population-based surveys being conducted in the Western Cape and Mpumalanga (see Weyer et al., 2003 and 2004). Not withstanding, there is still much controversy surrounding the understanding of these resistant strains. Their infectiousness is still disputed, as is their reaction to various anti-bacterial agents.

Additionally the treatment of resistant forms of tuberculosis within a setting of standard treatment regimes also yields much debate. For example, Westwater (1996) declares very convincingly and boldly that tuberculosis drug-resistance in South Africa develops independently of poor treatment regimes and that standardised treatment should not be blamed. His study of Nkqubela Chest Hospital in the Eastern Cape Province, suggests that despite the absconding rate at Nkqubela, which averages 78%, there is no significant development of drug-resistant strains. Contrary to



Westwater, Weyer and Stander (1996) – working for the MRC – argue findings which clearly show a link between poor treatment and the development of acquired drugresistant tuberculosis. Based on more comprehensive studies done throughout South Africa, their findings reveal that multi drug-resistant tuberculosis prevalence rates for those who develop initial infection of resistant strains to be at 1%. Prevalence rates for those who acquire resistance, due to poor treatment, stood at about 4%. Additionally they emphasise that patient cure rates for multi drug-resistant tuberculosis were only about 30% and therefore resistant strains of tuberculosis place a high burden on the country's health services and this needs to be addressed adequately (Weyer and Stander, 1996: 1658).

Drug-resistant tuberculosis is undoubtedly a concern for all those involved in tuberculosis control, both locally in South Africa and globally. Heightened attention given to drug-resistance has raised new issues in tuberculosis discourse. One of these issues concerns the isolation of patients with drug-resistant tuberculosis. Compulsory isolation of patients infected with highly/extremely resistant strains involves a degree of security that developing countries cannot always financially afford. Cuba has presented a good example of how a middle-income country can use compulsory isolation at the *start* of an epidemic to dramatically reduce the spread of the disease (Farmer, 1992). There can be no doubt to the success of Cuba's HIV/AIDS control programme in terms of HIV control – one only has to look at their extremely low percentage of HIV positive people (Scheper-Hughes, 1993). But tuberculosis is not by any chance at a beginning phase and in a globalised world where health care and "development" is dominated by issues of human rights, few governments are willing to risk the international controversy caused by enforcing compulsory isolation of patients with extremely drug-resistant tuberculosis.

Another issue raised by the emergence of extremely drug-resistant strains of tuberculosis concerns health inequalities and their relation to poverty. Health inequality is a hotly debated topic in economic, development, health care and policy arenas. "Describing health *inequalities* reflects a core value judgement that health *inequalities* are unfair, unjust and avoidable" (Hanson, 2002: 4). One side of this argument is for instance taken up by Woodward and Kawachi (2000) and focuses on equity of health as the right to equal *opportunity* for health. This approach suggests



that equal opportunities are enabled when historically induced issues of poverty and discrimination against ethnic groups, genders or disabled peoples are addressed. The other side suggests a more "weighted utilitarianism" that emphasise "those with the poorest health and not necessarily the health status of the poor" (Hanson, 2002: 5). This later approach often uses the language of economics to present health care as a service that should be *provided* in a *cost-effective* manner, through *efficient* bureaucracy and in a way that has long-term *sustainability*. The use of certain terms, such as those underlined in the previous sentence should not be ignored as irrelevant. Solomon, Benatar and van Rensburg (1996: 16) suggest that the various *terms* used to focus on specific perspectives in describing health care reflect the range of values that have been incorporated into medicine and interwoven into different kinds of health care systems. They point out that

those who speak of efficiency emphasize marketplace aspects of health care, while those who talk of *equity* are more concerned with social justice. *Liberty* and freedom are terms used mainly by privileged individualists while the unempowered poor speak the language of *rights*, and social conscience is expressed in the language of needs (Solomon, Benatar and van Rensburg, 1996: 16).

Paul Farmer is well known for his equity and rights-based approaches to addressing health care for the poor (Farmer, 2001 and 2003). Farmer argues that by not correctly treating poverty induced diseases, like tuberculosis, a government chooses to violate the basic human and civil rights of its citizens by actively allowing the neglect and abuse of the physical human body (Farmer, 2001 and 2003). In his view, individual health is a human right and it is the responsibility of the state to ensure the protection of the human rights of all its citizens. Therefore health becomes a civil right, an ideology which is no different to that held by members of post World War Two social democracies. For Farmer civil rights must also be defined alongside social and economic rights. He points out that in places like Boston in the United States of America (where Farmer works), people are wealthy and are able to pay for the treatment of their illnesses – when they are not offered freely by the State. Thus,



treatment *is* available, but only to individuals who can pay for it. This translates health into an aspect of social, political and economic opportunity (Farmer, 2003).

Access to opportunity is frequently minimised by what Farmer terms "structural violence". This is when "suffering is 'structured' by historically given (often economically driven) processes and forces that conspire – whether through routine, ritual or hard surfaces of life – to constrain agency, i.e. people's choices are limited by their own ignorance, cultural patterns, religious beliefs, but most often by economic or political constraints/inequalities" (Farmer, 1996: 162). For example, it can be argued in this vein that in South Africa the poverty and gross inequality experienced is due to structural inequalities resulting from a legacy of colonialism and apartheid as well as the new neo-liberal policies and economic reforms that advantage a small elite and not the majority of the population. Therefore in Farmer's viewpoint, some people in South Africa are structurally disadvantaged, i.e. they have unequal access to health resources, transport facilities, clean water, food, education, income, housing etc. This disadvantaged position causes harm to their physical bodies, often in the form of illness. As purposeful neglect of, or harm of another person's body is termed violence/abuse, Farmer equates structural inequality with "structural violence" (Farmer, 1996, 2003).

This equity-based approach to health care is compelling and demands a style of health provisioning that regards the individual to be as important as the communal/social. As such it emphasises the need for government commitment to enabling equal access to health services, by not only ensuring a functioning health care system, but also by actively working towards the undermining of social, political and economic barriers that hinder individual's ability to access these health care services. Much of this viewpoint stands in contradiction to the dominance of the reductionist biomedical, WHO supported approach to treating tuberculosis – the DOTS strategy. But due to the rise of extremely drug-resistant strains of the disease (especially in environments of high HIV levels) this overly simplified biomedical approach is being questioned. Experts are beginning to recognise that treatment which fails to take cognisance of the sociological factors hindering patient compliance to drug regimens is bound to fail in the long run. In conclusion, the dominant theme of drug-resistance in tuberculosis discourse may maintain a biomedical focus on medication and control strategies, but



it also allows for the emergence of ideas secondary to the reductionist biomedical approach to come to the surface. Although a biomedical approach is dominant in tuberculosis discourse, the arrival of HIV/AIDS has also become a key characteristic in tuberculosis discourse. In the following chapter, HIV/AIDS and its impact on tuberculosis discourse is addressed.



CHAPTER SIX

"TB is the stepchild of HIV"

"Your remedy does not treat the real seat of evil. It continually removes the traces of the enemy, but it still leaves him deep in the invaded country"

Arthur Conan Doyle¹⁴.

1. Introduction

HIV/AIDS first became a concern in South Africa in the early 1980s when the South African Medical Journal carried an editorial on the topic in February of 1982. By this time only two deaths from AIDS had been reported in the country. Initially the then Department of Health and Population Development set up three working groups to investigate this new disease. They were tasked with the stringent follow up of each case, with the building of screening programmes for high-risk groups, and with the development of an education and awareness campaign. By 1987, 63 AIDS cases had been detected and those suspected of being at greatest risk included mainly young males (both bisexual and homosexual). In 1990 the first national HIV survey of women attending antenatal clinics was conducted and of the 1 437 blood specimens taken from pregnant women, it was approximated that HIV prevalence in South Africa was 0,76% (Carswell, 1991). By this time it was already observed that HIV/AIDS in South Africa was more than just a homosexual disease and that heterosexuals, woman and children were contracting the virus. As such, in 1992 a National AIDS Committee of South Africa was formed in order to begin developing and writing an AIDS Plan for the country (Schneider, 2002: 146).

What is most significant about the arrival of HIV/AIDS in South Africa is that it occurred at a time when it was becoming increasingly globally unpopular to run "vertical" disease management programmes and a more integrated approach to health care was being encouraged. A primary health care approach was growing in reputation in the 1980s and the WHO strongly advocated its use specifically in developing countries. The essence of primary health care revolves around the

¹⁴ Arthur Conan Doyle, reporting Koch's invention of a vaccine against tuberculosis (quoted in Ryan, 1992: 148)



integration of health systems and the operation of health care at local "district" level. In other words a "horizontal" style of managing disease control programmes was endorsed.

