

Tuberculosis: the complexity of the phenomenon and the magnitude of the problem

The rationale for studying tuberculosis (TB) in a multidisciplinary manner is to be found in both the complex nature of the TB phenomenon and the magnitude of the TB problem. TB is caused, spread and sustained by various factors. To control the epidemic this multiplicity of factors has to be unravelled and coherently addressed. Primarily, TB is caused by tubercle *bacilli* that are dormant in most human beings from endemic regions. However, other factors such as poor living and working conditions, poverty and deprivation, low general immunity, bad diet and fatigue can trigger an epidemic. TB is generally labelled a “disease of poverty”. Despite the dedicated efforts of many, over a period of more than a century, to conquer or contain the disease in South Africa, the contexts and dynamics of deprivation and neglect, brought about by political-economic policies and socio-economic circumstances, have conspired to make TB an ostensibly invincible epidemic.

The material presented in this volume makes the scale and the escalation of TB — globally and in South Africa — abundantly clear. A third of the world’s population is infected with the TB *bacillus*; a new subject is infected every second, and the epidemic kills about three million people a year. Eighty percent of new cases occur in 22 high-burden countries (South Africa being one). By 2020, nearly one billion people will be newly infected and, despite the existence of effective treatments, 200 million will have fallen sick and 35 million have died of TB. The scourge of the disease is particularly evident in developing countries, where 95% of TB cases and 98% of TB deaths occur. The incidence and spread of TB are currently aggravated and accelerated by its close association with HIV/AIDS and the emergence of (multi)-drug resistance in this otherwise curable disease. It has become harder to control TB, as its increasing intricacy and complexity enable it to

outpace advances in science and stay ahead of research breakthroughs. In fact, TB has once again become a global emergency.

One side of the coin reveals that the failure to control TB hinges on numerous factors. Among other things, the ignorant, negligent, non-adherent and even absconding behaviour of infected individuals very directly results in diagnostic delay and treatment failure. Health workers and managers, often few in numbers and overburdened, contribute to these failures by way of negative opinions, reprimanding attitudes, punitive approaches, unprofessional behaviour, and neglect of patients. Furthermore, systemic barriers, poor quality of care and the unbecoming environments of poorly resourced and rundown healthcare institutions contribute in various ways to the persistence of the epidemic. The other side of the coin reveals that the successful control of TB hinges on the concerted, integrated efforts of an array of role-players. It is up to scientists and researchers (of all orientations), health professionals (of all sorts and at all levels), patients (together with their support systems) and politicians (the committed ones at least) to unravel the nature and dynamics of TB, and to release the chain of solutions necessary for its effective containment and control.

Joint research project on tuberculosis control in the Free State

This *Acta Academica Supplementum* volume on *Tuberculosis: multidisciplinary approaches to research, policy and practice*, is an outcome of a four-year collaborative research initiative entitled “Joint research project on tuberculosis control in the Free State — from infection to cure”. This Joint Project was conceptualised in 1999-2000 by researchers from the Centre for Health Systems Research & Development (University of the Free State, South Africa), the University of Antwerp and the Prince Leopold Institute of Tropical Medicine (Belgium). The research was conducted by a multidisciplinary and multi-institutional collective team of researchers, with close collaboration and full support from the Free State Department of Health and its staff at the provincial, district and facility levels.

The Joint Project studied TB in the Free State from various angles and with the explicit aim of informing the provincial TB programme

and enhancing the efficiency of TB control in the province. The original research was conceptualised in terms of two focal dimensions: social and health services. The social dimensions included, on the one hand, the TB patient's needs, perceptions, experiences and circumstances, health-seeking behaviour, health service utilisation and satisfaction, coping strategies, support systems, and adherence to treatment regimes. On the other hand, the social dimension also involved a focus on TB Control Programme managers and staff, as well as DOT supporters, studying their knowledge of TB control, attitudes towards TB patients, and adherence to national and provincial policy guidelines for TB control practice. The health service dimension comprised a comprehensive assessment of the provincial, district and facility-level implementations of the DOTS policy, including managerial support and training, financial support, diagnosis practice, laboratory sputum microscopy services, DOT support, drug supplies and record-keeping.

The TB hospitalisation policy, TB hospital services and the hospitalisation of TB patients at SANTA and district hospitals were also studied and compared. In addition to the two main dimensions, several cross-cutting dimensions were researched: first, microbiological ("fingerprint") analyses of sputum collected to provide information on strain diversity, geographical spread, transmission rates, reactivation rates, and predictors of multi-drug-resistant TB and, secondly, the economics of TB control, focusing on the cost of TB care to both government and patients. The papers in this publication address some of these dimensions.

