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Tuberculosis control in South Africa: reasons for persistent failure

This study reviews the origins and spread of tuberculosis in South Africa in the international context. It shows that TB is far from being under control, despite the availability of effective technology. Five arguments offer explanations for this failure. First, control strategies fail to eradicate the macro-conditions that create a breeding ground for TB. Secondly, new disease conditions — especially HIV/AIDS and MDRTB — confound efforts at control. Thirdly, the health system and its priorities are insufficiently focused and resourced to cope with TB. Fourthly, healthcare staff responsible for TB care are often weak links in the chain of control. Fifthly, TB patients fail due to ignorance, delay in seeking care, and non-adherence to treatment regimens. TB consequently remains a major public health challenge, today more than ever in its protracted history.

Tuberkulosebeheer in Suid-Afrika: redes vir voortdurende mislukkings

Hierdie bydrae gee 'n oorsig van die oorsprong en verspreiding van tuberkulose in Suid-Afrika teen die agtergrond van die internasionale gemeenskap. Dit toon dat TB hoegenaamd nie onder beheer is nie ten spyte van die beskikbaarheid van doeltreffende tegnologie. Vyf argumente word vir hierdie mislukking aangevoer. Eerstens faal beheerstrategieë om daardie makro-omstandighede uit te wis wat die teelaarde vir TB daarstel. Tweedens, nuwe siektetoestande — veral MIV/VIGS en MDRTB — bemoeilik kontrolepogings. Derdens, die gesondheidsstelsel en -prioriteite is nie genoegsaam gefokus en toegerus om TB suksesvol te hanteer nie. Vierdens, gesondheidspersoneel verantwoordelik vir TB-sorg is dikwels swak skakels in die kontroleketting. Vyfdens, TB-pasiënte faal dikwels deur hul onkunde, uitstel om behandeling te soek, en deur nie behandelingsvoorskrifte te volg nie. Gevolglik bly TB 'n hoof openbare gesondheidsprobleem, vandag meer as ooit tevore in sy uitgerekte geskiedenis.

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Tuberculosis (TB) remains a major public health challenge in South Africa — today more than ever in its protracted history. Failed attempts to manage TB have never been simply a matter of lacking human and material resources. The disease and its control are as often characterised by lack of commitment and direction, inactivity, neglect and discrimination. However, the important factors facilitating TB and hampering its control have been (and still are) poverty; unsanitary, stressful living and working conditions; poor nutritional status; ignorance; migration, and social disruption. These conditions leave certain groups highly vulnerable and at risk of contracting the “diseases of poverty”, such as TB. Besides societal factors, the fragmentation and lack of co-ordination in the healthcare system have crippled effective TB control. Such system deficiencies originated in the colonial past and were perpetuated in health policy and legislation. Especially under apartheid, the resourcing and distribution of and access to health services, as well as the quality of care, were inequitably meted out along racial, geographical, sectoral and class lines, resulting in grave disparities in the health status of the different population groups. In South Africa, TB became one dimension along which disease and death discriminated in a very pronounced manner in terms of white/non-white, poor/rich and rural/urban divides. This is still the situation today.

In the light of recent national and international developments in TB control, the purpose of this paper is to revisit the issue of TB and TB control in South Africa. Up-to-date accounts of the disease and its control will be provided with a view to answering the key question: why are we still failing? This paper also provides suitable temporal and interpretative frameworks for the other studies in this *Acta Academica Supplementum*, which addresses four interrelated contexts: first, developments in South African society at large; secondly, developments in broader health policy; thirdly, specific developments in TB control, and fourthly, superimposed on these three layers, TB and TB control in South Africa within the broader international context. TB incidence, policy, and sporadic changes in incidence and policy direction in South Africa closely reflect the international scene. Recently, this national-international connection has become more pronounced as a result of the internationalisation and globalisation of health and health policy.

The history of TB in South Africa proves that neither medical breakthroughs nor the taking of anti-TB drugs can determine the control of TB. On the contrary, the history often belies the one-dimensional application of the medical model as the solution to the epidemic, as do the daily activities of numerous non-compliant TB patients. The measures aimed at controlling the disease have always been predominantly medical, and they have failed dismally. Along with Dubovsky (1987), we have to recognise that TB is a socio-economic disease *par excellence*, and that the neglect of socio-economic factors was and still is the reason why TB control has constantly failed. Intervention measures, whether preventative or therapeutic, should therefore encompass the socio-economic aspect that propels the disease:

Without doubt the most important factor in the control of TB is improvement in living standards. Unless there is improvement in nutritional status, reduction in overcrowding, and improvement in the overall level of education no TB programme can hope to be more than marginally effective (Benatar 1986: 247).

The key to TB control, therefore, lies beyond mere medical interventions; social interventions need to be part of the solution. However, such interventions should not be confined to socio-economic conditions and deprivations, but should also deal with socio-political, socio-cultural, socio-demographic, socio-psychological and behavioural factors. In one way or another, these all play important roles in the onset and spread of the disease, and could thus also contribute to its prevention, treatment and cure.

The key question is: why are we still failing to control the TB epidemic? Our argumentation provides answers to this question by reviewing, from various perspectives, the course of the epidemic, the various measures taken to bring its escalation under control, and what we consider to be lacking in those measures.

2. Tuberculosis¹ — a global overview²

2.1 The origin, growth and magnitude of tuberculosis — the global situation

TB is an ancient disease known to human societies for millennia, although not always sharply distinguished from other diseases of the chest — cancer, silicosis, or lung abscesses. TB,³ as it is known today, rose to prominence as a major cause of death and an epidemic⁴ only relatively late in modern history. Major epidemic peaks occurred in

- 1 Over the centuries many names have been used for tuberculosis: “consumption”, “phthisis”, “the white plague” and “the white death” (Bryder 2001; Dubos & Dubos 1953; Metcalf 1991; Williams *et al* 1971). The term “tuberculosis” relates to the tubercle, first associated with the disease by Francis de la Boe in the seventeenth century. Bayle introduced the term “tuberculosis” for the first time at the beginning of the nineteenth century, and in 1839 Schönlein proposed the use of “tuberculosis” for all manifestations of phthisis, as the tubercle was the underlying pathology. Robert Koch’s identification of the tubercle bacillus as the causative agent of TB established the infectious nature of the disease in 1882. In 1891, Flower advocated discarding the terms “consumption” and “phthisis” in favour of “pulmonary TB”.
- 2 The nature, emergence and spread of the disease around the world — and the factors contributing to its emergence, spread and resurgence — are explored by Balt *et al* 1998; Brennan 2003; Bryder 2001; Collins 1982; Daniel *et al* 1994; Dubos & Dubos 1953; Gandy & Zumla 2002; Heunis 2004b; Metcalf 1991; Molecular Mycobacteriology Research Unit 1996a; Myers 1977; Raviglione 2003, and Snider 1993. The systematic reporting of the disease started only in the early twentieth century when notification was made compulsory — in Norway in 1901, Denmark in 1905, the USA in 1906, England in 1913 and Scotland in 1914.
- 3 In human beings, TB may affect any organ of the body, but the dominant site of infection is the lungs. This form, pulmonary TB, is the only communicable or contagious variant of the disease, and the one that causes most deaths (over 80%). Pulmonary TB dominates the TB scene in South Africa too.
- 4 The nature and course of TB epidemics differ markedly from other well-known epidemics (smallpox, cholera, plague, or influenza) in that TB epidemics span centuries. In Europe and America a TB epidemic began during the eighteenth century and ended only in the late twentieth century — a span of more than a hundred years. South Africa’s TB epidemic has also been in full swing for about that long, having started towards the end of the nineteenth century and probably peaked during the late 1950s and early 1960s (Collins 1982; Packard 1991).

England, Western Europe and North America in turn, around the mid-to-late eighteenth and early-to-mid nineteenth century. Such peaks were associated with the Industrial Revolution, and fuelled by the poor living and working conditions characteristic of large-scale migration and rapid urban sprawl, accompanied by poverty, poor housing, overcrowding, malnutrition and unsanitary circumstances. Likewise, stressful conditions of war, famine and societal collapse were known to result in escalating TB incidence. Ever since, TB has become closely associated with poverty and the socially disadvantaged classes, labelled a “social disease” and a “disease of poverty”. Consequently, the infected have often been stigmatised, ostracised and shunned as suffering from a hereditary taint, or as being part of the “unclean poor”, or guilty of miscreant behaviour (Bryder 2001: 831; Daniel *et al* 1994). Like many “incurable” or “rationally inexplicable” diseases of yesteryear, TB was also closely associated with superstition, while questionable methods, such as blood-letting or the laying-on of hands by kings, were used as remedies. At the other extreme, a “romantic iconography” developed about TB, because of the disease’s tendency to attack the young and the way in which it progressed, literally “consuming” its victims.⁵ Because many famous people suffered from it, TB was also associated with creativity and genius (cf Bryder 2001: 831; Metcalf 1991: 134).

The conquest of TB in the Western world had been largely accomplished by the 1980s, with the decline having commenced well before the use of isolation, surgical procedures, BCG vaccination and anti-TB chemotherapy. Historians associate this decline with improved nutrition and sanitary infrastructures, as well as elevated standards of living. Moreover, most modern historians agree that medical treatments had little if any effect on the course of the disease before the 1950s (Bryder 2001: 830). By contrast, TB incidence in developing countries continues to soar. By 1986, the incidence of TB in affluent westernised countries was recorded as less than 20/100 000, compared to 500/100 000 in developing countries. In South Africa the rates were then 20/100 000 for whites and 300/100 000 for coloureds (Benatar 1986: 247). Global figures for 2000 show that 8.2 million new TB cases oc-

5 For Bryder (2001: 831) this is patently illustrated by novels such as Alexandre Dumas’s, *La dame aux camellias* (1848) and operas such as Verdi’s *La Traviata* (1853) and Puccini’s *La Bohème*.

curred and that the disease accounts for 7% of deaths; more specifically, as Raviglione (2003: 10) has shown, it kills about three million people a year, and if the present trend continues, is likely to claim more than 30 million lives within the next decade.

The runaway scourge of TB is rife in developing countries as 95% of TB cases and 98% of TB deaths present here:

Eighty percent of new cases occur in 22 high-burden countries [South Africa being one of them]. By 2020, nearly 1 billion people will be newly infected, and despite the existence of effective treatments, 200 million will get sick, and 35 million will die from TB (CDC 2003).