Because it was assumed that HIV/AIDS was fuelling a global surge in tuberculosis incidence, calls to integrate the control of these two diseases began. Despite the fact that South Africa was still in the grip of apartheid, international pressure forced the de Klerk government to establish an AIDS Unit, headed by Manda Holmshaw, to integrate tuberculosis and HIV/AIDS management (Carswell, 1993). However, after only two years in operation this AIDS Unit was disbanded, the prevention programme interrupted and financing cut off (Kocheleff, 2006: 150). For the most part the separation of tuberculosis and HIV/AIDS in the health care sector continued until the early 2000s, when the National Tuberculosis Control Programme (NTCP) was eventually incorporated into a cluster division of the Department of Health, named "HIV/AIDS and TB", and steps were made to formalise simultaneous diagnosis and symptomatic treatment of the two diseases.

As the relationship between HIV/AIDS and tuberculosis became increasingly familiar to those in the health care industry, HIV/AIDS began to dominate tuberculosis discourse. The primary reason why the topic of HIV/AIDS features so heavily in tuberculosis discourse is because the two diseases are epidemiologically linked. This is especially so in Southern Africa. Figure 11 shows how in this region the HIV prevalence in tuberculosis cases is the highest in the world at over 50% of all cases. Because HIV positive individuals are more likely to develop active tuberculosis due to their lowered immunity, tuberculosis is often considered an indicator disease for HIV infection. Alternatively the onset of tuberculosis can speed up the progression of HIV into full-blown AIDS (Connolly, Davies and Wilkinson, 1998: 919, 920). Estimates for South Africa determine that in some areas 70% of adult tuberculosis patients are HIV positive and that mortality of tuberculosis patients is also highest among those who are HIV positive (Connolly, Davies and Wilkinson, 1998: 919, 920). There is no disputing the epidemiological links between tuberculosis and HIV/AIDS but the two diseases are also often linked conceptually and discursively because both are spread amongst similar populations: for example, those living in poverty.



HIV prevalence in TB cases, 15–49 years (%)

No estimate

0-4

5-19

20-49

50 or more

Figure 11. Estimated HIV prevalence in new tuberculosis cases, 2005

Source: Global tuberculosis control - surveillance, planning, financing. (WHO, 2005b)

The topic of HIV/AIDS has evolved to such an extent that it often overshadows other issues in tuberculosis discourse, such as those mentioned in the previous chapter (migration, gender, poverty etcetera). The linking in South Africa of tuberculosis to HIV/AIDS has the resultant effect of further edifying the reductionist biomedical approach to tuberculosis control. Three examples of how this occurs are given in this chapter. *Firstly*, HIV/AIDS treatment debates in the country weaken already subjugated viewpoints of poverty as a sociological factor influencing the prevalence of disease. The HIV/AIDS treatment debate in South Africa is divided between the government's premise that HIV is a disease of poverty and needs to be treated as such and the second viewpoint, which argues that HIV/AIDS should be treated principally using biomedical advances in medication. A result of this debate is that the government's emphasis on social issues is pushed aside in favour of dominantly biomedical treatment approaches. The unintended effect is that the biomedical basis for treating tuberculosis is thereby also justified.



Secondly, the individualisation of HIV/AIDS has been transposed onto tuberculosis, resulting in entrenching an already existing view of tuberculosis treatment. This is highlighted when examining how the language of HIV/AIDS is used increasingly in tuberculosis discourse. For example, the use of the word "client" in HIV/AIDS discourse is endowed with connotations of individualism and is now being used in South Africa when discussing tuberculosis treatment. Not only is tuberculosis (and HIV/AIDS) treatment subsequently individualised but so also is the expected outcome for the patient. Regrettably, the conceptualisation of treatment outcome as individual responsibility puts "the onus of the disease on the patient and not only weaken[s] the patient's ability to understand the range of plausible medical treatment [available] but also, implicitly, direct[s] the patient away from such treatment" (Sontag, 1978: 47).

As the dominance of the biomedical model is strengthened in tuberculosis discourse the state is able to withdraw from certain provisions in the health care sector. The state retains only the responsibility to provide a health service based on the biomedical healing system. Consequently a redefining of responsibility for certain welfare services occurs. In contrast to the post Second World War social democratic consensus where the state was seen as responsible for providing a safety net for the poor, this task is now taken up by individuals, communities, the non-profit sector and private industry. Therefore the *Third* example addresses the issue of community and home-based care in the era of HIV/AIDS. Although community-based care was advocated from the start of the primary health care movement in the 1970s, home-based care in South Africa only became a reality in the late 1990s. For the most part home-based care in South Africa is preformed by semi/un-skilled community health workers, volunteers and relatives of the sick. This leaves citizens with the burden of caring for terminally ill absolving the state of its responsibility and hence impoverishing the poor further.

2. The politics of HIV and AIDS treatment

The HIV/AIDS prevention and treatment discourse is dominated by an essentially North-South divide. Resource-poor, southern countries tend to emphasise the need for using both preventative and treatment strategies simultaneously to curb the spread of HIV. On the other-hand the resource-rich, northern countries adopt purely treatment-



based programmes in their own boarders but *suggest* that resource-poor countries would be better off by implementing seemingly more "cost-effective" prevention campaigns (Seidel, 1990: 476). In South Africa a preventative, more social approach is the focus of the government anti-HIV campaign. A more biomedical approach is taken by so-called AIDS activists, notoriously represented by the Treatment Action Campaign (TAC). There exists an ongoing battle between the ANC and the TAC since 1998 which elucidates the tension between a dominant reductionist medical discourse that demands biomedical treatment for those who are ill, and a more holistic approach to health care that takes cognisance of the social causes of disease.

Since 1998, the TAC in South Africa has campaigned for cheaper generic antiretrovirals (ARVs), has demanded that access to ARVs be a constitutional right and has berated the government for its apparently slow, irresponsible and ignorant approach to dealing with HIV/AIDS (Vandormael, 2005: 60). The TAC won a "victory" against the government when the constitutional court ruled that it was unlawful for the government to deny medicinal treatment for HIV/AIDS and compelled it to provide such treatment for free to pregnant HIV positive woman (TAC, 2007). As the government began to role out Nivirapene for pregnant woman it also conceded to make ARV treatment free for those living with the HI virus whose CD4 count was lower than 200. Additionally it provides free vitamin supplements to people living with HIV and it offers them the possibility of receiving prophylactic (Isoniazid) treatment for tuberculosis (NTCP, 2004c).

But as Vandormael argues, the discourse of HIV/AIDS in South Africa is marked by a "confrontation" in which two positions differ over the "central question concerning the most appropriate and effective response to the HIV/AIDS epidemic" (Vandormael, 2005: 57). The first position is held by the TAC, the media and most of the medical community in the country and is described by Vandormael as being "dominated by the Western hegemonic discourse" of disease. It regards a technical response to HIV/AIDS, "via the provision of ARV medication, as *the* feasible solution" to control of the disease (Vandormael, 2005: 58). "The second position is represented by the South African government, the ANC and various other marginal factions" and rejects or shows scepticism of this dominant medico-scientific discourse, "which considers HIV/AIDS to be a medical problem, or disease curable



by the invention of some vaccine, or by the development of an advanced series of medical intervention programs" (Vandormael, 2005: 58).

When the president of the country, Thabo Mbeki, announced his views in 2000 on the causal relationship between HIV/AIDS, the hysteria that erupted in public circles and in the media took him by surprise. For Mbeki, questioning the dominance of medicoscientific knowledge was key to the production of knowledge and he suggested that "there exists a scientific view that is supported by the majority who 'argue that the only freedom we have is to agree with what they decree to be established scientific truths' and that the government cooperates with scientists 'to freeze scientific discourse on HIV/AIDS'" (South African Government, 2000 – quoted in Vandormael, 2005: 59). Mbeki's suggestion that poverty is a key factor in the spread of disease and the Health Minister Manto Tshabalala-Msimang's recent articulations that beetroot, garlic, a healthy diet and exercise will help keep AIDS at bay (Blandy, 2006) have prompted much uproar over their apparent "simplification" of the disease's treatment. However, it is evident that Mbeki and the ANC have sought to challenge the approach which sees disease as a mere medical problem and have argued that Africa's health problems are not simply to be "blamed on a single virus" (Mbeki, 2000). In this way they are contending against the dominance and exclusivity of medical scientific knowledge. Therefore as Vandormael claims, the campaign of civil society organisations, like the TAC, has actually served to prevent a "constructive dialogue on the subject of HIV/AIDS and thus the development of an African-specific response to the epidemic" (Vandormael, 2005: 59).