The empirical part of the research was conducted in three high-burden sites, namely Welkom/Thabong, Qwaqwa and Thaba Nchu. In each of these study areas, three clinics were included for the purposes of data collection from health providers, managers and TB patients. Among other things, some 220 ambulant clinic patients and 90 institutionalised hospital patients were interviewed, as were 15 strategic informants on hospitalisation, and nine clinic TB co-ordinators. Clinics were observed, clinic TB registers were scrutinised, and environmental scans of the study sites were conducted. Five hospitals in the three areas were also concerned. Thus, case study material was drawn from a total of 14 healthcare facilities. A sizeable number of health workers and managers from health facilities and health districts not included

in the initial sample were involved in focus group discussions and workshops in order to more widely generalise certain aspects of the data.

Linked to the various disciplines participating in the larger project and to the different sub-projects comprising the Joint Project, a variety of research methodologies and methods were applied, spanning a broad spectrum of microscopic analysis of sputum samples, assessment of laboratory test results, in-depth interviews with care staff, focus group sessions with staff and patients, analyses of financial statements, and surveys of various categories of healthcare workers and TB patients by means of direct questioning and self-administered questionnaires. In the process, the existing policies and literatures were assessed and expanded.

One result of researching this spectrum of the dimensions of TB was that the “hard” and “soft” sciences, medical and social scientists of various orientations, gathered around the same table for discussions. In effect, then, the Joint Project became an enlightening venture, crossing multiple borders and bridging multiple divides by conducting TB research across disciplinary boundaries. It was about crossing the north-south and national boundaries between South Africa and Flanders; crossing borders between “researchers” and “practitioners”, and crossing divides between quite divergent disciplines and between different methodological approaches and research methods. With the crossing of these borders came abundant opportunities for interaction, exchange and cross-pollination. The crossing of multiple borders is also exemplified in the composition of this joint publication, where the authors have once again crossed both disciplinary divides and the North-South border.

The success of this Joint Project, and of the collaborative research conducted within its framework, was determined by finding a common problem, serious enough and multidimensional enough, to capture the interest and hold the attention of researchers from two very different countries and from divergent disciplines, over a protracted period. In addition, the collaborators’ openness and their willingness to see and grasp the opportunities that arose from talking to and working with each other, were crucial.

Tuberculosis: multidisciplinary approaches to research, policy and practice

The thirteen contributions in this *Acta Academica Supplementum* represent only one product proceeding from the Joint Research Project on tuberculosis control in the Free State. Thus far several doctoral and master's theses, numerous presentations at national and international conferences, as well as other contributions to scientific journals have originated from the project. Furthermore, the results of the research have been disseminated at two special occasions primarily devoted to this purpose. The first was the *Conference on Tuberculosis: a multidisciplinary approach to research, policy and practice* held at the University of the Free State, Bloemfontein, South Africa on 11-12 November 2003, and the second, the World TB Day 2004 Commemorative Conference on *Tuberculosis control in the Free State, South Africa: from infection to cure* held at the Institute of Tropical Medicine, Antwerp, Belgium on 5 March 2004.

While this volume is a product of the Joint Project, its content is not confined to that project's original framework and aims. As the research progressed, and as exchange took place over the four years, the project outgrew its original demarcation and profile. New topics are thus introduced and explored here. The Joint Project has fuelled increasing interest in TB and, indeed, inspired exploration of new dimensions of the TB phenomenon.

While this volume marks the completion of this particular collaborative project on TB, it also contains the seeds of further collaborative research on new themes, especially the links between TB and HIV/AIDS, and between anti-retroviral therapy and TB. As these new dimensions are studied and new research partnerships are formed, TB will remain a preoccupation and a main focus within the agenda of our collaborative research.

The reader should not seek too hard for a particular logic in the sequence of the thirteen contributions, or for a close-knit coherence among the quite divergent studies. TB alone is the common denominator, while the logic and coherence are to be found in the range of perspectives necessary to understand this multi-dimensional phenomenon scientifically, and to inform multi-disciplinary interventions aimed at controlling the epidemic. One-dimensional or mono-disci-

plinary approaches are simply not appropriate in dealing with TB. Each contribution highlights a significant dimension or dimensions of TB, in an attempt to further advance the search for a workable strategy to control the disease. The essence of each study will be briefly elucidated in the following paragraphs.