In recent years, sub-Saharan Africa still has the highest incidence rate (300/100 000), although in absolute terms 60% of all cases are in Asia (Harries & Maher 1996; Raviglione 2003; Snider 1993). Since southern Africa harbours simultaneously the highest proportion and the fastest increase in poverty on the globe, the prospects of containing TB on the sub-continent appear rather gloomy (Pelser 2004b).

There is growing evidence that TB (the “new” TB) is making a comeback in countries that had progressed to relatively TB-free status, while it is further escalating in countries where it is already rampant.⁶ Marsh (2003: 24) reports that the decline in TB in Britain may well have been reversed, since TB has become “so rife that rates in some parts of the country exceed those in Third-World nations [...] rising by almost 20 per cent in a decade”. Referring to the “impoverished” area of Newham in London “where refugees make up about 8% of the population”, Marsh deplores the fact that more TB cases are seen than in many erstwhile Soviet-bloc countries. Half of these cases are reportedly from India, Bangladesh and sub-Saharan Africa. The typical socio-economic conditions (now deteriorating), inequalities (now increasing), and population movements associated with TB are playing a vital role in this contemporary resurgence. As Gandy & Zumla (2002: 393) note:

The principal motor behind the resurgence of TB has been the sharp rise in global poverty which has undermined many of the public health advances of the twentieth century.

6 Cf Brennan 2003; Gandy & Zumla 2002; Raviglione 2003; Ssemakula 2004.

However, additional factors are also involved, particularly the emergence of multi-drug-resistant forms of the disease.⁷ The current extent of MDRTB is alarming and it is increasing at a frightening pace, with some countries already exceeding the 10%-level of all TB cases (Portaels 2003; 2004; also Brennan 2003; Espinal 2003).⁸ Again, adverse social conditions such as large-scale societal disruption and instability play a determining role in the onset and spread of MDRTB. However, it appears that countries with poor records of TB control tend to score high in MDRTB prevalence (Espinal 2003). Paradoxically,

... failure to institute [the] entire DOTS-plus package is likely to destroy the last tools available to combat [TB], and may ultimately result in the victory of the tubercle bacillus over mankind (Lambregts-Van Weezenbeek & Reichman 2000: 995).

In this light, the argument that “TB programmes which cannot ensure adequate levels of adherence are worse than no intervention at all” (Dick 1994: 3.23) rings true.

What is more, changes in human behaviour, ecology and climate; environmental threats; urbanisation; tourism; migration, and the expanded cross-border movement of people facilitate the international spread of infections and disease.⁹ So, too, amid healthcare systems absorbing an increasing share of resources, inequities among and within nations are growing, while access to health care is worsening for the

7 Brennan (2003), Espinal (2003), Gandy & Zumla (2002), Lambregts-van Weezenbeek & Reichman (2000), Portaels (2003; 2004) and Reichman *et al* (2002) shed light on the state and growth of MDRTB across the globe and in specific countries. The phenomenon of resistance to anti-TB drugs (drug-resistant TB) is not new; primary resistance, or resistance in new cases, set in soon after chemotherapy was first introduced for TB (with streptomycin in 1944). The introduction of all subsequent drugs was eventually followed by resistance. Later, multi-drug resistance (secondary resistance, or resistance in previously treated cases) emerged as combinations of drugs were introduced to treat TB. Mainly due to non-adherence to treatment, this form of resistance is in essence man-made (Brennan 2003; Espinal 2003).

8 There is as yet no clarity on the course that MDRTB will take in future: “mathematical modeling suggests that MDRTB may remain a locally severe problem rather than a global one, although others have predicted different scenarios” (Espinal 2003: 49).

9 Cf Snider 1993; WHO 1998a; Loeb Adler & Gielen 2003; Pelsler 2004a.

most vulnerable populations (Frenk *et al* 1997). HIV and AIDS have also rendered control of TB less efficient and caused drastic increases in the disease. Snider (1993: 26) explains the confounding impact thus:

HIV-infected persons with TB have a higher frequency of non-reactivity to the tuberculin test, a higher frequency of unusual or atypical chest radiographic findings and a higher frequency of extrapulmonary TB, all of which make TB more difficult to diagnose in HIV-infected persons. Also, since HIV-infected persons have a higher frequency of adverse reactions to drugs [...] patient management is more difficult.

2.2 Strides in controlling tuberculosis — global efforts and measures¹⁰

Koch's isolation of the tubercle bacillus (*Mycobacterium tuberculosis*) was a major step in TB control; he established the infectious nature of the disease and produced a tangible enemy to engage. However, it was to take several decades before anti-TB drugs were successfully used as a cure (in the 1940s). Meanwhile, several other strategies and therapies waxed and waned. For an entire century (1840 -1950) TB treatment was sanatorium-based.¹¹ The first sanatoria were typically self-contained communities or “total institutions” (*à la* Goffman), *i e* asylum-like retreats or luxury resorts for the long-term hospitalisation of middle- and upper-class patients. The treatment they offered was expensive, inaccessible to the majority of TB sufferers, and ineffective as treatment or cure.¹² With the arrival of effective anti-TB drugs, sanatoria largely disappeared from the scene.

10 The following literature provides historical reviews of TB control on the globe: Brennan 2003; Bryder 2001; Dubovsky 1991; Heunis 2004b; Metcalf 1991; Molecular Mycobacteriology Research Unit 1996b; Myers 1977, and Snider 1993.

11 The rise and demise of the sanatorium movement and other treatment measures are described in Bryder 2001; Dubos & Dubos 1953; Dubovsky 1991; Heunis 2004b; Metcalf 1991; Myers 1977; Snider 1993; Sucre 2003; Williams *et al* 1971, and Wilson 1967. Heunis (2004b) schematically summarises the sanatorium movement (1840-1974) in England, various European countries and the USA.

12 Sanatoria were also known as “waiting-rooms for death”, as TB was then synonymous with death, and death was ever-present: “However much the sanatorium resembled other institutions, it had one feature — the omnipresence of the shadow of death. Apart from it, nothing can be understood about sanatorium life, whether it was staff enforcing rules or patients seeking sexual pleasure. Staff tried to brush it off with aphorisms about being strong and determined. But in countless ways,

The sanatoria were accompanied by new TB specialists, who practised rest and work therapy (“graduated labour”), and from the 1920s introduced surgical interventions such as collapse therapy or artificial pneumothorax, and later thoracoplasty and pulmonary resection. However, there is no evidence that these regimens or procedures had any appreciable influence on the course of the disease. “Gold therapy” emerged as a recognised treatment for pulmonary TB in 1925, but soon vanished altogether (Dubovsky 1991; Molecular Mycobacteriology Research Unit 1996b). Attempts at preventing TB by inducing resistance to infection were also introduced in the 1920s. Calmette and Guérin successfully administered their BCG (bacille Calmette-Guérin) vaccine, used as a prevention or protective measure for extra-pulmonary forms of TB in children. Significantly, the International Union Against Tuberculosis and Lung Disease (IUATLD) was formed in 1920 (Snider 1993).

The discovery of streptomycin, para-aminosalicylic acid, and isoniazid in the 1940s and 1950s inaugurated the drug therapy era and major breakthroughs in TB control. It became possible for TB sufferers to take long-course antibiotic treatment (18 months to two years) without prolonged institutionalisation. Ongoing drug development in the 1950s further revolutionised TB treatment and led to a dramatic reduction in mortality as well as decreased disease transmission, since infectious cases were being cured. In time, hospitalisation of TB sufferers became redundant and was gradually abandoned as a treatment method. The introduction of rifampicin — short-course chemotherapy — in the 1970s as part of anti-TB combination drugs reinforced treatment by reducing regimens to between six and eight months and rendering patients non-infectious (Maher & Mikulencak 1999; Snider 1993). By the 1980s, TB had been largely overcome in industrialised nations. Unfortunately, this success and the resultant decline of TB in these countries to negligible levels led to waning interest, apathy, low prioritisation and complacency, accompanied by the gradual dismantling of control programmes and drug-resistance surveillance, leaving them unprepared for the new waves and guises of the disease which were to (re-)emerge (Espinal 2003).

some personal, others collective, the sanatorium experience was at its core an encounter with mortality” (Sucre 2003 <<http://www/faculty.virginia.edu/blueridgesanatorium/death.htm>>).

Regardless of the breakthroughs in drug therapy, the incidence of TB continued to soar in the developing world, accompanied by an increase in MDRTB.¹³ This lag between the availability of effective medication and successful treatment of the disease can be ascribed partly to socio-economic factors impacting negatively on TB control, but also to the poor management of TB control programmes. In the 1970s, to address this mismatch between medication and case management, Karel Styblo (of IUATLD) developed a model of TB control based on a managerial approach to case-finding and treatment. Styblo pioneered this model in Tanzania with nation-wide coverage (Maher & Mikulencak 1999).¹⁴

In 1993, the WHO's Global TB Programme declared TB a "global emergency". The Programme began to promote Styblo's strategy in a technical and management package, first launched as the Framework for Effective TB Control, and later branded as the Directly Observed Treatment, Short-course (DOTS). The strategy was developed from collective best practices, clinical trials and TB control programme operations (Weyer 2003a; WHO 1997), and based on the principles of political commitment, good diagnosis, quality drugs, short-course chemotherapy, and systematic monitoring and accountability (Maher & Mikulencak 1999; Raviglione 2003; WHO 1997). By means of DOTS there was for the first time hope for reversing the course of the TB epidemic, because the use of anti-TB drugs was now strictly managed within a specific treatment programme. DOTS does not require hospitalisation, high technology or a new structure; it can easily be

13 The development of drug resistance is not new in South Africa. Since the introduction of anti-TB drugs there have been references in historical accounts to the interruption of treatment regimens and the resultant pool of "half-cured, half-ill infectives". Several authors deal with the gradual development of resistance to TB medication and provide explanations for such resistance in earlier phases of TB control in South Africa (Collins 1982; Dubovsky 1991; Metcalf 1991; Packard 1991 & 1992).

14 The Styblo model proposed the use of an existing basic management unit (usually the health district) that would have the necessary staff and resources to diagnose and initiate treatment, record and report patients' treatment progress, and manage supplies in an area population of 100 000 to 150 000. Such a management unit would allow the technical aspects of TB control to be integrated within the extant general health services.

integrated into existing PHC systems. For these reasons the World Bank has ranked the DOTS strategy as “one of the most cost-effective of all interventions” (quoted in Raviglione 2003: 7).

