

A violation of citizens' rights : The health sector and tuberculosis

One's understanding of the problem of tuberculosis affects the choice of intervention strategies

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Tuberculosis was recognised by the new government of independent India in 1947 as one of the country's biggest public health problems. Interventions were introduced in 1948. This formed part of the government's constitutional mandate and pledge to protect and promote the health and well being of its citizens. BCG vaccination within a vertical programme was the main strategy with a focus on urban areas and children, among whom TB was then considered to be the major problem. With limited finances, it was felt that prevention was the best approach. Fortunately, indigenous research was initiated and supported by the government through the establishment of new institutional bodies, in order to understand the problem better.

Over the years, research findings challenged then current assumptions and gave shape to the National TB Programme (NTP) in 1962. By this time, effective chemotherapy was available at low cost. Better drug regimens were developed by the 1970s. The functional unit of the NTP was the District TB Programme (DTP). BCG, early case detection, domiciliary chemotherapy, integrated with general health services, supported by District and State TB Centres were conceptualised as the key strategic components. The NTP idea influenced TB control programmes globally through the WHO. Later, the world's largest controlled BCG trial in Chinglepet, India, found that the vaccine did not prevent adult pulmonary TB and that it played no role in controlling disease transmission.

Infrastructure for the NTP at state and district levels began to be established

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and team training of DTP teams was undertaken. Major problems in implementation became recognised and were reported by the government and other research institutions and bodies from the early 1970s. However, these findings and evaluation reports resulted in little change in action and performance.

Poor implementation has resulted in more than half a million deaths annually. Thus, from 1947, about 25 million people have died of a disease that has been curable at low cost from the 1960s. Many more millions suffer needlessly. The poor, at greatest risk, are most affected, having less access to effective care. A proportion get functionally disabled due to advanced disease and a substantial proportion also become indebted due to the disease.

Understanding and defining the problem

Policy makers and planners conventionally define and therefore understand the problem of Tuberculosis within epidemiological, bio-medical, public health and programmatic parameters. This is necessary and important and these dimensions are outlined in the next paragraph. However, they are insufficient to bring about a change in practice or in implementation of the programme. Hence, they are insufficient in producing an impact on the preventable disease burden among people and populations.

Epidemiological dimensions of disease burden: Tuberculosis has been known and named in India as *Rajya Roga*, the king of diseases, since many centuries. High rates of infection and disease have been noted from the early 20th century. Before this, it was reported to be more rare or infrequent.

A large proportion (30-52%) of the population gets infected. Only a small

proportion of those infected break down into disease at some point of time. The disease in all its forms (lung and extra-pulmonary disease where other organs are affected) currently affects 1.6-2.2% of the population. This is the disease prevalence. It is inclusive of 0.3-0.4% of people suffering from sputum positive TB of the lungs who are infectious to others. Public health planners focus on diagnosis and treatment of this smaller sub-group of patients with the hypothesis that the chain of transmission would be cut and the disease would be controlled. Patients with negative sputum smear, active pulmonary TB or with childhood or extra-pulmonary TB, being non-infectious and consequently not threatening society, receive cheaper, less effective drug regimens, through physically suffering as much or more. Justified by resource constraints, this policy is discriminatory and represents societal relations and state priorities.

The disease and infection prevalence rates with age and TB is largely an adult problem, with 8% occurring in children. While disease prevalence is higher among poorer socio-economic groups, this fact does not receive any particular policy attention. Disease prevalence is lower among women than men. But women have less access to general health care and hence possibly to TB care. More young women in the reproductive age die of TB than of other causes.

Though declining, the mortality from this preventable and curable disease is still unacceptably high at 50-84/100,000.

Currently India has approximately 13.5 - 17 million TB patients of whom 3.6 million are infections. In absolute numbers, more persons are affected now than in 1947. While this is due to demographic or population growth, it also indicates that control strategies



and interventions have been ineffective.

TB is equally prevalent in rural and urban areas. With a predominantly rural population of 74%, the TB problem is thus largely rural based. Patients are widely dispersed with roughly 10-12 patients in each village. This requires widespread basic health care services in order to make TB care available and accessible.

These epidemiological understandings and other findings derive from several good quality research studies undertaken by government research institutions.

Public health and programmatic parameters : These include rates concerning case-finding, case-holding, default, relapse and treatment failure. The research bodies mentioned above and others have repeatedly and consistently reported gaps between expected performance and outcome (1, 2, 3). After 40 years of intervention into what was termed India's most important public health programme, only approximately 8-16% of expected cases of TB received complete treatment from the public health services annually (4). Case detection in 1987 was 1/4th the annual incidence of TB (2). This was too low for any significant impact on the problem. Only 27% of those starting treatment made 12 or more monthly drug collections from 1982-86. Furthermore, poor functioning of the programme among those registered / treated is indicated by high case fatality rates [25% in a district using short course chemotherapy (Datta et al 1993)], high ratios of increasing drug resistance. This scenario is further compounded since the mid 1980s by HIV-TB co-infection, rates of which are increasing. A review in 1992 stated that "The programme is not having a measurable impact on transmission and appears to function far below its potential." (3)