For Vandormael, the TAC's campaign to force the government into providing HIV treatment has ambiguous outcomes. On the one hand, it has enabled HIV/AIDS treatment policy to be brought into the public realm where it can be contested by civil society. In doing so the dominant reductionst biomedical position is confronted with the subjugated ideas about the social, political and environmental aspects of health. As a result numerous sectors of society have been able to voice opinions about the disease. However, at the same time the TACs campaign has simultaneously "removed" the subject of HIV/AIDS "from the public realm by insulating it within the institutional domain of the scientific and biomedical establishment" (Vandormael,



2005: 65). This for example has left politicians excluded from having a significant influence in the discourse.

The debate between the South African government and the TAC does consist of a simple dichotomy between the ANC on the one hand, that proposes addressing poverty in health care, and the TAC on the other hand, that lobbies for the introduction of free antiretrovirals. The debate is far more nuanced than the scope of this study can address. Underlying the complexity however is the assumption by both parties that citizens are "victims" – "victims" of historically unjust colonial structures, or of greedy capitalist driven governments, or of large profit-driven pharmaceutical companies. The essence of such an assumption is that citizens are regarded as passive entities. The TAC regards the South African government as holding responsibility for delivering the medication needed to improve the lives of people living with HIV/AIDS.

The South African government has conceded and citizens are "expected to return to the daily affairs of their lives; content that sooner or later they will be able to access ARV medication" (Vandormael, 2005: 70). But the government's argument that addressing poverty will curb the spread of HIV/AIDS is no less empowering for citizens. Although the president is right to argue that discourses of health and healing should not disregard the social elements of disease, he does little to suggest how the state will address such issues when curbing the spread of HIV/AIDS. Instead the Health Minister goes on about individuals maintaining a healthy diet and lifestyle. But poor people usually do not have the luxury of maintaining such a lifestyle or of affording nutritious, immune boosting meals. State implemented and Aid Industry driven poverty alleviation strategies usually take years to take effect and in the meantime HIV/AIDS still effects predominantly the poor and marginalised in Southern Africa. Without a comprehensive solution the responsibility for addressing the spread of the disease is placed upon individuals or the "community". Therefore, Mbeki's statements do little to actually improve the health of his citizens and this places the burden upon their shoulders - disempowering them and making them victims of deferred responsibility.



What also becomes apparent from the above debate is that medicine has a sociopolitical impact because it can be used to achieve certain political aims, i.e. politicians bow to civil society pressure to provide health care in a manner that they demand. There is nothing wrong with politicians adhering to the requests of their constituents – it represents a core practice of democracy – but this scenario does highlight how medicine, and medical science are not politically or value neutral and can be used to further certain aims (such as making the ruling party look good or look bad). At times this use of biomedical science as a "tool" for political gain may not actually serve the well being of citizens in general (Figlio, 1982). It is for this reason that Marxists/conflict-based approaches to medical sociology contend – in the same vein as does Habermas – that scientific biomedicine should be seen as ideological (Gerhardt, 1989: 251). This view asserts that the power relationship between the dominant classes and the state facilitates the unchecked growth of the medical model and that medicine is identified as an institution of social control proliferating in modern society (Gerhardt, 1989: 286).

As can be seen from the example of the conflict between the TAC and the government, the political discourse of health and illness becomes dominated by technocrats (technical experts in the field); it becomes reduced to the apparently scientific rationality that biomedical treatment is the most effective to treating HIV/AIDS. As such the argument for biomedical intervention in disease control is strengthened, whilst the sociological arguments get relegated to the periphery. This scenario is strengthened in the case of tuberculosis when the outcome of chemotherapeutic treatment for the disease is perceived as being the responsibility of the each individual patient. As tuberculosis discourse becomes intertwined with HIV/AIDS discourse the individualisation of HIV/AIDS encourages a similar perception of tuberculosis. Individualising disease, or individualising treatment outcomes has the effect of dislocating disease and its control from the social context surrounding it.

3. Individualising tuberculosis treatment

In the language of HIV/AIDS activists the word "client" is frequently used to refer to HIV positive individuals. Regrettably the word is at times also used to refer to



tuberculosis patients as a direct result of the disease's close association with HIV/AIDS. Examples of the use of this word can also be found in government printed documents such as the *HIV and STI plan 2000*-2005 which states that there is a need to "conduct national HIV infections surveillance in selected populations and groups, including STD and TB *clients...*" or that "Health promotion materials...were not *client* sensitive" (NTCP, 1999a: 24). The 2004 *Tuberculosis Guidelines* (NTCP, 2004a: 61, 62) also refers to "clients" and not patients on various occasions. According to the Director of the NTCP the argument behind using the word "client" is that HIV-positive individuals are not necessarily ill or on treatment and can therefore not be termed patients.

"Client" is a Middle English word, taken from the French and Latin *client- and cliens*, denoting "dependant" or "follower". It is a noun meaning: "person who seeks advice" or someone who pays for goods or services (Mirriam-Webster, 2007). When used in a health care context the word carries the implied assumption that health care is a service which can be commodified and bought (potentially in exchange for a supporting vote). Such an exchange metaphor facilitates the notion that once a fee has been paid and a service is rendered or treatment is prescribed the onus of the outcome depends on how the "buyer" uses the purchased goods. For example, the state may provide tuberculosis treatment for free to individuals, although it does so at a set cost to its own budget, but the result of the treatment depends on the individuals' response to the treatment. He or she must adhere to the specifications of the medication/treatment or else it will not "work" (i.e. result in a cure). The onus of the treatment's success is therefore placed upon the individual user and not the provider of treatment.

In interviews with respondents this exchange metaphor was used to describe how nurses treated tuberculosis "defaulters". Respondents pointed out that when tuberculosis patients were found to have "defaulted" on medication, nurses reacted abruptly and antagonistically because further treatment would require excess paper work and longer supervision¹⁵, i.e. more work for the nurses. Although there is no conclusive evidence that nurses treat "defaulters" with less care than first-time

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¹⁵ Re-treatment periods for tuberculosis patients can be as long as two years.



tuberculosis patients, the mere suggestion that it occurs highlights the perception that such patients are treated differently because nurses regard these individuals as being at fault. Tuberculosis treatment outcomes are therefore individualised and resultant on patient behaviour. This conceptualisation is not unique to South Africa.

The individualisation of tuberculosis treatment began to develop within the WHO in the late 1960s. At this time, tuberculosis from the perspective of the WHO "began to be viewed in light of individual behaviour, choice and generalized social action" (Amrith, 2002: 31). The 1960s studies in Madras India initiated an emphasis on issues such as patient compliance to treatment, or treatment seeking behaviour (Amrith, 2002: 31). As this viewpoint gained dominance, not only was the source of tuberculosis linked to individual behaviour (as argued by Sontag) but so also was the outcome of its clinical treatment. In other words, responsibility for a successful cure (i.e. the restoration of health) was seen to rest primarily with the patient.

In reference to the contemporary treatment of tuberculosis symptoms, such a reductionist biomedical way of thinking merely encourages actions such as the taking of medication/pills or the undergoing of a clinical operation. This highlights how the nature of reductionist biomedicine is individual because it targets the disease and not the social causes of illness. In other words, the disease afflicting the individual has become the focus of treatment, not the sociological factors that have led to its development. It is because of this understanding that standardised treatment regimens for tuberculosis continue to be the accepted norm. Despite the fact that there are many extenuating circumstances that could hinder a patient's successful completion of his/her tuberculosis treatment, chemotherapeutic regimes in South Africa are still standardised for all patients and are not individually tailored. The individualisation of tuberculosis treatment outcomes places the responsibility for a cure, and ultimately health, on the patient's shoulders. In doing this, the social as well as the broader environmental factors governing patient adherence to anti-biotic treatment are ignored, leading to potential stigmatisation of the diseased person.

