TB Patients and Private For-Profit Health Care Providers in India

THE GLOBAL TB PROGRAMME OF THE WORLD HEALTH ORGANISATION
Acknowledgments

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Correspondence of this report should be addressed to:
Dr. Joel Almeda
Research and Surveillance Unit,
Global TB Programme,
World Health Organisation
Geneva, Switzerland

telephone: +41 22 791 2655
email: almeida@who.ch

Abstract

India has nearly one-third of the world’s TB patients. Private for-profit providers of health care abound in India. Indian TB patients, like other people with chest symptoms, usually seek professional help first from a private for-profit provider. Diagnosis of TB is often delayed and several providers are consulted before diagnosis. Patients purchase anti-TB drugs over the counter, often without a current prescription. Most patients fail to complete treatment, stopping treatment once they feel better. Private providers behave unsatisfactorily: no records are maintained and patients who do not turn up for appointments are generally not pursued. Progress and outcomes are not monitored. Indian TB patients together spend more than 150 million US dollars each year on private TB care, which typically buys them palliation instead of cure. TB patients steadily gravitate towards government-run services as they get progressively poorer and more ill.

If the behaviour and practices of private for-profit providers could be influenced to ensure more frequent cure among their patients, much of the death and suffering inflicted by TB could be averted. Interventions need to be devised and tested, to improve the outcomes of treatment among the many TB patients in India who first choose private providers of treatment.
TB Research

THANIA JOY,BHADA MARATHI

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THE GLOBAL PROGRAMME OF THE WORLD HEALTH ORGANIZATION
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This report is the first of the Global TB Programme’s Research Series. The DOTS strategy has transformed the outcomes of TB treatment from cure rates of below 50% to over 80%. This considerable achievement has taken place almost entirely in the public sector. Yet most patients with TB in many countries go first to a private provider of care. Our challenge now is to win over the private practitioners and private voluntary organisations to the DOTS strategy. This paper provides an analysis of the workings of the private for-profit practitioner in the country with the most TB patients in the world — India. I fully expect it will prove to be essential reading for all those committed to achieve “DOTS More Widely.”

There is little doubt that wider availability of high-quality care for TB is one of the world’s major public health priorities. Cure of infectious TB patients is currently the best form of prevention. Innovation to achieve “DOTS More Widely” is among the top priorities for efforts against TB.

DR. PAUL NUNN
Chief, Research and Surveillance
Global Tuberculosis Programme
World Health Organisation
Among the more than 900 million people in India today, every one of two adults is infected with the TB bacillus.

Executive Summary This is a review of the behaviour and interaction of TB (tuberculosis) patients and private for-profit health care providers in India. The Global TB Programme is interested in consistent documented cure among all TB patients, regardless of whether they first approach private or government-run services. Private for-profit providers in India are known to be plentiful, the first choice of TB patients, yet doing a poor job. Private voluntary organisations do not yet play an important role in TB care. The supply of government-run TB cure services in India will probably take many years to catch up with the demand from people who are already being disabled or killed by badly treated TB.
If the behaviour and practices of private for-profit providers could be influenced to ensure more frequent cure among their patients, much of the death and suffering inflicted by TB could be averted. This paper reviews current understanding of the behaviour and interactions of TB patients and private for-profit providers, as a pre-cursor to devising interventions for field testing.

TB in India does not spare any socio-economic group, although it is most frequent among the least well-off: those with lowest incomes, poorest housing and least schooling. The prevalence of TB is highest among adults, and higher among men than women.

Health-seeking behaviour
The general public was found to be reasonably aware of the symptoms of TB. A person with TB is visualized as being very weak, thin and with a persistent cough. Information about health care providers is usually obtained by word-of-mouth.

TB-like chest symptoms are common, being found among 5 to 10% of the general population. However, even among one sample of TB suspects with marked symptoms (including fever, chest pain and blood-staining of coughed up material) only 10% yielded TB bacteria on culture.