Recently DOTS has been adopted by 155 countries world-wide, and more than 10 million patients globally have been treated under the system. However, DOTS coverage still ranges from a low of 7% (Brazil) to a high of 100% (Kenya, Tanzania and Uganda). Most countries implementing DOTS have shown that they can achieve high cure rates (with a global average of 80% for the 1999 cohort), but the prospects for detecting 70% of sputum smear-positive cases are less certain. Few of the 22 high-burden countries have achieved full service coverage, and unless DOTS can reach beyond traditional public health reporting systems, case detection will not rise much above 40% in these countries.¹⁵ In view of this, the managers of the National TB Control Programmes (NTCPs) of the 22 high-burden countries (including South Africa), along with technical and financial partners as well as the global TB network of the WHO, agreed in 2000 to develop a Global DOTS Expansion Plan, part of which was the development of a National Medium-Term Development Plan (MTDP) in each country (WHO 2003).¹⁶

The successes of DOTS in several countries has demonstrated that the approach can be effective in a wide variety of social, political and economic contexts.¹⁷ However, to achieve this, the five elements of DOTS need to function optimally. For Raviglione (2003), this means that the core constraints have to be overcome, *i e* insufficient political will and commitment; lack of financing or ineffective use of financial resources; lack of trained human resources; lack of good management at the programme level, and deficiencies in the quality and supply of anti-TB drugs.

15 Cf Dye *et al* 2003; Frieden & Driver 2003; Narayan *et al* 2003; Raviglione 2003; WHO 2003.

16 Numerous other international initiatives in the campaign against TB have arisen during the late 1990s and the early 2000s. Among these are the Global Fund against AIDS, TB and Malaria; the Global Drug Facility; the WHO/IUATLD Global Drug-Resistance Surveillance Project; the DOTS-plus Strategy; the Stop TB Partnership; the Amsterdam Declaration to Stop TB; the Global DOTS Expansion Plan; the Global Plan to Stop TB, and the Strategic Framework to Decrease the Burden of TB/HIV (Raviglione 2003).

17 Cf Brennan 2003; Frieden & Driver 2003; Kathri 2003; Narayan *et al* 2003; WHO 2002; Zhao *et al* 2003.

3. Tuberculosis in South Africa — origin, spread and control measures¹⁸

3.1 The origins and progress of the epidemic — the first 50 years¹⁹

Following the introduction of compulsory registration of deaths in the Cape Colony in 1895, it became clear that TB was taking on serious proportions. Ever since, TB has remained a major public health problem, gradually assuming epidemic proportions. A series of socio-economic, socio-political and socio-demographic factors contributed to the inception and spread of the disease in South Africa. Exposure to waves of European consumptives was the first reason. It is unlikely that TB had presented to any notable extent among the races native to southern Africa prior to colonisation (Daniel *et al* 1994). Collins (1982: 781) explains:

Failure to develop a culture based on large-scale urban development and the lack of major outside intrusion into the interior of Africa are probably the key to the absence of any major TB epidemics in southern Africa until the colonial era [...] conditions favourable for the spread of the disease did not exist. There were no overcrowded cities or industrial complexes.

Apparently, then, TB was brought to South Africa in the late eighteenth and early nineteenth century by European colonists at the time when the disease was peaking in England and Europe. The initial spread of the disease seems to have been related to the degree of contact between the indigenous people and Europeans, and was accordingly more pronounced among the KhoiKhoi around the Cape, while the populations in non-colonised areas remained relatively TB-free for longer (Glatthaar 1991; Metcalf 1991).

From the late nineteenth century, Europeans again played a role in the importation and spread of TB through the influx of European con-

18 Attempts to control the disease in South Africa over the years are well documented by Collins 1982; Department of Health 1979; 2000; Dubovsky 1991; Edginton 2000; Ember & Ember 2001; Ginwala & Collins 1991; Heunis 2004b; Lee & Buch 1991; Metcalf 1991; Packard 1991; 1992. Heunis (2004b), and tabulates the main events in this history from 1875 to 2003.

19 Cf Benatar 1986; Collins 1982; Coovadia & Benatar 1991; Dubovsky 1991; Glatthaar 1991; Heunis 2004b; Metcalf 1991; Packard 1991; 1992.

sumptives searching for a climatic cure for their TB in the belief that high altitude and sunny, dry weather are conducive to a cure. Conceived as a remedy, the sanatorium movement became in effect nothing but a “selective immigration of tuberculotics” that boosted the pool of infected people. Cape Town was the main port of entry, while several Karoo towns became popular destinations and, subsequently, “hot spots” of TB from which the disease spread further.²⁰ By the time the government stopped this influx the damage had been done. The discovery of diamonds (1867) and gold (1886) spurred yet another wave of TB importation via the immigration of skilled mineworkers and fortune-seekers from abroad, again expanding the pool of consumptives, this time into an industry which would soon become pivotal in the country.

The flourishing mining industry, accompanied by urban sprawl and appalling living and working conditions, fuelled the incidence of TB. Overcrowded mine compounds, poorly ventilated, humid shafts, deficient hygiene, poor nutrition and malnourishment, long hours of physically demanding work, low payment, and disrupted family life, all served as fertile soil for susceptibility and transmission of the disease. Additionally, a huge migrant labour system was created in Southern Africa to satisfy the insatiable demand for cheap labour on the mines. In time, this system became the notorious conveyer of TB to rural areas and neighbouring countries from which mineworkers were recruited. Once they developed TB, these mineworkers were callously repatriated to their homes, thus facilitating the spread of TB among their families.²¹ Small wonder that the 1912 Tuberculosis Commission found that TB in rural areas was directly related to the exposure of an area's population to migrant labour, and declared the mining industry one

20 The best known of these sanatoria was the Nelspoort Sanatorium near Beaufort West, established in 1924. Other popular destinations included Beaufort West itself, Kimberley, Bloemfontein, Harrismith, Cradock and Middelburg. Many patients arrived in South Africa with very advanced TB and could not travel to such inland locations; as a result they settled in and around Cape Town, which led to the establishment of sanatoria there. The TB mortality rate in Cape Town was thought to exceed those of its British counterparts, while Cradock and Beaufort West had the highest incidence rates in the country (cf Collins 1982; Heunis 2004b; Metcalf 1991; Packard 1991 & 1992; Rosenthal 1982).

21 Cf Balt *et al* 1998; Collins 1982; Metcalf 1991; Packard 1991 & 1992; Pelsler 2003; WHO 1997.

of the most important factors in TB among blacks in southern Africa (Collins 1982; Metcalf 1991). Although a decline in TB incidence was reported among mineworkers after 1913, due to control measures implemented in the wake of the Commission, TB was increasing among other blacks (Metcalf 1991). In 1920, the year after TB became a compulsorily notifiable condition, there were 3 313 TB notifications and an estimated 24 000 active TB cases. In 1921 the notification rate stood at 43/100 000 (Van Rensburg & Mans 1982). Increasing migration of rural people to urban centres, characterised by deteriorating conditions among both the white and the black populations — aggravated by the Great Depression of the 1930s — accounts for this steady increase in TB (Collins 1982). However, it was also during this period that the colour bar was introduced into the workplace, which gradually led to severe race-based inequalities (Packard 1991). For TB, this privileging and discrimination along racial lines held important implications, as the disease struck increasingly disproportionately among the different population groups.

Rapid industrialisation during and after World Wars I and II heightened demands for labour, while urbanisation escalated further. These developments again triggered housing shortages, urban squalor, overcrowding, stressful labour, malnutrition and unsanitary living and working conditions. Sporadic droughts and economic recessions brought further impoverishment and food shortages. Concurrent with these conditions, physical and mental stress, exhaustion, alcoholism, chronic stomach complaints and infections obviously increased vulnerability to TB (Metcalf 1991). The strong focus on urban areas certainly did not mean that rural dwellers were better off in respect of TB. On the contrary, TB was grossly neglected in rural areas, especially in the erstwhile native reserves (and later homelands), where the provisioning, distribution and accessibility of health services were notoriously unequal and of poorer quality, while inadequate housing, low educational standards, inferior standards of living and bad diet prevailed. By law, rural blacks had only temporary status in “white” urban areas, and upon their (often forced) return home those infected with TB would spread the disease to the rural areas (Dubovsky 1987).

By the 1940s, then, TB had assumed a rather fixed profile, generally characterised by huge disparities in incidence and mortality in the va-

rious population groups. Among blacks TB increased steeply, while it gradually decreased among whites. In the absence of an effective cure for TB, the only way to control the disease would have been to improve the general living, working and health conditions of the affected populations, especially the disadvantaged, “non-white” and “poor white” classes. Amid brooding dissatisfaction and militancy in the mining and industrial workforces, several committees and commissions of enquiry were set up in these years to devise reform strategies. Time and again, however, successive governments lacked the political will to implement the often fundamental reforms proposed as a means of improving the health and well-being of the expanding working class. This period also brought about the systematic political marginalisation of the majority, depriving them of the power to engage in collective bargaining for better conditions. This marginalisation would soon crystallise into the politics of exclusion and oppression (Pillay 1995).

3.2 Early TB control measures

Shortly after Robert Koch’s discovery of the infectious nature of TB, awareness of the disease was present in South Africa, as medical officials were alluding to the high TB mortality rate as early as 1885. A series of developments followed: in 1904, a public meeting was held in Cape Town to mobilise the local community against TB;²² in 1905, a Special Committee appointed by the South African Medical Congress raised concern about the increasing prevalence of TB, especially in Coloured towns; in 1907, the first accommodation specifically for TB patients was provided in the 32-bed City Infectious Disease Hospital in Cape Town. In view of alarming incidence rates, the Federal Council of Municipal Associations of South Africa urged the governments of the then colonies to investigate the TB situation, and to identify the best means of preventing the disease. The Tuberculosis Commission

22 Ever since this modest beginning, voluntary organisations have played an important role in TB control efforts in the country, although in a rather uncoordinated manner, because they generally operated “locally and independently” until 1947. In that year they amalgamated to form the umbrella organisation, SANTA (originally, the South African National Anti-TB Association, later to become the South African National TB Association) (Ginwala & Collins 1991).

was appointed in 1912²³ and reported in 1914. Its findings stimulated public pressure, leading to improved conditions in the mines by means of stricter screening of mine recruits and rejection of those susceptible to TB (Benatar 1986; Collins 1982; Metcalf 1991). In 1913, in what was perhaps the first legal measure of TB control, the newly established Union Government (on the recommendation of the Commission) inaugurated the Immigrants Regulation Act of 1913 which prohibited the large-scale immigration of “tuberculosics” to the country (Metcalf 1991). In 1919, further legal control measures followed when the Public Health Act made TB, along with other communicable diseases, a compulsorily notifiable medical condition and provided for

improvements in housing and sanitation, education, [the] enforcement of precautions against the spread of the disease, the provision of facilities for early diagnosis of cases, [TB] dispensaries, hospitals and sanatoriums (Packard 1991: 45).²⁴

However, this same legislation also introduced the notorious three-tiered fragmentation of the healthcare system that would become one of the most constraining distortions in health care. This tripartite dispensation had the important implication that TB control would, henceforth, be a function of local government and in a clearly secondary position in relation to the hospital sector under provincial jurisdiction. In subsequent legislation this fragmentation of services was maintained, to the detriment of integrated service delivery and amid shortfalls and discrimination in access along white/non-white, rich/poor and urban/rural lines (Heunis 2004b; Van Rensburg & Harrison 1995). TB control often suffered breakdowns, for example when frequent disputes

23 After the TB Commission of 1912 (Report of the TB Commission 1914), inquiries into the state of TB in South Africa followed at regular intervals, eg 1924 (Report of the TB survey of the Union of South Africa, Allen) and 1932 (TB in South African Natives with special reference to the disease among the mine labourers on the Witwatersrand, TB Research Committee).