Another illustration of how patients' health is individualised and of how the social causes perpetuating disease are ignored is the NTCP's lack of grant money or food provisioning for poor tuberculosis patients. According to the Director, the South



African NTCP does not encourage the provision of any form of social assistance to patients receiving tuberculosis treatment. The *Training Manual for Health Workers* explicitly states as well that "no patient should be kept in hospital for nutritional support only" and that instead some form of nutritional support "should be arranged for patients with inadequate access to food at home" (NTCP, 1998: 56). Antituberculosis chemotherapeutic drugs are toxic, with serious side effects and the 2004 *Practical Guidelines* recommends that medication, especially Rifampicin, "be taken with food" (NTCP, 2004a: 80).

Organising nutritional support requires arranging a social worker to consult the patients at his/her home and to conduct a needs assessment. In a social work system already overloaded it could be week before one visits the patient. Nurses and medical practitioners realise this and from interviews with managers of the NTCP it became evident that some districts were still providing food parcels of small grants to tuberculosis patients – contrary to the NTCP guidelines. This caused much frustration for some respondents in this study as they argued it caused "patient dependence" and because it gave them a sense of loss of control over the organisation. In their view this practice increased the possibility that patients would actively default on completing their medication in order to remain sputum test positive (thus diseased) and hence continue to receive the food parcel or grant supply. This suggests that respondents are aware of the social nature of tuberculosis but cannot get their minds around the idea. It also means that they knowingly allow malnourished people to die of tuberculosis.

Evidently the respondent's perception (as there is no research-based evidence supporting these claims) that patients would default in order to retain the grant or welfare support reaffirms the conceptualisation of tuberculosis as an individual disease and successful treatment as the result of individual choice. In other words, the perpetual solution to the disease is understood to lie in each individual taking their medications, not in addressing the social, environmental causes of the illness. Clearly therefore, there exists a dominant view of tuberculosis as an "individual" disease. This hinders the successful treatment and eradication of this disease because such a viewpoint is supported by almost mythical and stereotypical assumptions, (especially due to its association with HIV/AIDS) that stigmatise patients and place blame on the individual and not on structures or strategies. As Farmer suggests, the result is that:



authorities rarely blame the recrudescence of tuberculosis on the inequalities that structure our society. Instead, we hear mostly about biological factors (the advent of HIV, the mutations that led to drug-resistance) or about cultural and psychological barriers that result in 'non-compliance'. Through these two sets of explanatory mechanisms, one can expediently attribute high rates of treatment failure to the organism or to uncooperative patients (Farmer, 2003: 147).

An example of this is confirmed in NTCP publications which focus on how to address HIV/AIDS in tuberculosis patients yet make little mention of how to address poverty amongst these patients. One document entitled Tuberculosis and HIV/AIDS (NTCP, 2000) is devoted entirely to addressing the simultaneous treatment of both diseases. The Tuberculosis Training Manual for Health Workers (NTCP, 2004b) has a whole chapter on HIV but only an appendix on how poverty affects people's chances of developing tuberculosis. This is despite the fact that the WHO has developed a guideline for national tuberculosis control programmes on how to address poverty and tuberculosis entitled Addressing poverty in TB control: options for national TB control programmes (WHO, 2005c). This booklet for instance argues that in order to perform their jobs properly, "those working in medicine and public health must understand the social context of health interventions and the social and economic forces that shape people's chances for well-being" (WHO, 2005c: 4). It addresses the barriers to accessing tuberculosis services by poor and vulnerable groups and suggests potential actions to overcome these barriers. Suggestions include the provision of free treatment and incentives to completed treatment, the undermining of stigma, the provision of treatment close to affected communities and a focus on alleviating the burden of treatment on the patient (WHO, 2005c: 31). This WHO publication challenges prevailing methods of tuberculosis control that focus exclusively on technological approaches and encourages national tuberculosis control programmes to consider innovative ways of combating the effects of poverty on tuberculosis.

When disease is dislocated from its social context the state is justified in it its provision of treatment forms that address only the biological aspects of a disease. The



sociological aspects are thus left to the responsibility of individuals, charities or private enterprise. In South Africa, the adoption of the primary health care approach encouraged a movement of health care towards the district or community level and the dispersion of health care services into the homes. But it has not been the state that has taken the responsibility for health care in homes. Instead this responsibility has been born primarily by individual citizens, charities or other private enterprises.

4. Recasting responsibility

After 1994, tuberculosis control began to be viewed as a primary health care concern. A primary health care approach entailed making basic health services available to all people. This facilitated a general shift away from hospital-based care, to a more community centred approach. Although community centred health care has many advantages for citizens it has the latent result of allowing the state to withdraw from fulfilling certain obligations and functions. The example of how HIV/AIDS and tuberculosis control in South Africa is conceptualised perfectly illustrates this.

The implementation of the biomedically based DOTS strategy entailed the development of a dispersed medical "surveillance system". Primarily this is because the most essential requirement for eradicating tuberculosis using a drug regimen is to ensure that a patient completes his/her treatment. This is so vital that the entire DOTS strategy hinges around a government's commitment and ability to ensure the necessary policies and structures are in place to facilitate "patient adherence" (WHO, 1997 and 1998b). In light of the growing burden of HIV/AIDS and because many developing countries, like South Africa, do not have the resources to hospitalise all tuberculosis patients for the full term of their treatment (and thus to ensure completion of medication) the WHO and the STOP TB Alliance, recommends the building of "partnerships" with the private sector and civil society to aid in the development of so called "community-centred" health care. This proposal is expressed for example in the report of a 3 year long WHO collaborative study on six high-prevalence, developing countries in Africa, where is was determined that "the HIV-fuelled tuberculosis (TB) epidemic is outstripping the ability of health services to cope" and that "since National TB Programmes (NTPs) are often not achieving adequate case-detection and treatment outcomes, it is necessary to explore ways of complementing government health service provision of TB care" (Maher, 2003: 6 italics mine).



The study report made a suggestion that in the context of HIV/AIDS there should be a decentralisation of "the provision of TB care beyond health facilities and into the community" in order to contribute to effectiveness of National Tuberculosis Programmes' performance (Maher, 2003: 3). Effectively, decentralised health care implies the adoption of community-based health care programmes. This approach is underlined by an ideology that poor communities should be "involved" in their own development to the extent that they should offer their time and energy in semi-volunteer services and be expected to fulfil a wide range of services for very little reward. This ideology assumes that the reward is to be found in personal satisfaction for doing good.

Government documents and interviews with respondents reveal that health officials encourage the involvement of individual citizens, charities and non-governmental organisations in health care services. This is articulated as the need to form "partnerships" for service delivery. Respondents in this study mentioned that government, private industry, business and NGOs (used here to refer to all charities, community-based and international aid organisations) should work in "partnership" to provide health care to the citizens of the country. A key document in this study, *The National Tuberculosis Programme Plan, for 2000-2005*, uses this phrasing to discuss the future of tuberculosis control:

In the multi-facetted and decentralised health sector, *partnerships* will be established and/or strengthened at the national level among the various departments, institutions and organisations relevant to the NTCP: HIV/AIDS&STD, strategic health programmes, laboratory, health service delivery, academic institutions, private for profit health organisations, NGOs, police, correctional services, military services, mines, etc. At the international level *partnerships* will be strengthened/built with a/o Belgian Government, CDC, DFID, IUATLD, KNCV, SADC, SATCI, USAID and WHO (NTCP, 2001: 20 italics mine).



In March of 2000 the government committed itself to combating tuberculosis by signing the declaration of Amsterdam, along with the other 22 high-burden countries, The South African NTCP was encouraged to adopt the recommendations made by the Global DOTS Expansion Plan, set by the WHO in November 2000, and to formulate a Medium Term Development Plan as soon as possible. This Plan was then drawn up for 2002-2005 and aimed to encourage the "building of partnerships" in order to mobilise the necessary human and financial resources for expanding the NTCP (NTCP, 2001: 15).

Encouraging relationships with private sector providers in both the non- and for-profit sectors reflects a "prevailing ideological view of the potentially greater quality and efficiency of the private sector and the virtues of using competitive contracting as a way of shaking up the public sector" (Standing, 2002: 21). Private enterprise, as nonstate, is as such assumed to be efficient, productive, economically rational, dynamic, adaptable and politically neutral (Gibbon and Olukoshi, 1996). It is this ideology that underpins neo-liberal policies, which emphasise a decentralisation of public services – such as health services – as a way of increasing "accountability to local populations". In a way this entails a privatisation of arguably traditional state functions. This privatisation is a classic example of neo-liberal practices and is often expressed in the language of the markets, such as in the use of the terms "cost and effect" and "partnership". By privatising traditionally state functions the state maintains a selective involvement and responsibility for the provision of basic services. Privatisation skews the service sector in a market driven direction. In the health care industry for example private for-profit organisations provide health services in ways that give them greatest financial gain; and not-for-profit organisations that take up this responsibility only provide services that appeal most to donors (example, HIV/AIDS). Important health care issues are thus marginalised in favour of dominating concerns and the overall health welfare to the poor is compromised.