The process of health seeking for a TB patient in India is often complex and may well last several years. It is a high involvement process on the part of the patient impinging on his/her physical well being and requiring the commitment of considerable time and money. It also places demands on family members and relatives. Continuous learning goes on during this process.

Choice of provider
Most persons in India requiring curative treatment, without hospitalization, choose private providers. People simply go to the nearest trusted health care provider, who is usually a private for-profit provider. This is true even of the poorest people. People with chest symptoms are no exception, even in hilly regions which have relatively few private providers.

Patients perceive that private providers are more sympathetic, more conveniently located, more effective, and more likely to uphold privacy than government-run services. Government-run services were perceived as having condescending doctors, substandard drugs, inconvenient opening hours and long waiting times. However, once patients had switched from private to government-run providers, they became far more appreciative of government-run services, drugs and staff: although they missed the shorter waiting times and convenient opening hours of private providers.

Behaviour of TB patients
Early symptoms of pulmonary (lung) TB resemble other chest symptoms: cough, chest pain, fever. Although help seeking for chest symptoms is typically delayed, TB patients steadily worsen and eventually seek help. Fewer than half the TB patients were found to seek professional help within a month of symptoms appearing. The poorest people tend to delay help seeking even longer: typically, until their condition becomes unbearable. Like other ill people, most TB patients (50 to 80%) first seek professional help from a private for-profit provider.

Diagnosis of TB is often delayed for weeks after first contact with a private provider. Patients “shop” for diagnosis among several private providers. About three-quarters of “sputum positive” patients found in the care of private providers, in one mid-seventies population-based survey, were not being treated for TB. About half the patients continue treatment with the private provider who diagnosed the TB.

Regularity of treatment
Patients often know that they have TB even when the provider tries to conceal this stigmatizing diagnosis. Most patients also know that TB cure requires prolonged regular treatment. Patients generally start off by taking their drugs, but lose interest as they gain symptomatic relief and begin to grudge the cost and inconvenience of taking regular treatment. Patients in one careful study were found significantly more likely to discontinue treatment if they had conspicuously low incomes (e.g., less than USD 150 per capita per year) and little schooling (e.g., illiteracy). One or more drugs might be omitted as the patient feels increasingly better and therefore reluctant to pay. With time, work and social commitments increasingly displace the chore of taking regular treatment. Pessimism about the patient, from the health worker, contributed to treatment being abandoned. Patients in one survey knew that irregular treatment could lead to deterioration and possible death. However, this knowledge did not prevent irregular treatment.

Switching between providers
TB patients of private providers steadily switch to government-run services, or discontinue treatment, as their funds become depleted. This steady switching from private to government-run providers is not matched by switches from government-run to private providers. Government-run services, except in areas where the WHO-recommended DOTS strategy is practiced, do not achieve consistent cure. As implied by these events, long-duration patients accumulate in government-run services. Most
patients on the register of government-run services are, as predicted, relatively poor.

**Stigma**

Many patients believe that TB carries a social stigma. This may be because many people believe that TB is brought on by wrong-doing. Further, 70% of people in a West Bengal survey agreed that TB might well be hereditary. Ex-TB patients are less likely than average to find marriage partners in West Bengal. Illiterate respondents were found to have the most misconceptions about TB, in one study. Many TB patients are predictably reluctant to talk about the disease, and often give wrong names and addresses to avoid being exposed as TB patients before their acquaintances.

**Gender**

Women TB patients face special difficulties, especially if they are married. They tend to neglect their illness in favour of household responsibilities: unlike male patients who are often given lighter work loads and allowed to rest. Women tend to delay care-seeking until they are too ill to do their normal chores. Their time is often not their own, nor do they have as much control over family finances as men do. In addition, they fear divorce if their husbands discover that they have TB. Unmarried girls with TB fear that they might never find a spouse. Women are typically less well placed than men to ensure their own cure.