The contributions

The first articles review TB in the global, the African and especially the South African contexts. Thereafter, the focus shifts to the micro-biological level, followed by studies on TB patients and their circumstances, the healthcare system and programmes for TB control, and certain specific aspects and processes important to that control. As the articles proceed, there is also increasing concentration on TB in the Free State, the location of the main emphasis of this *Supplementum*.

- The global, African and South African contexts

The first two articles place TB in a broader context by describing the state of TB in South Africa, on the African continent and world-wide.

Van Rensburg *et al* review the origins and the relentless spread of tuberculosis in South Africa against an international backdrop of soaring TB incidence and wavering TB policy in developing countries. The history of the epidemic is sketched over a period of more than a century in which poverty, unsanitary, stressful living and working conditions, poor nutritional status, ignorance, migration and social disruption enabled the disease to take hold and spread rapidly. A very negative picture emerges, showing that TB is far from under control. Despite the fact that effective technology has been available for more than fifty years, the epidemic is, in fact, currently escalating. The failure of control efforts often relates to lack of commitment, direction, inaction, neglect and discrimination amid insufficient socio-political and socio-economic contexts. Besides societal factors, deficiencies in health systems and programmes, staff errors and non-adhering patients in the chain of TB care undermine and prevent effective TB control. On top of these factors, there are new disease conditions — HIV/AIDS and MDRTB — which compound efforts to cope with the epidemic. It is

clear that the key to TB control goes beyond mere medical intervention; multi-levelled social interventions must be part of the solution.

Rigouts & Portaels go beyond South Africa and analyse (drug-resistant) TB on the African continent. Drug-susceptibility testing (DST) is performed to achieve two major objectives. For individual patients DST provides the information necessary for optimal treatment, whereas for epidemiological purposes DST is used to perform the surveillance of the resistance profiles in a population. A well-functioning TB control programme should be reflected in low or even decreasing drug-resistance levels over time. During the past decade, information on the worldwide prevalence of drug-resistant TB has been gathered through continuous monitoring in most high-income countries and sporadic drug-resistance surveys in some middle- and low-income countries, but data remain scarce, especially for the latter areas. An overview of the overall prevalence of drug-resistant TB is presented, with the emphasis on the situation on the African continent. The authors also highlight the importance of good TB control measures for preventing the creation of drug-resistant TB. They also show how drug-resistant TB could hamper efforts to control TB in high-prevalence countries. A summary of unanswered questions focuses attention on the main microbiological requirements in the campaign against (multi-)drug-resistant TB.

- Microbiological contributions

The next two contributions delve deeper into the intricate nature and dynamics of the microbiological world of TB and the interventions possible at this level.

Van der Spoel-van Dijk *et al* applied the standard DNA-fingerprinting technique on a representative sample of *M tuberculosis* isolates from smear-positive pulmonary TB patients in order to document the TB population dynamics. They observed a heterogeneous TB population, suggesting that reactivation might be an important factor in the area studied. There were significant differences in clustering between the districts studied. The combined use of DST and DNA-fingerprinting analysis provides important information for both patient care and programme evaluation, especially in settings with high levels of drug resistance. The authors may have detected re-infection during treat-

ment or initial mixed infections among patients with serial isolates. However, the attempt to combine microbiological data with sociological data on the same study sample was riddled with problems. Sampling proved to be the first major problem, mainly due to overburdened staff not dedicated to focusing on TB alone, and certainly not convinced of the value of TB research. This study taught us that specimen sampling for a prospective multi-disciplinary follow-up study requires long-term intensive preparations in order to make the coverage as complete as possible and that it should preferably be started before the onset of the other aspects of the study.

Mokhethi *et al* present results on the distribution of isoniazid-resistant TB strains in the Free State and Northern Cape provinces of South Africa. Drug-susceptibility testing alone does not provide information on the transmission or spread of specific drug-resistant *M tuberculosis* strains. Strain-specific typing requires DNA-fingerprinting analysis distinguishing between epidemiological non-linked isolates and clustering of linked isolates. High clustering rates in a representative sample suggest high levels of recent transmission, whereas low clustering rates are indicative of high reactivation rates. The authors observed a high strain diversity, which suggested a low recent transmission rate of isoniazid-resistant TB strains in these provinces. In general, in regions with high recent transmission levels, TB control measures should focus on transmission prevention, *i e* early detection of infectious cases followed by efficient treatment. Low clustering of drug-resistant isolates could result either from reactivation of a previous case of drug-resistant TB or from newly developed TB. In the former case, cultivation of bacilli and DST is recommended when TB is diagnosed, in order to allow for immediate adaptation of the treatment regimen. In the latter case, TB control programmes should focus on treatment compliance, efficient drug-supply and overall efficiency.