Policy process perspectives : The technical indices mentioned earlier though crucially important, do not

explore or reveal the reasons for the dismal scenario or for the disparities and discrimination that exists within those affected by TB. It has been observed that techno-managerial approaches to TB control policies are insufficient to grasp important socio-political and policy process factors that influence and determine implementation (15). Underlying epidemiological and public health indices are conflictual societal relations and interests which surface in sectoral action and non-action. These include inadequate manufacture of TB drugs by pharmaceuticals despite indigenous availability of technology and expertise. Production meets market demands but not epidemiological need (6) and government Primary Health Centres and District TB Centres chronically report inadequate and irregular drug supplies, preventing good chemotherapeutic practice. There has been a lack of research into newer TB drugs till the re-emergence of TB in "developed" countries. Another factor has been the promotion of the growth of the private medical care sector, which dominates TB care with little regulation or standardisation of diagnostic and treatment practices. Irrational prescribing practices for TB by private practitioners (7), overmedication and overdiagnosis of X-ray positive suspects benefits the industry and providers. The poor are financially unable to complete treatment with the private sector.

Distressingly high rates of indebtedness have been reported among this impoverished group of patients (8, 5). This pushes their families further into the cycle of poverty, which with the associated under-nutrition and poor housing is itself a breeding ground for TB.

Governmental neglect of the NTP is evident in the under-financing of the programme, which received only about 1.5% of the Central health budget till a few years ago. Budgets below critical levels, with most expenditure on salaries and maintenance rather than

on effective services are wasteful and counterproductive. Drug resistance in TB due to low funding and consequent irregular, poor quality drug supplies is additionally harmful and costly, besides violating the human rights of patients and society.

In the absence of effective public sector services, 80% of health care utilisation occurs in the private for profit and voluntary sector. Rough estimates suggest considerable national spending on TB, with gains accruing to the diagnostics and drug industries and to medical professionals whose macro interests differ from those of patients and of public health (5).

Weakness in State intervention is further evident in infrastructural gaps in the public health care system. For instance, the large proportion of vacancies in microscopists/laboratory technicians posts at Primary Health Centres (PHC) makes diagnosis difficult. Frequently absent staff (including doctors), and rude behaviour towards patients, particularly the poor, also aggravates the situation. It has been found that the programme is the weakest at the PHC level, which was conceptualised as being the main interface between the majority rural population and the general health service with which TB care was integrated. This was the point closest to peoples' homes. The District TB Centres, supposedly the technical backbone of the programme are reduced to being curative centres for those living nearby. In the absence of adequate trained staff and vehicles, their more important role of providing professional leadership and support through training, supervision, analysis of records and research is not performed. Poorly functioning and weak peripheral institutions serving the majority rural population, reflect power relations in society and comprise an important reason for poor implementation. Even here, better off patients can access the private sector or the services of the government sector for a fee, exemplifying the



stratification of society and the lack of entitlement of the poorest to essential health care. This stands in sharp contrast to the Family Welfare programme, with its population control undertones, which received Rs. 65,000 million or 1.5 % of the total Ninth Plan Outlay (1992-97) as against the entire Health budget which received 1.7% of the total plan outlay. Another contemporary comparison is with the national AIDS programme which in the early 1990s received 25% of the central health budget though its epidemiological magnitude is much smaller than TB. The use of conditionalities and aid as leverage for policy change, by multilateral and bilateral agencies is one of the factors responsible for this.

More broadly support to the growth of an unregulated private for profit sector, including the pharmaceutical sector, has undermined the NTP and public sector. Direct and indirect policies such as subsidies to education producing graduates for the private sector, support to capitation fee medical colleges, allowing or turning a blind eye to private practice by government medical officers and others have promoted the private sector. Thus TB services were made available in the market. More powerful sections of society with ability to pay access these private services reducing pressure on the public sector to perform

Implication of problem definition on strategies

It has been hypothesised that the way one understands the problem of TB influences the choice of intervention strategies (5). This is indicated in the table above.

These are not either/or approaches. One needs to recognise that groups working at different levels are in solidarity with one another and better

linkages and alliances across sectors would be beneficial.

Another illustration is the strategies employed, depending on the way in which an issue such as default gets understood. In one approach, patient related failures and factors get stressed with an element of victim blaming, without adequately addressing health system failures or the circumstances of deprivation and difficulty in which the person lives. This approach then focuses on patient education that may be guilt producing and on supervised

TB and society : Levels of analysis and strategies (1)

Levels of Analysis of TB	Causal Understanding	Control Strategies
Surface phenomenon (medical and public health problem)	Infectious Disease / Germ Theory	BCG, Case Finding and Chemotherapy
Underlying cause (symptom of inequitable relations)	Poverty/deprivation, unequal access to resources	Land reforms, social movements towards an egalitarian society
Basic cause (inter and intra-national relations)	Contradictions and inequalities in socio-economic and political	More just inter and intra-national trade, finance and political relations. systems at international, national and local levels

therapy to ensure compliance. This is justified on technical grounds of preventing transmission and development of drug resistance. Other approaches see default as also resulting from poor TB case management deriving from systemic failures of the health and related services. This approach would stress the need for increased funding, improved infrastructural functioning (with microscopes, microscopists, doctors, uninterrupted drug supplies, follow-up by health workers, management of concurrent illnesses/drug side-effects/ complications etc.), support and supervision and humane attitude and behaviour of health personnel with patients. While theoretically an integrated approach is used, in practice, the second approach has been greatly neglected by the state sector in India. The experience of NGOs who have adopted these approaches show much better success in terms of cure rates and patient satisfaction.