24 After World War II, many TB hospitals were established and run along sanatorium lines. Whereas sanatoria overseas went into a decline at this stage, more were established in South Africa in subsequent decades “to meet the demand of heavy new case loads [...] The sanatorium regimen was ideally suited for the newly introduced and successful prolonged chemotherapy of 18 to 24 months’ duration” (Dubovsky 1991: 40).

over black residential areas led to delays in or exclusion from treatment (Packard 1991 & 1992).

One government commission or committee of inquiry after another was called upon to investigate the health conditions of the population and to recommend strategies to deal with these challenges.²⁵ Reform, however, did not materialise, mainly due to opposition from the dominant powers in South African health care at the time, especially the medical profession and major employers. During this time, too, the forced removal of people became a measure in TB control. Based on the concept of “sanitary segregation”, the 1934 Slums Clearance Act removed entire communities from “problematic” locations. Such removals were indeed associated with a decline in TB rates in urban centres. However, TB was clearly being relocated rather than overcome (Collins 1982; Metcalf 1991; Packard 1991 & 1992). In the 1940s the large-scale migration of blacks to urban centres in response to the war-time economy and the collapse of rural reserves, combined with the continued unwillingness of the state, local authorities and commerce to provide for the welfare of the growing black working class, or to curtail high rates of inflation, produced a major upsurge in urban TB mortality. A renewed awareness of the need for large-scale reform to attack the root causes of TB came about.

The earlier notion of a national health service for South Africa was further pursued by the National Health Services Commission (the Gluckman Commission), appointed in 1942.²⁶ This Commission also

25 The Vos Committee (1925) and the Loram Committee (1928) pointed out the deteriorating condition of the health of the black population in both rural and urban areas, while the latter also warned that this posed a risk of spreading contagious and communicable diseases. Along with these inquiries went calls for the reform of the health dispensation, eg the establishment of a State Native Medical Service; more and better hospitals for blacks, and rural health units. Likewise, the Collie Committee (1936) investigated the feasibility of introducing an urban-based national health insurance scheme, as well as the expansion of the district surgeon’s and nursing services to rural areas and the “native reserves”. Calls for reform also came from sectors of the medical profession and the Chamber of Mines at intervals during the 1930s.

26 Note that at this time similar steps towards the establishment of a National Health Service were also being taken on the international front, specifically in the United Kingdom (under Beveridge, thus the Beveridge model) and in British

alluded to deteriorating social conditions, growing political tension, labour unrest, the war situation, and government's greater willingness to embark on reform. The aim of the Gluckman Commission (1944: 8) was to establish a national health service with a view to

[bringing] these services within reach of all sections of the population, according to their need, and without regard to race, colour, means or station in life.

Four core problems in the health system were highlighted, namely a lack of co-ordination; shortages of services; private practice, and inappropriate emphases and priorities (Gluckman Commission 1944). The Commission was convinced that improvements in the general socio-economic system and in conditions related to nutrition, housing and health education were essential to the achievement of any significant improvement in public health. Vested political, professional and economic interests smothered these reform-minded ideas, but they never entirely vanished from the scene. They continued to set the tone and serve as a source of directives for the fundamental transformation of the health system, as in the Freedom Charter of 1955; the agenda of the patriotic health front of the 1980s, and ultimately the reforms since 1994. In retrospect, one could speculate as to why and how the introduction of a National Health Service for South Africa would or could have benefited TB control. With our current knowledge of the prerequisites of effective control measures, as explicated in the DOTS strategy, one might assume that it would have been much easier to implement an effective and efficient TB control programme based on the core principles proposed by the Gluckman Commission.²⁷ Although

Commonwealth countries, particularly Australia and New Zealand. As in the United Kingdom, trade unions (most strongly represented by the South African Trades and Labour Council) were, along with the Communist Party of South Africa and the African National Congress, significant proponents of a National Health Service (Pillay 1995).

- 27 Foremost among these were: a unified health system; state health services rendered free of charge; a network of community health centres; a referral chain linking community health centres to hospitals; the training of more health personnel and of new levels of health workers, and adaptation of the service in response to local needs. In theory, the district-based PHC system inaugurated in 1994 does indeed contain these essentials (Van Rensburg & Pelser 2004).

both the government and SANTA²⁸ waged a full-scale war on TB in the decades to come, it was ineffective, in the absence of any adequate network of co-ordinated health services to carry a successful TB control programme. In any case, the establishment of the apartheid regime soon dampened the promise. The introduction of anti-TB drugs also wrongly created the expectation that TB might be eradicated by purely medical means.

It would be safe to say that TB control was, for most of the first half of the twentieth century, characterised by *laissez-faire* policies, inaction, and even gross neglect and deliberate discrimination. The two crucial factors that fuelled the TB epidemic, namely “conditions that increased opportunities for infection and factors that lowered the ability of the host population to cope with infection” (Packard 1992: 121), remained in full swing. Furthermore, the general undersupply of hospital facilities²⁹ for TB patients continued, but with more marked shortfalls for blacks. Packard (1991: 45, 47) skeptically observes that “there was much more discussion of the TB problem in South Africa than action”, and that “this awareness produced more rhetoric than action”.

28 During the 1940s SANTA came into being as an important role-player in the sphere of TB control. It was established in 1947 as a non-profit, voluntary organisation, comprising a number of voluntary organisations in the sphere of TB; its sole purpose was to combat TB in the country (Ginwala & Collins 1991). Historically, SANTA has been the leading NGO in the field of TB control in South Africa. The organisation has built up a network of branches and care groups responsible for creating awareness, fundraising and providing support for patients and their families countrywide. In time, the SANTA initiative gave its own emphasis and imprint to TB control, while it also developed intrinsic limitations. SANTA became heavily hospital-based and in recent years ran 22 specialised TB hospitals for in-patient TB care, mainly funded by provincial health departments. Later it adopted the DOTS strategy and with it, the elements of ambulatory and community-based care via its network of regional and local branches (Taitz 1999). SANTA claims to have “pioneered the provision of low-cost TB bed accommodation, combined with adequate nutrition and high-quality medical and nursing care” (SANTA 2003a; also Heunis 2004b; Kironde & Bamford 2002).

29 Heunis (2004a & 2004b) analyses the development and the current state of TB hospitals and the hospitalisation of TB patients in great detail within the broader framework of hospitals and hospitalisation in South Africa.

3.3 The TB epidemic in the apartheid context

From 1948 onwards apartheid introduced and sustained many socio-economic, socio-political and socio-demographic conditions conducive to the heightened incidence and rapid escalation of South Africa's TB epidemic. During this time the so-called "non-white" population had negligible political rights, while legal measures restricted their freedom of movement and settlement. Poor and slum conditions in settlements continued, and social security and state support systems for these population groups were discriminatory, inequitable, and generally of lesser quality. Oppressive conditions for black people prevailed as the government enforced draconian measures to maintain the temporary status of blacks in "white South Africa" and to resettle them in the "homelands", though keeping enough of them to satisfy the mining industry and the general labour market. In the homelands severe poverty reigned amid disrupted family life, as workers were obliged to leave their families behind in order to earn a living in the mines and industries of South Africa. The practice of banishing those with TB to their original homes further fuelled the epidemic through the infection of families and friends in rural areas, where people had minimal access to TB services. Once a patient was relegated to a rural area his/her chance of receiving a full course of treatment declined sharply. One important consequence was the emergence of resistance to various anti-TB drugs after their large-scale introduction in the 1950s. TB had been poorly controlled despite the availability of effective treatment:

In short, efforts to attack the underlying causes of TB in South Africa after the Second World War did little to improve black living conditions, and represented a continuation, on a grander and ultimately more tragic scale, of the policies of exclusion that marked earlier control efforts (Packard 1991: 48).

While there was a general decline in the notification rates for all the population groups during the two decades of 1954 to 1974, the trajectories of the declines were strikingly dissimilar, with grave race-specific disparities: the rates for whites dropped from 56.9 to 18.1, that for Asians from 203.2 to 143.0, that for coloureds from 537.4 to 327.7, and that for blacks from 308.6 to 285.2 per 100 000. In the peak period, the general notification rate soared to 371/100 000 (1963) and in 1964 the race-specific TB notification rates stood at 475.5

(blacks), 458.1 (coloureds), 208.2 (Asians) and a mere 34.9 whites per 100 000 (Van Rensburg & Mans 1982). The upsurge in TB from the mid-1950s to the early 1960s is partly attributable to intensified case detection by mass X-ray screening and compulsory notification. From the late 1960s, however, there was a dramatic fall in TB notifications, as also in the late 1970s, the latter being partially ascribable to the exclusion of the TB statistics of the independent homelands (TBVC countries) from the South African records (Collins 1982; Metcalf 1991). Bradshaw *et al* (1987) estimate that in 1984 up to 150 000 new cases presented each year, of which a mere one-third were diagnosed and given treatment, while two-thirds remained undiagnosed and thus untreated. In 1990 the notification rate for pulmonary TB in the country was set at 175.7/100 000, more specifically 511.7 for coloureds, 171.4 for blacks, 55.9 for Asians and 14.3 for whites (Van Rensburg *et al* 1992).