**Out-of-pocket costs for TB treatment**

The out-of-pocket costs for TB diagnosis and successful treatment in India are estimated at between 100 and 150 US dollars per patient. This forms a substantial proportion of the annual income of a daily wage labourer, estimated at about USD 200. Given the normal day-to-day expenditures, the time and money lost through illness and the low proportion of success in treatment, it is not surprising that nearly half the urban patients in one study became indebted as a result of TB.

Private individuals are the main purchasers of TB treatment in India. Most consumption of services and goods in India is private, and health care or TB care are no exception. Individual out-of-pocket expenditure on TB treatment dwarfs the substantial sums expended by the government on the national TB control programme. However, private expenditures on private TB treatment, which are estimated to exceed USD 150 million per year, are typically rewarded by palliation rather than cure of TB.

**Private for-profit providers**

The private for-profit health care sector is the major provider of services in India. Qualified providers form a small minority, probably less than one fourth of all private for-profit providers, and tend to congregate in cities and towns. Official health statistics are known to underestimate the number of private for-profit providers.

In villages, unqualified private for-profit providers abound. A survey in UP state revealed that the typical rural private provider there was an unqualified male, with about 10 to 12 years of schooling, aged about 40 years, practising an unorthodox blend of Western and traditional medicine. Modern allopathic medicines were being bought at stores, unpackaged, relabelled and sold at a profit. Most of such unqualified providers had learnt their skills from family members, or while working as pharmacists or assistants to qualified providers. They earned less (USD 400 per year) from health care than the lowest-paid government health sector employees, and health care was only one among their remunerative activities.

Private for-profit providers operate mainly as entrepreneurs, often individually. Interviews with private providers suggest that a central goal of treatment is to relieve symptoms before the patient decides to switch providers. Providers attract custom largely by word-of-mouth recommendation from previous patients. Less-than-fully qualified private providers generally express keen interest in courses of continuing medical education, and in joining medical associations.

**TB diagnosis and treatment practices**

Over-diagnosis and over-prescription among private for-profit providers are predictable and observed. X-rays were found the test of choice to rule out TB, with sputum examination done in only 10 to 20% of suspects. Most private providers refer TB suspects to private laboratories for diagnostic tests, and to consultants for specialist opinions. Kickbacks from diagnostic and consultation fees are known to occur. Patients too poor to afford private diagnostic facilities are referred to government-run services.

Treatment regimens prescribed typically lasted more than six months, with a four-drug intensive phase of two to three months being the norm. Most of the regimens prescribed were probably adequate to achieve cure, if actually taken.

Over 80% of private providers issued prescriptions rather than drugs for TB treatment, but expensive dietary supplements and alcohol-based tonics were frequently dispensed (at a profit) by the private provider. Private
providers without allopathic qualifications did not appear to differ from those with qualifications, in their prescribing behaviour, possibly because drug manufacturers' representatives are the main source of information for both groups.

Weekly X-rays during anti-TB treatment were believed desirable by 30% of qualified allopaths in one study, while patients were asked to visit such practitioners at least once a month. Consultation fees per visit ranged between USD 0.50 to USD 7.00.

**Treatment outcomes**

Private providers generally keep no patient records. About half the private providers in one study admitted that they made no attempt to contact patients who defaulted from follow-up visits, while the other half claimed that they sent a message to the patient through someone. Only 15% of private providers interviewed volunteered that three consecutive negative sputum smears were desirable as evidence of cure. Outcomes of treatment were generally not measured by private providers.

**Importance of TB treatment to private providers**

TB patients do not form an important part of the business of private for-profit providers. Fewer than 1% of patients seeking care at qualified allopathic providers possibly had TB, in one multi-site study. Another study found that about half the qualified private providers had care of fewer than five TB patients at any time, while many (a third) of the non-allopaths had no TB patients at all. However, chest specialists might consider TB an important part of their business; information is insufficient to decide.

**A promising innovation**

Some private providers have already made promising innovations to improve results among the poorest patients. In one example from South Bombay, a center was set up where patient records were kept and drugs dispensed by a social worker. The government services contributed a part of the drug requirements. Treatment was provided free to the poorest patients. This innovation points to a possible scenario for private/public collaboration to deliver results.