- TB patients, their circumstances and types of care

In respect of the TB patient, three contributions present views and findings on selected dimensions of being and acting as a TB patient. In different ways, these studies make connections between patients and the healthcare system, and between behaviour and TB control.

Meulemans *et al* pose the questions: where do TB patients go for help? Do they visit a PHC facility and thus retain contact with their families and communities? Or are they hospitalised, which means they can no longer perform their normal roles? To find the answers, a data set compiled from interviews with a random sample of 310 pulmonary TB patients in the Free State was analysed. Among the determinants explaining the locus of treatment, social capital takes priority. TB patients who are in a position to rely on an extended network of relationships are much more committed to treatment in PHC settings. The relationships taken into account in operationalising social capital were found at various levels: among family, friends, colleagues and the local community. The referral of TB patients to PHC facilities generally occurred quite naturally and spontaneously. PHC facilities functioned not only as places of treatment, but also as points of referral to higher levels of care. The dynamics associated with referring patients to the most adequate and humane places of treatment imply that the many activities directed towards TB control have to be firmly embedded in a strong general healthcare system. Caregivers feel a need for templates that can map out both the needs and the range of human capabilities of TB patients in local communities, health districts and sub-districts in the Free State, in order to address the concomitant problems by means of effective, customised solutions.

Matebesi *et al* show via the results of an empirical study among TB patients accessing PHC facilities that early detection and treatment of TB is critical for its control. Various factors cause TB patients to delay seeking health care. If TB is to be diagnosed earlier, a better understanding of these factors is required, hence the authors investigate factors that influence healthcare seeking among Free State TB patients. Information was collected by means of face-to-face interviews with 220 patients accessing PHC facilities in the aforementioned three high-burden areas of the Free State. The results show that lack of awareness of TB and having used a home remedy were significantly associated with a delay of longer than two weeks before seeking health care. These findings indicate that TB awareness and knowledge about the symptoms of the disease must be improved. There is an urgent need to educate communities about the signs and symptoms of TB, as well as about the need to visit designated health facilities for early

diagnosis and proper treatment. The authors recommend that future studies should identify the home remedies or alternative treatments that patients use before presenting to healthcare providers. Integration of public- and private-sector efforts towards TB control is also considered beneficial in ensuring earlier diagnosis and treatment of TB.

Verbergt *et al* try to understand the forces and patterns underlying the persistent spread of TB. They argue that the legacy of apartheid, poverty among certain groups in society, and the exponential increase of HIV/AIDS render TB control in South Africa extremely difficult. In their efforts to understand and explain, they distinguish micro-, meso- and macro-levels. At the micro-level, they confront the concept of disease, TB in particular, as perceived by lay people within the Western medical frame of reference. When the patient is reluctant to use Western medicine, DOT may not be effective unless modern medicine co-operates with traditional health practitioners. At the meso-level, the Weberian concept of "lifestyle" clarifies why some people are at higher risk of getting infected than others, but also why some people adhere to their treatment and others do not. At the macro-level, poverty alleviation needs to be prioritised, as should general access to basic health care. Much needs to be done to eliminate the still conspicuous traces of social inequality in the South African healthcare system. The measures that have been taken by the government should be further investigated and evaluated.

- TB-care systems, communication and cost-effective models

The TB-care system in both PHC facilities and hospitals, communication in a multicultural context, and the search for cost-effective models for TB diagnosis and treatment are the respective foci of the next four articles.

Janse van Rensburg-Bonthuyzen points out that, to date, the success of the DOTS strategy recommended by the WHO to combat tuberculosis in South Africa has been limited. Throughout the country, TB control targets remain unmet. While many factors contribute to this situation, this study concentrates mainly on certain limitations in the public healthcare system which negatively influence the success of the TB programme. It explores the extent and nature of shortcomings in the intra-clinic human and material resources used in the

TB programme in nine Free State clinics. The findings included that the training and capacity of TB personnel in these clinics were lacking, that management support required improvement, and that programme-specific material resources such as drugs, supplies, policy guidelines and posters/pamphlets were sometimes in short supply. By identifying problems relating to the resource-, capacity-related and infrastructural components within some PHC clinics and alerting health managers and personnel at all levels to the existence and extent of these problems, a contribution can be made towards addressing some of them, thus improving TB control.