The main reasons for the constant failure to contain the disease during apartheid were first, inefficient treatment programmes, due mainly to fragmented, unco-ordinated services and a dearth of health resources for black people; secondly, under-reporting and notification, which contributed to an unparalleled reservoir of undetected cases, neither diagnosed nor treated. In these ways a growing pool of unsuccessfully treated, half-cured and drug-resistant TB cases was created. These people further infected others, thus fuelling the rising TB tide. By 1986 an estimated 15% of TB patients had acquired primary resistance to isoniazid, with the figure being set at 50% for many rural areas. Nation-wide, only 25% of ambulatory TB patients were thought to have been effectively cured (Packard 1991 & 1992; Van Rensburg *et al* 1992). Furthermore, there was a great difference between urban and rural TB services. By 1986 75% of patients were completing treatment in Cape Town, compared to a low completion rate of only 25% in Ciskei clinics. In Natal, urban clinics recorded a 68% compliance rate, compared to only 28% in rural clinics. In Soweto, only 21% of TB patients were receiving 80% or more of their treatment (Packard 1992).

3.4 TB control measures under apartheid

Apartheid in the societal and health spheres under the nationalist government (1948 to 1994) nullified the short-lived promise of the enlightened 1940s. Several forces in the socio-political make-up of apart-

heid society and its healthcare system militated against effective TB control. Firstly, the gaping disparities between the living standards of the various population groups continued, while there were growing inequalities in the provisioning, distribution, access and quality of care between the white and black populations, urban and rural dwellers, and the insured as opposed to those dependent on state services. Secondly, the progressive, multi-dimensional fragmentation of the “national” health system eventually produced eighteen relatively independent departments of health. Time and again this fragmentation was deepened and broadened by the introduction of new dimensions of apartheid (the series of apartheid and segregation laws, the homelands policy, and the tri-cameral parliament). Thirdly, distinct emphases developed in the provisioning of health care, which was significantly hospital-based, doctor-centred and privately driven. Lastly, policies of privatisation stimulated the development of a two-class healthcare system embodied in a strong private health sector as opposed to a weak and overburdened public health sector. As a result, health services under apartheid were, for the majority of the population, inadequate, inaccessible and of dubious quality, while the health profiles of the various population groups revealed enormous disparities.³⁰

For TB control, the poor state of public health meant poorly funded and inadequate health services directly responsible for the under-treatment of patients, especially those from disadvantaged groups. Numerous apartheid-specific measures and distortions had a negative effect on TB control: some of the homelands used different drug regimens or applied dissimilar and unco-ordinated TB control programmes, which easily led to discontinuation of treatment regimes, a growing pool of half-cured chronic and infectious cases, and the development of drug resistance; the temporary residential status of blacks in white South Africa created obstacles for blacks seeking treatment and heightened the risk of defaulting; the repatriation of TB cases to the rural homelands implied sending them to dismally failing treatment systems; the system of disability grants for TB patients was highly discriminatory in racial terms and only available to temporary residents, and racial segregation in TB hospitalisation led to huge shortfalls in ac-

30 Cf Van Rensburg & Benatar 1993: 99 as well as Christopher 1994; Pillay 1995; Van Rensburg & Harrison 1995; Van Rensburg *et al* 1992; Van Rensburg 2004a.

commodation for black TB sufferers.³¹ In short, although a national TB control programme did exist from 1979,

... the complexity of attempting to co-ordinate vertically controlled TB services for 18 fragmented health authorities of the various 'affairs' for different races, and for 'homelands' and 'independent' states rendered it unworkable (Fourie 2002).

Benatar (1986: 247) also captures the limitations of TB control efforts in apartheid times:

In an environment where people are poorly nourished, poorly educated, poorly housed, and oppressed, it is impossible to implement such a programme effectively,

ie to identify all patients with the disease and treat them fully. Hence, he claimed that

... a national, non-discriminatory, unitary health service together with the abolition of apartheid and the adoption of a bill of human rights could contribute to the social and political progress urgently needed to improve the health status of the whole South African population,

identifying these as the chain of prerequisites to rectify the failure of TB control and "to make possible the control of TB" (Benatar 1986: 248). Taylor & Benatar (1989; also Lee & Buch 1991) urged an intensified effort to combat TB, especially in light of the fact that South Africa was then already awaiting the full effects of AIDS. They hinted at addressing the fragmentation of the the TBCP caused by the homeland dispensation, and pleaded for a comprehensive strategy and the integration of the TBCP into adequately structured and funded PHC programmes.³² Dubovsky (1991) highlights additional deficiencies in the TB control of the time: TB treatment was based on hospitalisation,

31 Cf Benatar 1986; Edginton 2000; Packard 1991 & 1992; Taylor & Benatar 1989.

32 Taylor & Benatar (1989; also Lee & Buch 1991) argued that the notion of a vertical programme (with tight central control but peripheral fragmentation) directed at such a widespread disease has fallen into disrepute. They referred to an expert committee of the WHO which, in 1986, described this approach as "unproductive" and recommended the integration of TB control activities within primary health care. The reason was that, in practice, no developing country can afford to fund a vertical programme heavily enough to ensure thorough countrywide coverage. In their motivation for such a comprehensive TBCP, the deficiencies in the preparedness and capacity of the NTCP of the day were clearly exposed.

which involved long stays and the use of expensive second-line drugs; it relied heavily on X-ray diagnosis; laboratory results took weeks while patients remained infectious; links between hospitals and clinics were weak and patients were often lost during transfers, and there was no reliable system of either tracking patients' treatment in the community, or tracking patients after they left the hospital.

Another consequence of apartheid which had an adverse effect on TB control in the country was the international isolation and sanctions that the system incurred. Because of apartheid, South Africa was excluded from the international community and thus forfeited the benefits of advances made by the international health system in respect of TB, in particular the World Health Organization and the International Union Against TB and Lung Disease. The TB control policies and programmes, expert advice and resources of these organisations were therefore not available in South Africa until the new dispensation. It was also at this time, 1978 to be precise, that the Declaration of Alma-Ata was accepted. This manifesto strongly promoted comprehensive PHC as the appropriate strategy for the delivery of health care in developing countries.³³ By contrast, the principles steering the South African health system at the time — fragmentation, with hospital-based, doctor-centred, privately driven health care — were very different. PHC

These pertained to the state of coverage, resource allocation, efficiency and cost-effectiveness, measured outcomes, and community acceptability of and participation in the programme. Importantly, they were of the opinion that the supervision of all patients' treatment by health care professionals results in a loss of productivity and also has the psychological effect of infantilisation. They therefore proposed moving away from the prevailing hospital-based system (which served only a small proportion of TB patients) towards a community-based TB control system. At the time, approximately two-thirds of the annual TB budget was allocated to the hospitalisation of patients.

- 33 In essence, PHC focuses on preventative and promotive interventions, and presupposes interdepartmental and intersectoral collaboration, community involvement, community ownership and self-reliance, people-centredness and people's empowerment — all closely tied in with broader social and community development objectives. Its main aim is to make "essential health care universally accessible to individuals and families in the community in an acceptable and affordable way and with their full participation" (WHO 1978: 38).

had a “Cinderella status”, while community involvement and participation were smothered by the autocratic, repressive, exclusive styles characteristic of the existing socio-political framework (Van Rensburg & Harrison 1995).

Nonetheless, the National Party did indeed muster increased government and private (voluntary organisation) efforts to control TB. In the 1950s, case detection was intensified and, as a result, many thousands of people were screened and diagnosed in mass X-ray surveys, while educational campaigns were launched. The 1950s also saw the introduction of new anti-TB drugs, as well as the expansion of TB hospitals, with a total of 24 000 beds for TB patients eventually becoming available; one-third of these were provided in SANTA hospitals, with support mainly from the government. In the late 1950s, anti-TB drugs became more widely used and distributed in the country, resulting in a drastic drop in the TB mortality rate. The BCG vaccine was also made available on large scale; in fact, vaccination of all newborn infants and other at-risk groups was made compulsory in 1973 and thus increased significantly during the 1970s and 1980s. Government expenditure on TB control increased steadily after World War II, reaching R50 million a year in the early 1980s.³⁴ The TBCP was introduced in 1979 (Dept of Health 1979), albeit within the restrictive apartheid framework and subject to the distortions of that system (Lee & Buch 1991).

3.5 Tuberculosis in post-1994 South Africa

TB remains a major public health and healthcare challenge in South Africa, today perhaps more than ever in the protracted history of the disease in the country. With an estimated incidence of 494/100 000 (all cases), South Africa’s burden of TB in 2002 ranked ninth in the global context, and third in the WHO Afro Region. Recent trends in TB (1995 to 2002) — expressed in terms of the annual number of reported cases (and the corresponding rate per 100 000 of the population) — are startling. Reported TB cases (all forms) have more than tripled from 73 917 to 224 420 (with the corresponding rate jumping

34 Cf Collins 1982; Packard 1991 & 1992; Van Rensburg & Mans 1982; Van Rensburg *et al* 1992.

from 187 to 494/100 000).³⁵ There was also a significant decline in the incidence of pulmonary tuberculosis (PTB) in relation to extra-pulmonary TB (EPTB) during this period — from 95.4% to 85% (Dept of Health 2004). This can probably be ascribed to the raging HIV/AIDS epidemic, as it is widely reported that this epidemic has an escalating effect on both PTB and EPTB (Orlovic 2000; Weyer 2003b). On the basis of an annual population increase of 1.47% and an additional annual increase in TB incidence of 10%, it is estimated that South Africa will have an incidence rate of 876.9/100 000 population by 2005 and an alarming rate of 1 000/100 000 population by 2020 (Dept of Health 2002; Redelinghuys & Van Rensburg 2004). It is well known that novel factors further confound and fuel the epidemic, especially the emergence of MDRTB and the escalation TB/HIV co-infection. The National Population Unit (2000: 63) warns of the looming predicament:

If current trends persist, 3.5 million South Africans may contract TB during the next ten years; 90 000 will die of HIV infection. By the year 2004, 13 in every 1 000 could be actively suffering from TB, of whom 9 could be HIV-positive.