An example of how the dominating concern of HIV/AIDS has contributed towards privatisation and state withdrawal from provisioning of health care is highlighted when examining the change in tuberculosis control from hospital-based treatment to community, home-based treatment. In large part this move towards community centred treatment was a result of the individualisation of tuberculosis and of the



global pressure for developing countries to adopt a community-centred approach as a cost-effective system of health care. In response to the growing rise of tuberculosis in developing countries (due to HIV/AIDS), Amrith argues that the DOTS system of control in these countries took on a primarily outpatient-based approach.

In South Africa, non-profit organisations or charities were recruited in "partnership" with the NTCP to begin training and managing so-called tuberculosis/DOTS supporters. These supporters ensure that each patient under their charge (maximum of 15) swallows their pills daily and goes for regular checkups and sputum tests. Tuberculosis supporters are often family members, friends or work colleagues but usually they are volunteers affiliated with local community-based organisations who take an interest in tuberculosis control. Although some municipalities offer stipends to the tuberculosis supporters, most give of their time voluntarily. With the increase in HIV/AIDS the need to extend the knowledge and tasks of such volunteers has resulted in the conceptualisation of what is today known as Community Health Workers.

Community Health Workers fulfil a role similar to that of the health workers found in other African countries during the 1970s and 1980s (see chapter four). In 2002 the Minister of Health, Dr. Manto Tshabalala-Msimang (2004a) officially launched the Community Health Workers programme, allowing for legislation determining the training, responsibilities and financial compensation of Community Health Workers. According to the Community Health Workers Policy Framework they are considered to be "community-based generalists who will combine competencies in health promotion, primary health care and health-resource networking & coordination" (Department of Health, 2004: 1). Although required to only provide a "limited health service" they are expected to "enter communities and households, engage with community members, determine what health or other service requirements are needed and coordinate that these services are made available" (Department of Health, 2004: 1). In this instance the "community" refers to "the people that reside in the catchment area of a clinic" (Department of Health, 2004: 5). Community Health Workers are government recognised, "formalised" caregivers and are offered a very small stipend which can range anywhere from about R500 - R1200 per month. On the other hand informal caregivers include relatives of the sick or community members who voluntarily shoulder the responsibility of caring for ill strangers.



The emphasis on Community Health Workers is part of a move by the South African government towards a focus on home-based care. According to the Minister of Health, "home and community-based care is a very important component of [the government's] response to HIV and AIDS, TB and other debilitating diseases. It is centred around the principles of Batho Pele¹⁶ and geared towards community empowerment" (Tshabalala-Msimang, 2004b). She emphasises that "there is no way that government can single handedly provide the holistic care that is required for people with TB, HIV and AIDS" and that there must be a "social contract between government and communities including NGOs and CBOs that clearly outlines the responsibility towards each other" (Tshabalala-Msimang, 2004b). The Minister stated that South Africans need to start "owning" the health programmes and that there must be a move towards "self-reliance" (Tshabalala-Msimang, 2004b italics mine). Such a statement implies that individuals should take up the responsibility for health and that in essence the state is justified in eschewing responsibility for providing comprehensive health care. The underlying rational assumes that individuals should "partner" with the state and show "ownership" of their health because disease and its control is the responsibility primarily of individuals. However, clearly this does not empower citizens but leaves them instead with additional burdens, increased potential to be blamed, and decreased accountability of the state.

5. Home-base care in the era of HIV and AIDS

The growth of the home-based care model is a feature of the era of HIV/AIDS. Terminally ill patients stretch state health-care facilities and infrastructure and thus an approach advocating for the care of these patients in their homes relieves the state health care system of this burden. Findings from some studies reveal that if properly planned home-based care programmes *can* alleviate the pressure that caring for HIV/AIDS patients has on formal health care facilities, and also that such

¹⁶ Batho Pele is a SeSotho phrase meaning "people first" and is a slogan of the South African Department of Public Service and Administration. Interestingly it is a similar to popular slogans used in the 1970s in many African countries to denote "self-reliance". The social context in which such phrases are used determines their nature. As government's fail to deliver on their promises however, these slogans often end up representing oppressive practices that discourage the empowerment of citizens and hence undermine their literal meaning - "people first within society". In this example neoliberal discourse uses "leftist" or "populist" slogans, which sound positive but are in fact oppressive in consequence.



programmes have clear health, social and economic benefits for the patients and their families (Nsutebu et al., 2001 and Akintola, 2006). But in South Africa evidence suggests that home-based care places an increased burden on poor citizens, especially woman – causing physical, emotional, economic and social stress. Poor citizens are thereby further impoverished and the general well being of society is reduced.

Examples of home based-care initiatives abound across African countries. In South Africa's KwaZulu-Natal province traditional healers have served as community-based healers for generations but their services are now being called upon to administer DOTS supervision, to provide health education, to render basic diagnosis and to make referrals to the respective health facilities (Colvin et al., 2001). A Medical Research Council study reported that traditional healers who are involved as DOTS supporters usually perform other occasional home-based visits, bringing food and council to their patients and their families, greatly improving the satisfaction of patients and successful treatment completion rates (Colvin et al., 2001). The study reports that with regards to tuberculosis patients:

Overall, 89% of those supervised by traditional healers completed treatment, compared with 67% of those supervised by others. The mortality rate among those supervised by traditional healers was 6%, whereas it was 18% for those supervised by others. Interestingly, none of the patients supervised by traditional healers transferred out of the district during treatment, while 5% of those supervised by others did (Colvin et al., 2001).

In another study comparing South Africa's home-based care initiative with Uganda's programme the most noticeable difference was that in Uganda home-based care was marked by professionalism (Akintola, 2004). Community-based organisations, NGOs and charities who aided HIV/AIDS, tuberculosis or terminally ill patients in Uganda usually hired skilled health care workers, such as nurses and doctors to care for the patients. Not only could these health care workers provide medical support in the form of administering injections, medications and so forth, but they also provided social support by educating family members on good hygiene, basic nutrition, terminal care, and so forth. A similar study in Kenya reported the same findings,



whereby Community Health Workers included qualified nurses and midwives who offered supplementary services to family caregivers by visiting them in their homes (Pathfinder International, 2006). In contrast in South Africa, most home-base care initiatives are serviced by unskilled volunteers who cannot administer drugs and medical care. Their capacity is thus limited to the provision of spiritual, moral, and basic hygiene support to the ill and their families (Akintola, 2004: 21).

Akintola suggests that South Africa's poorly planned and implemented home-based care model can lead to the latent impoverishment of people, especially for females. It is usually women who volunteer their time and energy as home-based caregivers (both formally and informally). In part, this is because stereotypically woman fill the role of caregiver in the home or of nurse in the clinic. These women spend their time caring for the ill, either their own family members or non-relations. For instance, a Health-e News article describes the work of a Community Health Worker in Soweto, Near Johannesburg (Bodibe, 2007). Phandile Nhlapo cares for ill patients in a poor settlement. The article describes how Phandile listens to an ill woman's fears that she will die and leave her children orphaned and her adolescent daughters vulnerable to potential sexual abuse (Bodibe, 2007). Phandile listens to the woman's tragic story and offers what little advice she can give, but she is also poor, only has a high school qualification, and has no counselling training. In the meantime Phandile brings the woman food and helps her clean her little shack (Bodibe, 2007). This story is similar to that of many other caregivers and the stress of Phandile's daily task is overwhelming. These individual caregivers are expected to advise households on primary health care, basic sanitation and are required to provide basic care services, such as bathing and feeding the terminally ill (Cruse, 1997: 2). Heggenhougen et al. argue that family caregivers or volunteer Community Health Workers "cannot be little supermen...who provide and promote comprehensive health activities while health and other sectors proceed unchanged as before" (Heggenhougen et al., 1987: 154).

Akintola's study also reveals how many of these women who are caregivers show a high rate of attrition due to the lack of financial compensation, the long hours and the high stress levels incurred from caring for the seriously ill (Akintola, 2004). Caring for ill patients is both emotionally and physically stressful. According to Akintola, "physical stress usually comes from lifting and supporting patients, bathing patients,



doing household chores and other duties for the sick person and, for some of the volunteer caregivers, walking long distance in the sun to the patient's houses" (Akintola, 2004: 24). She identified physiological stress symptoms resulting from the worry and anxiety of the inability to give patients what they needed and their difficulty in coming to terms with the inevitability of their patient's death.