Heunis looks at the non-governmental healthcare providers in the Free State who have traditionally provided long-term hospitalisation services for TB patients. This history has now come to an end. The author documents the stances of a purposive selection of public health workers and managers in respect of TB-related hospitalisation. The views and experiences of health workers and managers at the district, provincial and national levels were recorded by means of self-administered questionnaires and personal interviews during 2001-2003. In the Free State this period was characterised by an array of intricate problems, especially in so far as the role of the Santoord Hospital (an NGO institution run by SANTA) was concerned. Amid nationwide allegations of financial impropriety levelled at SANTA, the Santoord Hospital was closed down. On the positive side, the indications are that public district hospitals have been able to absorb the extra burden brought about by the sequential closure of the former Allanridge Chest and Santoord hospitals.

Pauwels maintains that communication, including communication in the domain of health, is a culturally embedded practice par excellence which derives its usefulness largely from its cultural responsiveness and sensitivity. Health communication projects are pivotal instruments in disease prevention and alleviation, as well as in health promotion and education in a broader sense, but only to the extent that they are grounded in a thorough understanding of the general context of the health issue, and developed in concert with other instruments and aspects of health care. The author demonstrates that such a complex undertaking calls for a strategic, integrated approach involving many different types of expertise and research. To render

health communication effective, three layers of complexity have to be synchronised: first, strategic communication theory and principles, with the challenge of converting them into practice; secondly, health care as a particularly all-encompassing and specialised professional field, and thirdly, knowledge and skills in respect of the specific — often multicultural — context in which everything finally has to come together. Communication, then, is a meeting ground on which general principles and insights may provide a solid point of departure, but where success is largely determined by an integrated, culturally customised approach.

De Graeve *et al* demonstrate that economic evaluation studies on diagnostic pathways and treatments of TB are useful in guiding priority-setting within the health sector; in promoting, enlarging or reducing budgets, and in choosing between different options for TB control. The authors screened bibliographical databases for all original economic evaluation studies related to the diagnosis or treatment of TB in high-burden, low-/middle-income countries. The evidence points to a possible gain in cost-efficiency when moving from the Ziehl-Neelsen staining method to fluorescence microscopy, and from three to two sputum examinations. In respect of treatment alternatives, community-based DOTS is confirmed as being more cost-effective than the conventional approach. Community involvement appears to be an attractive economic option for both providers and patients. By shifting care from hospitals to the community, access to treatment can be increased, while community-based care is less expensive than conventional treatment. Increasing patient compliance is another factor affecting the cost-effectiveness of TB treatment: the lower the costs incurred by patients, the better their compliance. Recent economic evaluations understand this message: they include patient costs and consider treatment alternatives in which compliance plays an important role. Further research on the diagnosis and treatment of MDRTB, on guidelines for implementing collaborative TB and HIV programmes, and on public-private collaboration seems necessary.

- TB and HIV/AIDS

Within the context of interventions, the last two articles either draw a pertinent link between TB and HIV/AIDS or deal with TB and HIV/AIDS within the same context.

Peters & Heunis depict TB and HIV/AIDS as a dual epidemic requiring joint action. They review key global and South African policy developments in relation to TB-HIV/AIDS control. The World Health Organization's interim policy for collaborative TB-HIV/AIDS control promotes a complex and multi-faceted approach aimed at establishing mechanisms for collaboration, decreasing the burden of HIV in people living with TB, and lessening the burden of TB in people living with HIV. The early response of the Free State to global and national directives to implement integrated TB-HIV/AIDS programmes is described. From the experience of the first TB-HIV training site in the Free State, Mafube local municipality, it would seem that integrated TB and HIV/AIDS control is facilitated by actual practical interventions, as well as by the collaboration of a range of role-players. In Mafube, and later also in the Free State at large, attempts at integration have resulted in substantially more TB patients undergoing voluntary counselling and testing for HIV.

Finally, Pauwels demonstrates that health promotion materials should, both visually and verbally, "talk the language of the receivers". This implies more than using a language the latter can understand; it must also be a language with which they feel comfortable. The author presents and analyses TB and AIDS-related health promotion materials in use recently in the Free State and Lesotho: individual health posters, as well as photographs of health messages, in their context of use. Being mainly exploratory in nature and intent, his visual essay does not seek to provide any conclusive answers. The materials discussed were chosen primarily for their ability to convey several crucial points about designing effective health messages and to illustrate possible cultural misunderstandings. It is evident that a more representative and systematic approach can only be acquired through extensive multi-disciplinary research that would imply the active involvement of the target audiences and different types of cultural experts and professionals in many fields.

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