**Costs of government-run services**

Patients gravitate towards the government-run services as they get poorer and more ill with time. Patients in one survey were found to spend about USD 1.50 on average, after registering with government-run services. Government-run services are nominally free. However, waiting times, wages lost and drug unavailability (even overlooking possible unofficial payments) impose costs and inconveniences on patients. Under the traditional National TB Programme, spot checks revealed that more than 50% of government primary health centers (PHCs) had one or more TB drugs unavailable. Although more than half of surveyed households knew that government-run primary health centers existed, only 15% knew that free TB treatment was available there. Government-run health care services in India typically have a poor image.

**Drug retailers**

Drug retailers in India consistently sell restricted drugs without requiring prescriptions. When patients could not afford all the drugs on a prescription, it was typically left to the discretion of the pharmacist to decide which ones to omit.

**Legal and regulatory environment**

The legal and regulatory environment for health care in India is in a state of flux. Prescription and dispensing of drugs in India appear well regulated on paper, but fairly unregulated in practice. Even potentially lethal drugs are known to be available over the counter. Consumer Protection Councils in India have taken an active role in pursuing cases of possible medical malpractice. However, the role and competence of CPCs has been vigorously questioned by the Indian Medical Association, which has a membership of nearly 100,000 qualified practitioners. The IMA is one of the main opponents of medical practice by unqualified practitioners. A recent Indian Supreme Court ruling confines doctors to the system of medicine in which they were qualified.

**Intervention options**

Several options for intervention are outlined and discussed, ranging from exclusion of private providers through to holding them responsible for specified tasks within contractual arrangements. Only field tests will reveal the advantages and perils of particular sets of interventions.
As the patient feels better, work takes priority over regular, complete treatment.

Introduction  Private for-profit providers of health care abound in most parts of India. India happens to have nearly one-third of the world's TB patients (Figure 1). Six to eight months of regular treatment are required to ensure cure. Apart from demonstration projects which successfully apply the WHO-recommended DOTS strategy for TB cure, TB patients are not being consistently cured by government-run services. Programmatic approaches to improve results of TB treatment through the private/public mix depend on a clear understanding of TB patients and of private providers of treatment.
The term “private for-profit provider” is used to describe any person who offers private health care professionally and for profit. It covers both qualified and unqualified practitioners.

Private voluntary organisations (PVOs or NGOs) do not appear to play an important role in the treatment of TB in India. Informed guesses suggest that no more than about 5% of TB patients have been in the care of the private voluntary sector. This could be changed. However, this review focuses on the problematic case of private for-profit providers and TB patients.

The National Tuberculosis Programme in India was initiated in 1962. Results have been disappointing, with typical cure rates of only 35%. A successful TB control programme, focused on consistent documented cure of infectious patients, has been found to depend on at least the following five points:

- Government commitment;
- Passive case-finding (discouragement of active case-finding);
- Supervised treatment with standardized six to eight month regimens;
- Reliable supply of anti-TB drugs;
- A standardized monitoring system, including recording of outcomes in every patient.

The Revised NTP adopted in 1992 by the Indian Ministry of Health and Family Welfare in consultation with WHO, systematically tackles each of the shortcomings, while decentralizing service delivery to the level of health centers and strengthening training. Cure rates over 80% have been demonstrated in the pilot phase. Clinical diagnosis is performed at any health facility selected by the patient. Laboratory diagnosis takes place at selected microscopy centers. Once the patient is diagnosed as having TB, treatment is delivered at the health facility closest to the patient’s home, and a designated health worker (or substitute) identifies directly observe ingestion of drugs: three times a week for the initial “intensive” phase (two or three months) followed by once a week thereafter. Progress is monitored by sputum microscopy. Quality control of laboratory diagnosis, patient registration and final outcomes is monitored by a Tuberculosis Unit (sub-district level) which follows a regular supervision programme and clear reporting responsibilities.