The nature of the TB problem and its control are complicated by patients' continuous failure to adhere to treatment, low conversion and high re-treatment, as well as discontinuity in the treatment line due to staff turnover. Recent treatment outcomes in new smear-positive PTB patients reveal that the national cure rate has improved slightly over the period 1995-2001 — from 49.9% to 53.7%. This still falls far short of the national and international target of an 85% cure rate. There are vast disparities in the cure rates of the various provinces: for the Western Cape the rate stood at 65.3% in 2001, while KwaZulu-Natal could only manage 24.7%. Provincial interruption rates in new smear-positive patients were also highly diverse: in 2001, the Northern Cape reported a high 15.9% as against Mpumalanga's low 7.7%. The treatment failure rate in new smear-positive PTB patients improved steadily over the period 1995-2001 (from 5.0% to 1.6%), while the death rate increased from 5.2% to 6.7% (Dept of Health 2004; cf also Kironde & Bamford 2002).

35 Cf Dept of Health 2004 as well as Bamford 1999; Kironde 2000; Kironde & Bamford 2002; SATCI 2000; Weyer 1997a; WHO 2002.

3.6 The framework of the new dispensation — TB control after 1994

Since 1994 the African National Congress-led government has brought drastic changes in both health policy and TB control. It has largely succeeded in dismantling apartheid and the concomitant fragmentation and inequities. It explicitly subscribes to a series of basic human and health rights, including equity, equality and access in health and health care for all South Africans. This has been done along lines stipulated in a succession of policy documents, giving specific content to these broad policy guidelines and amply particularising the direction of policy on TB control.³⁶ The new government has also ensured a return to the international health system as the emerging district-based PHC system has adopted the principles of the Alma-Ata Declaration. This reform of the South African health sector has created a favourable environment for effective control of TB within a clinic- and community-based PHC setting. Furthermore, decentralisation, which is the basis of the district health system, has meant, among other things, that even the smallest district hospital has become pivotal in the reorganisation of TB control services. In effect, such hospitals are now (also) “important”. From this has followed a much improved network of PHC clinics and community health centres linked to higher care levels by a much more appropriate referral chain, and eventually also the introduction of a comprehensive (integrated) PHC service package and access to essential drugs, medical equipment, nursing personnel, referral hospitals and medical officers. For TB control this has meant that TB care can be integrated with other PHC programmes offered at PHC facilities. All that was still needed in the early post-apartheid years was an effective TB control programme.

This would follow soon as immediate inputs came from the international health system, and most specifically on TB control in the country. As early as 1994, South Africa enlisted expert assistance from

36 Foremost among these policy documents are the Reconstruction and Development Programme (ANC 1994a), the National Health Plan for South Africa (ANC 1994b), the Constitution of the Republic of South Africa (RSA 1996), the White Paper for the Transformation of the Health System in South Africa (Dept of Health 1997), the National Health Bill (Dept of Health 2002) and the Health Act (Dept of Health 2004).

the international community in the form of a rapid appraisal of the TB situation and in 1996, the World Health Organization and the South African Department of Health jointly conducted a review of TB control in the country. This review revealed that this epidemic was one of the worst in the world. It also highlighted the increasing HIV prevalence among TB patients; the emergence of multi-drug resistance; and the failure to control the epidemic, in spite of huge annual expenditure (Dept of Health 2001).

Several recommendations for improvement followed from the review, among others, that the seriousness of the disease in South Africa should be declared; that the management of TB at all levels should be strengthened; that the DOTS strategy should be implemented; that the Department of Health should invest adequate resources in training and TB control; that adequate microscopy services should be established, and that accountability should be ensured by using the TB register to monitor patients until they are cured. South Africa responded to these recommendations by declaring the treatment of TB a top national priority and committed itself to implementing the DOTS strategy (WHO 1997).³⁷ In 1996 a revised NTCP was adopted, based on the *Framework for Effective TB Control* and incorporating the DOTS strategy as formulated by the WHO in 1991. Clear aims were set: to cure 85% of all smear-positive TB cases detected; to reduce the interruption rate to less than 10%; to detect 70% of estimated TB cases; to attain a smear conversion rate of 85% in new smear-positive cases and 80% in re-treatment cases at the end of the intensive phase of treatment; to contain and then reduce the rising incidence of TB expected as a result of the HIV epidemic; to prevent MDRTB, and to achieve DOTS coverage in all districts. The new NTCP was based on four elements, namely (1) detecting TB cases by using the sputum smear

37 Note that the province of Mpumalanga had begun as early as 1995 to train communicable disease co-ordinators to manage TB services and to keep detailed registers of TB patients, thereby documenting their treatment (WHO 1997). These co-ordinators were also responsible for the supervision and in-service training of clinic staff. Hundreds of people at all levels were being trained, and patients were beginning to receive directly observed treatment according to the WHO's guidelines for the DOTS strategy, under which more than 80% of TB patients were successfully treated.

microscopy method among suspected TB patients presenting to health services; (2) establishing and ensuring a regular supply of anti-TB drugs; (3) enhancing patient adherence to treatment by supervised ambulatory care, and (4) establishing a standardised comprehensive reporting system to facilitate the assessment of TB incidence, prevalence and treatment results.³⁸

In 2002, as an extension of the NTCP, the South African strategic plan for TB control was launched in the form of the Medium-Term Development Plan (MTDP) 2001-2005 (Dept of Health 2003; WHO 2002b; 2003). Based on the objectives of the NTCP, the national MTDP offered a template for mobilising the necessary human and financial resources to expand TB control in order to achieve the targets set. The MTDP, again, strongly emphasised the importance of political commitment, sufficient resources, full access to laboratory testing, uninterrupted supplies of quality drugs, the technical soundness of DOT, proper reporting and recording systems, partnership building, a MDRTB policy, an advocacy and social mobilisation plan, and access to voluntary counselling and HIV testing for all TB patients following major strategies (Dept of Health 2003; Parliamentary Monitoring Group 2002). Subsequently province-specific MTDPs for TB were cloned from this national MTDP.

Whereas TB control in South Africa until the early 1990s could rightfully be depicted as “ineffective treatment strategies for TB control” (WHO 1997), notable progress has been made since 1994, including the following steps:³⁹

- 1994 - Expert help enlisted: Dr Karel Styblo invited to perform a rapid appraisal of the TB situation.
- 1995 - Introduction of the TB Register.
- 1996 - Joint WHO-South African national review of TB; proclamation of TB as a national priority; appointment of provincial and

38 Cf Bamford 1999; Balt *et al* 1998; Dept of Health 1998a, 1999a, 2000 & 2001b; Dick *et al* 1999; Weyer 1997a; WHO 2001.

39 The following sources highlight the various dimensions of this progress in TB control: Bamford 1999; Dept of Health 2003; Dick *et al* 1999; Fourie 2002; Heunis 2004b; Kironde 2000; Kironde & Bamford 2002; Matebesi 2004b; Molehe 2004; SATCI 2000; Weyer 1997b, 2000 & 2003.

district-level TB co-ordinators in all provinces; establishment of the initial TB Control Programme and adoption of the DOTS strategy; implementation of practical guidelines for the diagnosis and treatment of TB (*The South African tuberculosis control programme: practical guidelines*); setting of a sputum turnaround time of 48 hours as the standard target for PHC facilities; implementation of a reporting and monitoring system based on the TB register across the country; development of standardised treatment guidelines for MDRTB.⁴⁰

- 1997 - Commencement of establishment of Demonstration Training Districts (DTDs).
- 1999 - Introduction of combination anti-TB drugs.
- 2000 - Establishment of TB/HIV pilot districts and implementation of treatment policies for MDRTB; signing of the *Amsterdam Declaration to Stop TB* for accelerated action against TB and commitment to improving TB control through expansion of the DOTS strategy.
- 2002 - Launch of Medium-Term Development Plan (MTDP); multi-million Rand agreement between the TB Research Lead Programme of the MRC of South Africa and the Centre for Disease Control (CDC) of the USA.
- 2003 - Launch of the National Advocacy and Social Mobilisation Plan.

There are now indications that the NTCP has begun to deliver on its aims in several respects.⁴¹

4. Reasons for the persistent failure to control South Africa's TB epidemic

Our explanation thus far has shown that the core ingredients for effective control of TB are already available. Effective chemotherapy for TB has been available since the 1950s, and has become ever more ef-

40 Heunis (2004b) provides a synoptic analysis of policies pertaining to MDRTB internationally and in South Africa.

41 Cf Dept of Health 2001 & 2004; Kironde 2000; Kironde & Bamford 2002; WHO 2002b & 2003.

fective in improved short-course regimens since. The applicable framework for TB case management (DOTS) has also been in use for several years now. But still we fail. Why? What is missing? In the discussion that follows we put forward five clusters of reasons for the continued failure of TB control in South Africa. Our arguments are substantiated by the past and present, international and local experiences in TB control outlined above as well as by the wealth of materials generated in the Joint Research Project on TB in the Free State, the results of which are presented in this volume.

4.1 Macro-contexts conducive to TB and the failure of TB control

Whichever way we argue, we cannot escape the predominant role that social macro-contexts played, and still play today, in the origin and spread of TB, especially factors inherent in the socio-economic, socio-political, socio-cultural and socio-demographic make-up of society. The central and often adverse influence of these contexts forms the main explanatory framework in historical accounts of the growth of the epidemic in South Africa.⁴² Abject poverty, unemployment, crowded living conditions, mass population movement, stressful living and working conditions, as well as unequal access to and poor quality of health care remain rife, and may even be deteriorating for the majority in post-apartheid society. The breeding ground of TB in society at large and in individual households has thus not advanced to levels with any brighter or better prospects of controlling the epidemic.⁴³

In 2000, about half of the South African population was still living in poverty, meaning that some 22 million people lived in the poorest 40% of households, while more than a quarter of the population — 27% or 12 million — lived in the poorest 20% (Pelser 2004b). Of course, the new population movements in the post-apartheid era — increased internal population migration and urbanisation, as well as the mass influx of immigrants (both legal and illegal), labour migrants and refugees from countries to the north — did not ameliorate

42 Cf Collins 1982; Dubovsky 1991; Metcalf 1991; Packard 1991 & 1992.

43 Cf Bradshaw 1997; Pelser 2003 & 2004b; Van Rensburg 2004b; Van Rensburg & Ngwena 2000; Weyer 1997b.

the poor living and working conditions of these South Africans; on the contrary, their plight has in fact been aggravated (Pelser 2003). Moreover, HIV/AIDS is profoundly changing the structure and dynamics of populations, entailing far-reaching consequences for conventional support systems, increased dependency ratios and the overburdening of healthcare systems (Pelser 2004a). HIV/AIDS aggravates impoverishment since it diverts a great deal of resources, as people living with AIDS, their relatives and extended family, governments and society as a whole struggle with the pandemic and its effects (Ssemakula 2004).