Moreover, most caregivers who offer home-based care rarely receive any financial remuneration because they are family members of the sick and are not associated with any community-based organisation. They offer their services voluntarily or out of commitment and obligation. Whilst caring for their ill family members their ability to spend time finding better paid employment is diminished. This applies to both informal and formal caregivers. Volunteer caregivers and formal Community Health Workers also often experience social stress because they are isolated in their task of providing twenty-four hour care for their patients (Akintola, 2004: 26). Their task is time consuming and in the case of HIV/AIDS, often carries an attached social stigma. As such, caregivers – generally women – are severely disadvantaged by a health care system that defers patient care to the home and, although the Minister's call to "self-reliance" and "ownership" of health is compelling, it is not a viable, sustainable option for many of the poor – in fact it undermines the general health and well-being of patients and caregivers, and ultimately entire households.

Not only does the move towards community and home-based care disadvantage individuals directly involved as caregivers, but it has also had dramatic effects on the role of charities in tuberculosis control. Community Health Workers are recruited through community-based non-profit organisations (charities), as well as larger non-governmental organisations affiliated with local clinics. These organisations rely on donor funds to continue operating. If they are involved in the training and coordination of Community Health Workers or tuberculosis supporters then these funds usually come from government, but funds are also sourced from the global and local philanthropic networks. However, in a medico-development industry dominated by the issue of HIV/AIDS, those community-based organisations that focus primarily on tuberculosis care (despite the fact that they may also be involved in feeding and job creation schemes or patient support programmes) may find themselves severely short of funds. For this reason these latter organisations find it more profitable to align



their visions and missions with some form of HIV/AIDS concern, which draws far more media attention and therefore the support of outside donors. Scrambling for scraps of funding by linking themselves to an HIV/AIDS campaign leaves the mandate of tuberculosis centred community-based organisations diluted and unfocused.

What becomes apparent is that the role of non-profit/charity/community-based organisations in tuberculosis control has changed. As mentioned previously, the implementation of the DOTS strategy entailed that many tuberculosis non-profit organisations (such as those affiliated with SANTA) shift their involvement in tuberculosis control from a hospital treatment-based support capacity towards a community treatment-based support capacity. Secondly, the influence on HIV/AIDS on donor funding of these organisations has necessitated a shift in focus towards the training and recruiting of Community Health Workers. Thirdly, the increased attention given to biomedical treatment of HIV/AIDS and tuberculosis has forced community-based organisations to supplement the states reductionist medical service. Many such organisations thus emphasise their ability to offer non-medical services to the community, such as providing food parcels, clothing, skills development and so forth. According to the CEO of SANTA, non-profit organisations that offer these services do so because they recognise that tuberculosis is a disease associated with the high levels of poverty and inequality and that these factors need to be addressed in its control. As the Chairman's review of SANTA in 2006 states "it is regrettable that so many of these types of projects [the feeding schemes and so forth] were discontinued due to the pressure and emphasis on DOTS" (SANTA, 2006: 1). Notwithstanding, the non-profit industry's involvement in tuberculosis control in South Africa has always been the major force compelling attention towards tuberculosis as a social disease needing social, and not just clinical, intervention.

The poverty alleviation services offered by tuberculosis focused community-based organisations maintain a marginalised theme in tuberculosis discourse, that tuberculosis is a disease of poverty and must be treated as such by addressing issues like inequality, poor nutrition, overcrowding, substance abuse, and lowered immunity. One such organisation is the TB Care Association situated in the Western Cape. According to the Director, TB Care provides holistic care to poor tuberculosis patients



by servicing some of the community's non-medical needs. TB Care therefore hosts skills workshops for unemployed people, it offers parenting courses and alcohol awareness campaigns and community support groups. Additionally, it trains volunteers in the workplaces of the Cape Town region as DOTS supporters and promotes workplace policies that do not discriminate against people with tuberculosis. Finally because of the high rate of tuberculosis in prisons, TB Care offers an invaluable service of educating prisoners about the spread of the disease and trains DOTS supporters in the prisons (TB Care Association, 2007).

The services that organisations like TB Care provide are essential for tuberculosis control. Tuberculosis patients who are extremely poor (as is often the case) and cannot take their medication on a full stomach are vulnerable to the harmful effects of powerful chemotherapeutic agents. Additionally it is most likely the poor who will suddenly move mid-way through their treatment because they find employment in another city. Managing the effects of poverty during chemotherapeutic treatment is vital therefore if the treatment is to succeed. The state health care department does not provide grants or nutritional food for patients on tuberculosis treatment. Instead it has relinquished this responsibility to community-based or non-profit based organisations, like TB Care.

However, the reliance on such "complementary partnerships" with community-based organisations, charities or even private enterprise for the "success" of service provision should not be considered a long-term solution for social welfare, because when donor funds dry up it leaves these services in jeopardy. The dependence on community-based organisations to address the social issues in health care is thus not a "sustainable solution". Those promoting a cost-effective approach to health care often argue that the DOTS strategy is ideal for developing countries because it represents an opportunity to combat tuberculosis in a partnership-based manner between the state and civil society.

This prevailing thinking suggests that even though the state supplied tuberculosis treatment is dominantly biomedical the private and civil sectors can be relied upon to address the surrounding social issues of tuberculosis. Such propositions reflect a foundational neo-liberal ideology of development whereby individuals are seen as



needing to take responsibility for their own welfare. As a matter of fact, this is the key assumption behind the so-called "free market" (a term synonymous with neo-liberal discourse) in which individuals can "freely" compete for profit and gain to individually develop their capacity. In the health care industry this ideology manifests itself in the example of community-based care for tuberculosis treatment. Here, the provision of vital comprehensive health-promoting services (such as providing food with which to take medication) are disregarded by the state and left to the responsibility of either individuals themselves or to the private sector (both for- and not-for-profit).

The suggestions that partnership is the key to addressing the social causes of tuberculosis is therefore unsatisfactory because it has the unintended consequence of leaving citizens with little ability to exact any structural change, or to exercise agency. In an era of HIV/AIDS, when community and home-based care are promoted, weak state health-care systems come to rely on community-based organisations and NGOs to fulfil this task. However, NGOs are generally accountable only to their donors and not to the citizens themselves, leaving citizens unable to hold the actions of these agencies accountable when their actions have negative influence. Additionally, when social services and the basic needs of citizens are met by NGOs, charities and private enterprise, citizens have no need to compel the state to deliver. As Neocosmos (2006) and others argue, this results in a pacification of citizenship - an argument of "victimhood" – whereby people no longer demand the state to fulfil its duties and are incapacitated in their ability to rally for dramatic yet necessary social change. As such the political agency of citizens is undermined and they are disempowered. Individuals therefore become victims of the state's withdrawal of involvement in health care provisioning.

In conclusion then, the association of tuberculosis with HIV/AIDS leads to the ignoring of the socio-economic context of disease and dislocates disease from this context. As a result tuberculosis is individualised and treatment is structured around this understanding. Tuberculosis discourse becomes dominated by the topic of HIV/AIDS and by a biomedical ideology, which emphasises a reductionist biomedical approach to infectious disease control. This tendency is noted by Doyal and Pennell who argue that in a neo-liberal setting "despite the obvious importance of social and



economic factors in the causation of ill health, the characteristic response to health problems has not been prevention, but an almost total reliance on after-the-event medical intervention of a curative kind" (Doyal and Pennel, 1981: 139). When state welfare/health care is regarded as being the act of providing only biomedical intervention, it does not bode well for health care in general. Citizens are hence burdened with the task of maintaining their health by struggling to address, in their everyday lives, the social issues surrounding disease and wellness.



CONCLUSION

"There is a tide in the affairs of men, which taken at the flood, leads on to fortune; omitted, all the voyage of their life is bound in shallows and in miseries. On such a full sea are we now afloat. And we must take the current when it serves, or lose our ventures"

William Shakespeare - Julius Caesar, iv iii, 217

This study has taken a medical-sociological approach to studying tuberculosis discourse. It has been underlined by the premise that an understanding of "physical and chemical laws governing disease must be seen to operate within a social and economic context which is constantly changing" (Doyal and Pennell, 1979: 47). Based on the understanding that medical sociology is primarily a social discipline before it is a medical one, this study embarked on an analysis of tuberculosis discourse in South Africa. Doing so revealed not only related, but also contrasting conceptualisations of the disease and unveiled the ideological context in which tuberculosis is situated.