Impact of implementation gaps on patients, families and society

Loss of life often in young adulthood, disablement and indebtedness comprise the heavy price paid by patients and their families. this situation is particularly true for the poor. While the middle class and rich also get TB, they have access to early care and cure and hence do not suffer these consequences.

The economic loss to patients, families and the nation is significant, while suffering is immeasurable. Economic costs from TB have been estimated at Rs. 20,000 million a year through person hours of work lost (10). Indirect costs of treatment to affected families are high, including transport, food, costs of accompanying person, loss of economic productivity of the patient and at least one other member of the family. These are larger than direct costs of diagnosis and treatment (8).

It is a reflection of the structure and priorities of our society that we spend millions obtaining the latest medical technology, even in government institutions to diagnose relatively untreatable conditions, while resource constraint arguments are put forward to fund the treatment of killer diseases like TB which can be diagnosed relatively easily and cured. When one considers the amounts spent for sports extravaganzas and defence of borders, the disparities become more stark and obscene. Somehow, the loss of half a million lives is not considered a national security problem calling for the best and urgent social defence. Some lives perhaps are more important than others.

The magnitude of the human problem caused by TB, especially with its current co-infection status with HIV



is such that it is ethically imperative for all to respond in some measure. If morals do not convince, at least the instinct of self-preservation should. The spectre of drug resistant TB may touch anyone. The government sector has to be pressured to perform with a sense of accountability. This is because the major source of funding of the government health services is from the tax-payer who is largely the common person, as indirect taxes form the major source. Also, the Government has now taken a large loan from the World Bank for the TB programme on which interest will be paid, also by the tax payer. Besides, it is a Constitutional mandate. For NGOs, critical collaboration needs to be established with the Government in which one's watching role and issue raising capacity as citizens of the country need to be acknowledged. This should not be swamped over by playing the alternate service provider role which is what may often be looked for. NGO expertise, personnel and services need to be specifically focussed on the poor. While the role of the private sector is recognised, regulation of standards of care in maintaining accepted norms in diagnosis and treatment needs to be ensured. The public sector will have to be a major actor in what is still a major public health problem. It has to take the responsibility of ensuring implementation of its own strategy of early diagnosis and provision and completion of effective treatment and supportive care for all forms of TB in partnership with the major stakeholders of the programme, namely, the patients. This requires the strengthening and non-fragmentation of basic health care services through Primary Health Centres in rural areas and Municipal Corporation Dispensaries and hospitals in urban areas. Additionally, social security and rehabilitation measures for advanced cases is required. More flexible, area-specific, community-based, humane approaches are required. These have proven to work in India and elsewhere. In spite of adverse economic trends,

countries like Cuba have achieved success in their TB control programmes.

We need to be alert regarding the functioning of the NTP and supportive of TB work in whatever way we can. TB is also in a way, a case study, and, much of what is said would be applicable to infectious disease and more importantly, to general health care services.

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Short notes

Coercion in TB control

The resurgence of tuberculosis confronts policy-makers with difficult legal and ethical questions about the proper use of state power and resources to protect public health. This essay examines the implications of expanded use of invasive or coercive measures—including directly observed therapy, involuntary detention of noncompliant patients, and forced administration of medications—designed to reduce the risk of tuberculosis transmission and to ensure that those with TB are fully treated. These measures focus attention on the limitations of government power and obligation and on the delicate balance between the demands of civil liberty and the demands of public health.

Bayer R, Dupuis L: Tuberculosis, public health, and civil liberties. *Annual Review Public Health* 1995;16:307-26

Wrongly focussed

This analysis of New York City TB programme notes that TB control in the city has been limited by two problems that hamper many public health programmes. First, antituberculosis measures, while appropriately targeting the poor, have been inconsistently funded and poorly coordinated. Second, efforts have emphasised detection and treatment of individual cases rather than improvement of underlying social conditions.

Lerner BH: New York City's tuberculosis control efforts: the historical limitations of the "war on consumption". *Am J Public Health* 1993 May;83(5):758-66

India's TB programme

This publication by the Voluntary Health Association of India has earlier been mentioned in *Issues in Medical Ethics*, but deserves another reference given this issue's focus on TB. Dr Debabar Banerji's detailed critique of the Revised National TB Control Programme is followed by a report of a discussion on the subject, with a World Bank team; and the comments of a number of senior government and non-government public health professionals working in the area of TB.

Banerji D: Serious implications of the proposed revised national tuberculosis control programme for India. Voluntary Health Association of India and Nucleus for Health Policies and Programmes. New Delhi, 1997.