There are no “quick fixes” for these deep and protracted structural fault-lines in societies. However, at the same time, we are aware that the political willingness and commitment to addressing the gross inequalities in the allotment of wealth and health care within and between societies are still lacking or failing. Addressing such inequalities is a precondition if we are to tackle the TB crisis to any effect (Gandy & Zumla 2002; Sachs 1999).

4.2 New dimensions of the TB epidemic — co-infection, HIV/AIDS prevalence, and drug resistance

In attempting to explain the failure to control the TB epidemic we have to recognise the significance of changing profiles of disease and infection. As has been repeatedly mentioned, the nature of TB is being confounded by its close alliance with HIV infection and the rise of MDRTB. In recent times, the number of TB infections has risen rapidly as a result of the HIV/AIDS epidemic — HIV prevalence in South Africa has risen from less than 1% in 1990 to 22.4% in 1999 (Kironde 2000; Wilkinson 1999). The HIV/AIDS pandemic adds new dimensions to the TB epidemic: TB facilitates HIV infection; likewise, HIV and AIDS serve as easy corridors to TB infection. Such co-infection has risen to the status of a major precipitating factor for TB and renders its control much more difficult, if not practically impossible. HIV-infected individuals have a thirty times higher probability of acquiring TB than non-HIV-infected people. In 2000, it was estimated that HIV-co-infection would lead to 123 616 new cases of TB that would not otherwise have occurred. This would contribute 42% of the expected caseload for that year. The warning was clear:

HIV infection, if it remains uncontrolled, has the potential to swamp progress made in TB control as it is the most important risk factor for the progression from latent to active disease in people infected with the tubercle bacillus (Kironde 2000: 342).

Figures for 2000 and 2002 further demonstrate the growth of this new dimension of the TB epidemic in South Africa. The national rate of TB cases which were also HIV-positive stood at 47.6%, with the provinces ranging between a high of 64.6% (KwaZulu-Natal) and a low of 31.6% (Western Cape) (Kironde 2000; SATCI 2000; WHO 2002). The aggravated challenges for the healthcare system and in particular for the NTCP are obvious, and failures in the system become inevitable.

Seen from a different angle, HIV/AIDS has in recent years come to overwhelm the healthcare scene 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. Ssemakula (2004) aptly depicts this diversion of attention and distortion in emphasis:

In Africa, it increasingly appears that health and health-related problems are only really given serious attention when viewed through the prism of HIV/AIDS. And the prism of HIV/AIDS is dark indeed, with little or no good news [...] HIV/AIDS has become so monolithic in the public health arena, that it is now warping the surroundings it appears in. It eclipses all other diseases. And this is having the unwanted and potentially dangerous effect of diverting attention and resources from other pressing concerns that are just as devastating in terms of debility and mortality as HIV [TB for one], but actually have treatment, cures and prevention methods that have been proven to work [...] the danger of viewing health problems through the prism of AIDS is that it has the effect of making these health issues appear hazy and out of focus, while bringing AIDS into sharp relief. And this gives rise to the (false) impression that if we just find a solution to the AIDS problem, all other health problems will also magically be solved.

Everywhere and in everything HIV/AIDS is “lurking in the background, looming over everything”. Examples to illustrate the point include the fact that food security is now often viewed in the context of HIV/AIDS and that the Global Fund, launched amid much fanfare as *The Global Fund to fight AIDS, TB and Malaria* in reality tends to refer only to AIDS. The latest trend is the fixation on ARV treatment, which again results in significant national resources being channelled

to HIV/AIDS, to the detriment of other health problems, while reasonable success is by no means guaranteed (Ssemakula 2004). This cruel distraction appears to be a plausible reason for our failure to address the problem of TB.

The other complicating factor that adds new dimensions to the TB problem while also magnifying the challenge of successfully controlling the disease, is the emergence of MDR strains of TB. Recent developments in science and research on the microbiology of TB have put the growing challenge of multi-drug resistance (with its multiple strains) and the, as yet, “uncontrollable” nature of this new dimension of TB more squarely in focus. Each year roughly 400 000 new cases of MDRTB are added to the pool in more than 100 countries, so drug resistance poses a major threat to TB control (Portaels 2003; 2004). The potency of this emerging “epidemic” in South Africa is illustrated in recent figures: MDR presented in 1% of new TB cases and 4% of previously treated cases. This translates to approximately 2 000 new MDRTB cases in South Africa every year. Fortunately, South Africa still is not (yet) numbered among the MDRTB “hot spot” countries.⁴⁴ Patients infected with MDRTB require prolonged chemotherapy with very expensive medication that will at best cure only half of those infected. In response, DOTS-plus is currently under development to manage MDRTB.⁴⁵

In short, the runaway scourge of TB is dramatically magnified in its confluence with HIV/AIDS and the building up of multi-drug resistance around this otherwise curable disease. Control of TB therefore becomes more challenging as its aggravating intricacy and complexity outpace advances in science and stay ahead of research breakthroughs. In the words of a prestigious international journal,

The towering twin threats to global TB control are the continued explosion of HIV-related TB and the increasing prevalence of drug resistance. The former threatens to overwhelm treatment capacity in many parts of the world, while the latter raises the spectre of incurable disease that can be transmitted in the community (Editorial 1999: 1).

44 Cf Dept of Health 2001; Fourie 2000; Portaels 2003 & 2004; Weyer 2003a.

45 Portaels (2003 & 2004) describes DOTS-plus as a case-management strategy under development, designed to manage MDRTB by using second-line drugs within the DOTS strategy in low- and middle-income countries. Cf also Weyer (2000 & 2003).

The failure of the healthcare system at large in the face of these new dimensions of the TB epidemic is itself an important contributor to faltering TB control.

4.3 Failure in the TB control system

The third cluster of reasons for failing TB control is to be found in the NTCP itself, especially in the implementation of the programme. To recap: despite the more conducive policy environment for control brought about by the reforms since 1994, despite the progressive measures introduced by the new NTCP since 1996, and despite having the technology and resources for effective TB control in place, TB incidence is increasing at an alarming rate. Everything indicates that TB control still needs to be stepped up. Dick *et al* (1999) allude to several contextual and systemic factors in post-1994 South Africa that constrain progress in TB control. The following are highlighted: the extensive social, political, economic and health system reforms that detract from the specialised problems of TB; health district development that has tended to focus on structural issues at the expense of the content and quality of service provision; the co-existent HIV/AIDS epidemic; a lack of political commitment; economic constraints; lack of support and supervision of staff; low staff morale, and less than adequate interaction between health providers and patients which may affect treatment adherence. Moreover, TB has remained a low priority amid a welter of problems deemed more pressing by some policy-makers (WHO 1997). Against this backdrop the observation that South Africa “lacks the will” is not entirely unjustified, either at the time or currently (*Mail & Guardian* (1998: 1).

Kironde & Bamford (2002) elaborate on the systemic deficiencies of both the health and the TB services that hamper DOTS expansion. These include a lack of adequate funding at the provincial and district levels; inadequate integration of TB and HIV programme activities; a lack of integration of the national strategic plan into provincial and district-level TB control activities; insufficient success in creating and sustaining commitment to DOTS at all levels; inadequate extension of services to special populations; unsatisfactory treatment outcomes at the district level in some provinces, reflecting inadequate staffing and skills; the need to ensure that TB remains a top health priority

at all levels of the health service; a lack of sufficient cohort analysis; persistently high interruption rates and insufficient defaulter tracing; a lack of adequate administrative tools to reduce the risk of nosocomial TB transmission; overcrowding and lengthy admission procedures for patients in specialised TB facilities; insufficient links between the various components of the TB services, and the absence of a uniform national approach to the management of drug-resistance surveillance.

Linked to the above, there is abundant evidence of major programme-specific deficiencies in the implementation of the NTCP.⁴⁶ Among those that surface repeatedly are the following: TB programme managers are often ill-equipped to plan, implement and monitor the components of a TB control programme; DOTS is widely misunderstood or poorly implemented, and substantial effort is required to organise community-based DOTS; the four-drug combination has not yet been generally implemented; TB registers and routine information are not optimally utilised for managing TB programmes; referrals from hospitals to clinics and between clinics constitute a weak link in TB control; stock control is often at fault, with expired drugs still on shelves; treatment interruption rates remain high, while laxity prevails in tracing interrupters and addressing the reasons for interruption; sputum turnaround times fall far short of the goal of 48 hours; many districts are still struggling to establish the basic components of a well-functioning TB service, *i e* effective drug and transport management systems, access to laboratory services, and trained personnel; not all health personnel use or are aware of the excellent practical diagnostic and treatment protocols available, and communities still need to be better informed in respect of TB, its symptoms, and the services available to combat the disease. It appears, then, that the introduction of the refined NTCP, along with its accompanying proven guidelines, is still no guarantee of success in TB control. The present challenge is still to achieve optimal translation of the available resources into real improvements in treatment outcomes for people with TB. Increased adherence (both to TB medication and to the programme guidelines) becomes crucial to

46 CF Bamford 1999; Báez 2003; Dept of Health 2000; Edginton 2000 & 2003; Heunis *et al* 2003; Janse Van Rensburg-Bonthuyzen 2002a, 2002b, 2002c & 2003; Health Systems Trust 1997b; Edwards-Miller 1998; Van Rensburg *et al* 2000; Viljoen *et al* 2000.

the success of any TB control programme. We continue to fail to control TB because the healthcare system and the NTCP do not succeed in accomplishing such adherence.

Dealing with TB in terms of the socio-economic, socio-political and socio-demographic forces that fuel the epidemic, and/or in terms of national policy and structural measures — as history often does — often neglects the micro-dimensions of the disease and its control which are intrinsic to the personal “TB stories” of staff at the health facility or programme implementation levels and the “life histories” or “personal careers” of individual TB patients. In this regard, we have to bear in mind that, in addition to the macro- and meso-contexts and processes in TB control, these smaller, socio-psychological contexts and personal experiences or “histories” are also party to the control, or the loss of control over TB. In particular, they directly and continuously influence the interpretation and implementation of TB policy, as these are closely associated with, on the one hand, the unresolved challenges of laxity and faltering in the application of treatment guidelines as well as late detection and diagnosis of TB patients, and, on the other, the late presentation of patients with TB and their failure to adhere to or complete their treatment. Our remaining arguments hint at these micro-level clusters which also explain the failures in TB control, linking the failures to personal TB histories and life stories as these present among healthcare staff and TB patients. The failure of TB control should thus also be viewed from these essential micro-perspectives.