Chapter one began with a methodological outline, expanding on the notion of how one goes about doing a "sociology of discourse". Chapter two and three explored, from the global to the local, the historic, political and economic background surrounding health care. Chapter two highlighted the fact that throughout history, tuberculosis has been perceived as an ambiguous disease, both regarded as social and individual in nature. Its emphasis was on how historical evidence strongly suggests that towards the end of the nineteenth century tuberculosis began to be closely associated with poverty. The rise of germ theory, which made known the biological causes of disease, and the noticeable inequality in health conditions seen amongst the citizens of late industrial Europe, facilitated the development of an understanding that disease control should recognise both social as well as biomedical interventions by public agencies. The aim of chapter two was thus to show that the association between tuberculosis and poverty stems from a historical understanding that some diseases are social in their very nature and aetiology, and that sickness lies not only with the individual but also with the social system at large Gerhardt (1989: 322).



What became apparent from the study in chapter two was that general consensus during the nineteenth and twentieth centuries in Europe regarded tuberculosis as being a result of society's move towards an exploitative capitalist method of production, marked by large-scale urbanisation, increasing poverty and city slum conditions. Before this, philanthropist businessmen, such as Joseph Rowndtree (Joseph Rowndtree Foundation, 2007) often took on the responsibility of funding and promoting poverty alleviation programmes that would improve the living and health conditions of the poor and often conducted some of the first social surveys. But it was the need for state regulated poverty alleviation programmes that spurred on the development of the welfarist mentality in Western Europe and initiated a move to institute better sanitary systems and poverty alleviation projects throughout the big cities.

At the same time, early capitalism assumed "the necessity of regulated spending, saving, accounting, discipline – an economy that [depended] on the rational limitation of desire" (Sontag, 1978: 63). What is evident is that tuberculosis was and often still is described in images that sum up the "negative behaviour of nineteenth-century homo economicus: consumption; wasting; squandering of vitality" (Sontag, 1978: 63). Chapter two also elucidated how in industrial Europe, tuberculosis was the hated and the detested, a vile evil that needed to be eradicated from society. Consensus of the time agreed that this eradication entailed medical as well as social interventions. Tuberculosis was viewed not only as a mere health inequality but also as "the social disease of the nineteenth century, perhaps the first penalty that capitalistic society had to pay for the ruthless exploitation of labour" (Dubos, 1953: 207 italics mine).

This social conceptualisation of tuberculosis was consistent with a growing state-led social welfare consensus that came to prevail in the post-war twentieth century at the time in Western Europe and continued up until about the 1980s. As discussed in chapter three, social welfare as the responsibility of the state, was a feature of early twentieth century European social democracies. In this view, the provision of comprehensive health care was the responsibility of the state. Health care was holistically conceptualised as being more than the mere curing of disease but also the creation of an environment that allowed individuals access to life sustaining, nutritious food, physical safety and so forth. This thinking can be noted for example –



as was pointed out – in the wording of the WHO Constitution drawn up in the 1940s, which regards health as more than the mere absence of disease and also makes clear that each state should ensure that the conditions for healthy living are made available to every citizen.

However, by the end of the twentieth century a growing neo-liberal ideology began to dominate development thinking. Chapter three highlighted how the growing neo-liberal paradigm in the 1980s stood in contrast to the welfarist paradigm and instead encouraged the state to minimise expenditure on welfare (such as comprehensive health care) and its involvement in private industry. It was argued that neo-liberalism discourages state control over market forces in order to encourage capitalist growth through advanced competition and free trade. Neo-liberalism is endowed with the reasoning that individuals can compete, grow and develop when they have little interference from the state.

This study has suggested that during the global economic recession of the 1980s many developing African countries were often forced to adopt such neo-liberal policies in the form of so-called Structural Adjustment Programmes, as a condition of large loans acquired from the World Bank and the IMF. Clearly neo-liberal ideology became hegemonic and the separation between the state and civil society increased. In chapter four it was pointed out that although South Africa was not subject to Structural Adjustment Programmes it adopted many neo-liberal policies during the 1980s. The fall of apartheid and the implementation of a new democratic government did little to undermine these policies and in fact only strengthened them.

Chapter four argued that the contemporary South African state welfare system is framed within this hegemonic neo-liberal ideology and comprehensive basic health care has become a product of market forces. The result is the formulation of disease treatment in ways that are deemed most "cost-effective" but largely ignore the social factors surround health and illness. As Farmer eloquently put it, "These are dangerous times. In the name of 'cost-effectiveness', we cut back health benefits to the poor, who are more likely to be sick than the non-poor. We miss our chance to heal. In the setting, we're told of 'scarce resources', we imperil the health safety net. In the name



of expenditure, we miss our chance to be humane and compassionate" (Farmer, 2005: 176).

Chapter four therefore marked a shift in emphasis in this study. Not only did it provide a contextual description of the South African health care system, both historically and ideologically but also, using tuberculosis as a case study, it addressed the move towards an internationalisation of health care in the mid 1900s. It was argued that during this time period large international agents like the WHO became prominent and began to define a system of health care for developing countries that was and still is predominantly biomedical in focus. What was evident in the example of tuberculosis discourse however was that the biomedical focus tended, and still tends, to be reductionist in its emphasis on technological intervention. In this way, medical practices (diagnoses, cures and treatments) became the focal point of biomedicine and the social factors surrounding disease were marginalised.

As a result health care became individualised and issues of poverty and social conditions surrounding disease were increasingly placed at the periphery of health and illness discourse. Thus a biomedical discourse began to dominate the international health organisations of the mid twentieth century. Consequently, as the focus of the WHO changed at the end of the twentieth century, the health care systems of many developing countries became marked by an individualisation of disease control and by a move towards the primary health care approach. In these countries this had the advantage of decentralising the management of state health care to district level but, it also placed a heavy burden on lower-level health services.

Chapter four described how the post 1994 South African health care system became framed within this ideology and how the system became modelled on a primary health care approach. Therefore chapter four provided a contextual description of the South African health care system, both historically but also ideologically. In the case of tuberculosis, the development of this health care thinking saw a shift in the focus of the disease's control, and an outpatient, community based approach became dominant. Within tuberculosis discourse the disease began to be viewed more individually and less socially and its treatment started to be formulated as such.



The global level introduction of the directly observed treatment method – using primarily chemotherapeutic interventions – in the 1980s, made possible a dominant focus on biomedical interventions and marginalised social ones. The treatment of tuberculosis from this period on thus became marked by a reductionist biomedical approach. Since then, tuberculosis discourse has become consumed by the issues surrounding how best to implement and manage this treatment. Tuberculosis discourse is therefore no longer dominated by ideas of total disease eradication or by concerns of poverty and inequality but is instead dominated by issues of biomedical interventions and disease maintenance.

Who or a country's national Department of Health) generate their own forms of discourse, and that these discourses construct the provisioning of health care as a particular kind of knowledge. As argued, this knowledge is dominantly medicoscientific and is located alongside a dominant neo-liberal ideology. A central suggestion of this study has been that a characteristic of both biomedical and neo-liberal ideology is their emphasis on the individual and their marginalisation of the social. When combined, the language of health care becomes intertwined with the language of the market and health is expressed as the outcome of a partnership between well planned, economically rational medical interventions on the one hand, and so-called "responsible" individual behaviour on the other hand.

Because the state is regarded as being an inefficient bureaucracy, and because neoliberal thinking suggests that private enterprise is more effective and efficient, health care becomes "privatised" and deferred to the community, to individuals and to the non-profit sector. In this way responsibility for the outcome of medico-scientific intervention is placed on individuals. As a result, individuals become the potential source of their own illness and certain actions are deemed inappropriate, irresponsible and irrational (such as defaulting on chemotherapeutic treatment). Further, this study has argued that the individualisation perpetuated by both neo-liberal thinking and biomedical science leads to the treatment of certain diseases – like tuberculosis – being formulated in a manner that disregards the broader social factors involved in their progression. The result is that disease and its control becomes detached, removed and separated from its social context.