4.4 Failure on the part of health carers

As far as the staff perspective is concerned, there is ample evidence that the effectiveness of any TB policy hinges to a great extent on having staff who apply, interpret, implement and supervise the policy and treatment guidelines at the practical, frontline level correctly, continuously and in a user-friendly manner. If this is not done, or is done with discourtesy to and abuse of patients, it can have discouraging effects on subsequent behaviour and detrimental outcomes for TB patients. Haynes & Hall (2002: 95) comment in a different context, but with equal applicability here:

Policy formulated at the national level frequently appears to reach the implementation levels more by accident than by design, and sometimes not at all.

This mismatch is attributed to a lack of communication between the “top” and “bottom” levels and spheres of the delivery structures, and failure to orientate or train staff properly. There are huge gaps between TB policy at the policy-maker level and the interpretation or implementation of such policy guidelines by the healthcare worker in the facility context and in the patient-carer relationship. Between these two levels there are a myriad of intermediate levels and intervening variables of management and supervision that can misdirect policy on its way to practical implementation. Frieden (1994: 1721-3) observes, TB control is essentially a management problem and, therefore, more than anything else, control programmes need good managers, with supportive supervisory staff. For patients to develop effective handling of their illness, the communication, attitudes, actions, support and interaction of healthcare providers are crucial, because

... patients adhere to treatment more frequently when they are satisfied with the quality of care which they receive ... [and] ... patients who are closely supervised during the course of their therapy appear to be more adherent.

The opposite scenarios, however, are equally true and get to the heart of breakdowns in the programme:

... newly notified patients may be lost in the crowds of patients attending TB clinics [... and ...] newly diagnosed TB patients are bewildered by the turmoil in busy clinics, and present as passive and unassertive (Dick 1994: 12.3, 12.10).

Similarly, in relation to MDRTB,

... the growth of drug resistance is related to changing patterns of healthcare provision and cannot be explained in bio-medical terms alone or simply by blaming patients for non-compliance (Gandy & Zumla 2002: 389).

Due to their numbers, focus, processes and amount of patient contact, nurses in South Africa are best positioned and qualified to affect the health and care-seeking behaviour of patients (such as reluctance to seek professional help and non-adherence to treatment); additionally, patient education is an important element of nursing care (Snoek & Visser 2003: 2). Healthcare providers at the clinic level are an essential link between the programme and the patients; they are responsible for detecting TB, for diagnosing correctly and timeously, for providing

effective treatment, and for maintaining registers. From a TB control point of view, informed and motivated frontline health-workers thus indubitably contribute to case-finding, case-holding and positive treatment outcomes. Conversely, de-motivated and ill-informed health-workers may contribute to interruptions and the resultant transmission of TB in affected communities. The health provider/patient relationship, and dysfunctional or negative hiatuses in the power, conduct and attitude of healthcare providers towards TB patients therefore become important determinants in care-seeking or in delaying doing so, in satisfaction or dissatisfaction with care, and in adherence or non-adherence to treatment.⁴⁷

Cognisant of this weak link in TB control (*i e* staff), among the range of strategies employed to improve and secure patient adherence are those aimed at changing long-standing deficient practices and behaviour among TB care providers, by training, motivation and supervision (Volmink & Garner 1997). This aspect of the failure of TB control thus pertains in particular to the failure of its individual staff in the chain of caring. The cumulative result of hundreds of healthcare providers failing to interpret and administer the rather complicated current NTCP correctly and without any breakdown in the essential continuity of care, is certainly an important factor in the general breakdown of the control programme.

4.5 Failure on the part of patients

Successful TB control also depends on individual patients who first have to decide to seek care and to enter the healthcare system without delay, and then have to refrain from high-risk behaviour and to comply with treatment guidelines and drug regimen. In all these respects, however, reality often paints a different picture: people often ignore symptoms and postpone seeking help; they persist in risky behaviour; they do not adhere to prescribed treatment regimens, and they abscond from treatment. The reality is that

⁴⁷ Many studies undertaken in other countries (Gandy & Zumla 2002; Jaiswal *et al* 2003; Johansson *et al* 1996; Stein 2000; Vermeire *et al* 2001) and in South Africa (Dick 1994; Heunis 2004b; Matebesi 2004b; Matebesi & Booysen 2004; Zwarenstein *et al* 1998) demonstrate the principles at stake in this argument.

... [p]atients cannot be assumed to be a group of willing suppliants, rushing with open arms to seek aid [...] It is no longer safe to assume that patients regard the treatment they are asked to undertake as being entirely for their own good and in their best interests (Zola 1981: 241),

and

no matter how severe the consequence, there is no assurance that all patients will take their medications as prescribed (Cramer 1998: 7).

Many authors⁴⁸ acknowledge that the complex interactions of a broad range of socio-economic, social, cultural, infrastructural and personal (individual) factors determine patient behaviour, and may lead them to refrain from seeking care, or to fail to adhere to or to complete treatment regimens. Among these factors are lack of knowledge and low levels of awareness of TB; misconceptions and misguided expectations regarding the disease; a lack of understanding of the course of the illness; hunger; the side-effects of drugs; lack of social and family support; prevailing social norms and expectations; the stigma attached to TB; social isolation; the complexity of the treatment regimen; the attitude of health care workers; the absence of supervised tablet-taking, and the long delays in obtaining diagnoses. Often treatments are abandoned not because they do not work well enough, but because they are “too

48 Of the numerous studies on the topic, the following studies aptly reflect the nature and determinants of TB patient behaviour in different countries: Demissie *et al* 2003; Farmer 1997; Gandy & Zumla 2002; Gardner 2001; Meulemans *et al* 2000; Heunis 2004b; Jaramillo 1999; Johansson *et al* 1996; Kane 2002; Khan *et al* 2000; Leigh & Reiser 1980; Liefoghe *et al* 1995; Liefoghe 2000; Long 2000; Long *et al* 2001; Love 2002; Mata 1985; Meulemans 2000; Meulemans *et al* 2000; Needham *et al* 2001; Nichter 1984, and Thorson 2001. In the South African context, the following research is illustrative of those factors that play a role in determining TB patient behaviour: Dick 1994; Heunis 2004b; Matebesi 2002, 2004a & 2004b; Matebesi & Booysen 2004; Verbergt 2004. Several theories also attempt to explain the behaviour of patients in the face of illness, care-seeking and treatment, including the Theory of Reasoned Action (Ajzen & Fishbein), the Health Belief Model (Hochbaum), the Theory of Self-Efficacy (Badura), Social Learning Behaviour (Badura) and the Theory of Health-Seeking Behaviour (Mechanic). These theories have also been applied to explain the behaviour, beliefs and attitudes (specifically adherence) in samples of South African TB patients (Dick 1994; Matebesi 2004).

much trouble to take” (Gregson 2002: 461). Such an “individual story” is told by Dick (1994: 5.10):

Healthcare providers sometimes encounter patients whose social functioning is so chaotic that their co-operation with treatment, and hence their physical health, is seriously impaired. The patient’s history is usually characterized by turmoil such as unemployment, poverty, and family disintegration. Rarely do these patients manage to plan ahead but they react to the demands of the day-to-day crises. These patients require assistance coping with their emotions, and assistance to develop skills in dealing with problems encountered.

Verberg’s (2004) differentiation between the roles played by “life choices” and “life chances” in determining the decisions and behaviour of individuals in relation to TB provides some clarity. Adherence to a drug regimen may be the “choice” of some patients (in terms of their “internal loci of control” — the necessary predisposition, awareness, knowledge, responsibility, willingness and determination to adhere), but often the choice is nullified by the slim “life chances” of patients within their immediate circumstances, which may render adherence difficult or impossible (in terms of “external loci of control” — obstacles or barriers located in dismal living and working conditions, unemployment, lack of access to basic services or infrastructure, poor nutrition, social marginalisation and exclusion) (Dick 1994).

As in the case of health providers, a range of strategies has been employed to improve and ensure adherence among patients, among others education, reminders and prompts for attendance, financial incentives, supervision of tablet-taking and defaulters tracing (Volmink & Garner 1997). Matebesi (2004b: 193) concludes:

[I]t is again emphasised that health care interventions, alone, will not win the battle against TB. Of even greater significance, is the need to recognise the patient perspective in TB control efforts.

The cumulative result of thousands of clients defaulting on treatment, whether by choice, due to ignorance or misguided beliefs and practices, or as a result of circumstances and barriers, thus become a formidable force in the failure to control the disease.

5. Conclusion

To summarise: we fail, firstly, because we cannot control global disparities in wealth and health, while the government, despite concerted efforts and well-intended strategies, cannot eradicate the conditions that constitute the breeding ground for TB. Secondly, we fail because new conditions — HIV/AIDS and MDRTB in particular — have entered the scene and methods and means have not yet been designed and appropriated to cope with these novel challenges. Thirdly, we fail because our health system is not sufficiently geared and resourced to deal with the overwhelming challenges posed by TB and its allies. What is more, our priorities are not always aligned to the real challenge of TB; during the past decade of reform, a divided focus on contending priorities has too often distracted attention and efforts from TB. Fourthly, healthcare staff, managers and supervisors attending to TB control are, at times, weak links in the chain of control; the cumulative effect of many health providers not implementing the programme accessibly, correctly and continuously allows control of the disease to fail and even spurs on the epidemic. Fifthly, TB patients fail because of ignorance, delay in seeking care, non-adherence to or completion of treatment regimens. In turn, their social support systems often fail them dismally.

There are sufficient grounds for gloom and pessimism. For more than a century efforts have been made to control TB, admittedly sometimes in undirected, misdirected, discriminatory, and *laissez-faire* ways. But it does not help to blame history and historical forces for our current dilemma. Perhaps we can argue that without these efforts the epidemic would have been worse in its extent and severity, and therefore deem past efforts to have been relative successes. There is little solace in such an argument, however. The complexity of conditions and factors that instigate and fuel the current TB epidemic is simply overwhelming, and it is precisely this deepening perplexity that creates such a bleak prospect, leading us to the conclusion that efforts to control the disease are still failing. Either intentionally or unintentionally, the government, the health system, healthcare workers, patients and their communities are all contributors to or at least facilitators of this failure. Only time will tell how long this situation will persist, and when and how it will end.

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