Chapter five and six highlighted how disease is dislocated from its social context when discourse is dominated by neo-liberalism and reductionist biomedical ideology. Chapter five pointed out that in the 1940s, with the discovery of efficacious pharmacological agents along with the overall rapid development of biomedicine, "the medical discourse on tuberculosis became rigidly defined and characterized by exclusive literature on the use of rapidly developing drugs" (Paluzzi, 2004: 770). For tuberculosis, access to newly emerging antibiotics came to "define treatment and prevention in both the biomedical and popular culture" (Paluzzi, 2004: 770). It was pointed out therefore that the contemporary discourse surrounding tuberculosis is biomedically reductionsist, i.e. it is dominantly medically orientated, cure-centred and individual-directed. The result is that social issues, such as poverty, migration and gender are increasingly marginalised, not only within tuberculosis discourse, but also within the larger conceptualisation of health care.

The example of the stringent implementation of the DOTS programme in this country reveals that despite the government's strong commitment to fighting tuberculosis, and despite the advocated strengths of directly observed chemotherapy, little impact on rising tuberculosis incidence has occurred in the past ten years. The argument showed that despite poor patient adherence to medicinal treatment and despite increasing drug-resistant strains, the tuberculosis control programme in the country remains focused on clinical and medicinal approaches whilst ignoring the social factors that hinder patients from completing their treatment. Chapter five therefore revealed how the discourse of tuberculosis towards the end of the 1900s had become more concerned with control and management than with disease eradication, which had dominated the discourse directly after World War Two. In effect, what has become apparent is that concerted efforts at tuberculosis elimination are marginal if, non-existent. This is discouraging and shows a malevolent attitude towards what Farmer (2003) calls the "diseases of the poor".

Chapter six addressed how the arrival of HIV/AIDS did little to better the situation for tuberculosis control and tuberculosis discourse. The argument in chapter six pointed out that the conceptualisation of tuberculosis, as that of associated HIV/AIDS related disease, has only served to reinforce the negative ideologies of disease and health care



that underpin South Africa's tuberculosis control programme. The first suggestion made was that HIV/AIDS often distracts attention and resources away from tuberculosis. HIV/AIDS weighs heavily on the health care industry in terms of expenditure and it also biases the donor industry. In this context, investments in scientific research on tuberculosis get sidelined in favour of HIV/AIDS and as one respondent worded it, "funds are put into HIV and not TB". This has become a global and not only a local problem. The same anti-tuberculosis drugs and the same diagnostic measures that were used roughly sixty years ago are still those being used in tuberculosis control today. This leaves government programmes with antiquated and slow processes of tuberculosis testing and a fairly lengthy treatment regime to monitor.

The second point made was that the language of HIV/AIDS is often also used to describe tuberculosis, with the result that the individualisation of HIV/AIDS is transposed to tuberculosis, entrenching the notion of disease as individual responsibility. The third point emphasised that because the two diseases are often conceptually linked, and as HIV/AIDS treatment in South Africa becomes increasingly characterised by a model of non-governmental and home-based care, tuberculosis control becomes similarly conceptualised. This argument suggested that the community-centred DOTS approach is strengthened by an HIV/AIDS discourse, which propelled by the non-profit industry and HIV/AIDS activists, encourages "community responsibility" and "self-reliance".

Chapter six thus showed that although home-based care is a system encouraging community involvement in health care and that it has many advantages (for patients and the health sector in general), if not properly planned and implemented it can place a severe added burden on citizens and civil organisations. The chapter's argument was that such thinking allows the state to gradually shift its responsibly onto communities that can ill afford it (Ginwala and Collins, 1992). As pointed out, the unintended consequences of this are that the general advancement of health and wellbeing are undermined, but also the ability of citizens to engage with the state in meaningful and significant ways is suppressed. Citizens become disempowered as they come to rely less and less on the state for basic welfare and more on the charity and private sectors. They become pacified in their ability to hold the state accountable for lack of service



provision, thereby perpetuating an environment that further disenfranchises the poor, defeating the purposes of health care. As such they become victims of a loss of political agency and victims of a system that actually undermines their overall wellbeing and health.

A key argument of this study is therefore that state welfare services that follow market directed functioning based on cost-effect arguments, weaken the state. As the state selectively conditions its health care responsibilities leaving the community, individuals and the private sector (not-for-profit and for-profit) to fill in the gaps, its ability to be held accountable diminishes. In the case of tuberculosis control, the state provides treatment for the disease based on globally accepted standards of control. But this treatment is reduced to the mere provision of drugs/medication, which requires a complex and dispersed network of control and patient surveillance. In the meantime the social factors that undermine the success of such treatment are ignored by the state.

Chapter six pointed out that those individuals and organisations that attempt to address the social issues affecting the spread of tuberculosis are caught up in a medico-development industry dominated by market forces of competition for resources. For the poorest citizens this means that the sociological forces structuring their lives are given little attention in the health care industry, leaving them continually exposed to potential illness. Additionally, as the state defers its responsibility to the private sector, citizens are unable to exercise their agency to hold accountable any central body of welfare. This jeopardises their access to comprehensive health welfare in times of dire need. For society, such a scenario implies that tuberculosis will remain yet a long time in our midst. In a gloomy prophesy Stanford, Grange and Pozniak (1991: 558) suggest that in the present era, where HIV/AIDS decreases the resistance of individuals towards the tubercle bacilli, the world is facing "the greatest public health disaster since the bubonic plague".

In conclusion then, this study has examined tuberculosis discourse in order to understand the ideological factors surrounding the disease. It has revealed that within tuberculosis discourse there is not a simple binary opposition between a focus on biomedicine and a focus on the social. There is today a definite recognition that social



factors influence both the spread and the control of tuberculosis but nevertheless this understanding has been marginalised in favour of the discourse on the biomedical. This dominant focus on biomedical issues and on HIV/AIDS has undermined existing perceptions of the social causes of tuberculosis. The effect is an individualising of the disease and its decontextualisation and removal from a social context. This together with a hegemonic neo-liberal viewpoint of development and state spending has dictated that a biomedical reductionist treatment for certain disease – like tuberculosis - is most "cost-effective" and thus should be advocated for disease control. Consequently, the state merely provides health-care in a manner that focuses on the treatment of symptoms and ignores the broader social context of disease and its eradication. The responsibility for the outcome of health care is therefore left to the individual. An unintended consequence becomes apparent when private citizens and organisations take up the state's responsibility, disempowering citizens by limiting their ability to hold the state accountable, or to engage in meaningful ways that brings about structural change. Consequently, an environment that further disenfranchises the poor and defeats the purposes of health care is perpetuated and diseases like tuberculosis continue their deadly campaign.



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List of Interviews and Dates

Department of Health Employees

Dr. Lindiwe Mvusi, Director of the NTCP, (March, 2006 and 2 February, 2007).

Pamela Richards, Deputy Director of the NTCP with a management portfolio focus on TB patient in hospitalisation management, (3 April, 2007).

Omphemetse Mokgotha, Assistant Director with a management portfolio focus on recording and reporting at the NTCP, (2 April, 2007).

Petrus Khoza, NGO management portfolio at the NTCP, (4 April, 2006).

Carina Idema, Responsible for Reporting and Recording (research) at the NTCP, (23 February, 2007 and 12 July, 2007).

Suzette Pretorius, DOT and NGO administrator at the NTCP, (11 July, 2006; 27 January, 2007 and 3 April, 2007).

Phumlani Ximiya, Advocacy and campaign organiser at the NTCP, (13 July, 2006).

Dr. Virginia de Azevedo, Director of TB Control for Cape Town city metropolitan, (4 August, 2006).

Respondents from outside the Department of Health

John Heindrich, CEO of SANTA, (26 February, 2007).

Vincent Pernzee, SANTA Hospital Manager, GP Marais building, Bergvliet, Cape Town, (3 August, 2006).

Lisa-Marie Smith, Executive Director of TADSA (TB alliance DOTS support association), (1 August, 2006).



Ria Grant, Manager of TB Care, Cape Town, (3 August, 2006).

Bernard Fourie, Former Director of the Tuberculosis Unit Medical Research Council, South Africa, (10 May, 2007).

Dr. David Barnes, Occupational Health Manager for Anglo Gold Ashanti, (8 June, 2007).

Dr. Neil Cameron, Former Director of the NTCP. Lecturer, University of Stellenbosch, (July, 2006 and 4 August, 2006).

Dr. Anneka Hasseling, Epidemiologist, University of Stellenbosch The Desmond Tutu TB Center, (2 August, 2006).

Dr. Peter Donald, Retired Medical Professor, University of Stellenbosch, (1 August, 2006).

Horst Kustner, Former Director of the Unit of Epidemiology, Department of Health and Social Welfare, (5 June, 2007).

Nonhlanhla Nxumalo, Tuberculosis Researcher at Health and Development Africa (18 July, 2006).