The supply of government-run TB cure services in India will probably take many years to catch up with the demand from people who are already being disabled or killed by badly treated TB. If the behaviour and practices of private for-profit providers could be influenced to ensure more frequent cure among their patients, much of the death and suffering inflicted by TB could be averted. This paper reviews current understanding of the behaviour and interactions of TB patients and private for-profit providers in India, as a precursor to devising interventions for field testing.

**FIGURE 1**

Existing cases of TB in the world

Percentage of prevalent TB cases in the world in 1990. Source: 3
Methods  Published studies were reviewed. In a few instances, the evidence was supplemented by interviews with knowledgeable experts who had first-hand information of the issues being discussed. Table 1 offers a summary of the methods in the studies reviewed. A fuller description and discussion of the methods in the studies reviewed will be found in the Appendix 1. The location of the study sites is shown in Figure 2. India is a vast and heterogeneous country. Therefore while taking advantage of the available information, the possibility of location specific peculiarities cannot be excluded. The rupee estimates from studies in the period 1992-95 have been converted to USD at 1 USD=Rs. 32.
### Table 1

Methods used in the studies reviewed  
*Summary of the study sites, year, sample characteristics and focus of the main studies reviewed*

<table>
<thead>
<tr>
<th>Study site, year, ref. no.</th>
<th>Sampling procedure</th>
<th>Focus</th>
</tr>
</thead>
</table>
| 24 Parganas District (rural), W. Bengal; 1986-87 (19)                                    | • 996 TB patients at a NGO clinic  
• All patients diagnosed and placed on treatment between 01-01-86 and 28-02-87  
• 213 heads of household from NGO project area and 50 from outside project area  
• Random sampling  
• 60 patients from NGO clinic; random sampling  
• 150 defaulters and 150 non-defaulters at government clinic  
• Random sample from daily attendance at clinic  
• 21,316 subjects; 98.8% of eligible population in 55 villages (those not absent for more than two months)  
• Cluster sampling  
• 60 patients at a government clinic  
• Convenience sampling  
• 16 TB patients at a NGO clinic  
• convenience sampling  
• Urban slum dwellers  
• 11,379 rural and 7,912 urban households  
• Multistage stratified sampling                                                                 | Case holding and treatment failures  
Community knowledge of and attitude towards TB; treatment adherence  
Treatment adherence  
Prevalence of chest symptoms and help seeking by chest symptomatics  
Health-seeking behaviour of TB patients  
Health-seeking behaviour of TB patients  
Health care utilisation and financing                                                                 |
| Agra city, Uttar Pradesh; 1973 (22)                                                        |                                                                                                                                                                                                                  |                                                                                           |
| Bangalore (rural), Karnataka; 1976 (5)                                                    |                                                                                                                                                                                                                  |                                                                                           |
| Bombay city, Maharashtra; 1992 (30)                                                       |                                                                                                                                                                                                                  |                                                                                           |
| Bombay city, Maharashtra; 1993-94 (16)                                                    |                                                                                                                                                                                                                  |                                                                                           |
| Gujarath, Maharashtra, Tamil Nadu, Uttar Pradesh, West Bengal; NSS 42nd round 1986-87 (9) |                                                                                                                                                                                                                  |                                                                                           |
| Jaipur, Rajasthan (predominantly urban); 1986 (25)                                        | • 1,000 respondents from general population  
• Convenience sampling  
• 22,847 residents of four villages  
• Prospective survey (monthly visits for two consecutive years)  
• 37 villages selected by stratified random sampling  
• 22,250 villagers surveyed                                                                 | Community knowledge of TB  
Prevalence and incidence of sputum positive cases of TB  
Prevalence of TB  
Treatment adherence                                                                 |  
| K V Kuppan Block, North Arcot Ambedkar District, Tamil Nadu; 1981 (1)                    |                                                                                                                                                                                                                  |                                                                                           |
| Karhal Block, Morena District, Madhya Pradesh; 1991-92 (4)                               |                                                                                                                                                                                                                  |                                                                                           |
| Lucknow, Uttar Pradesh (urban and rural); 1977 (20)                                       | • 400 cases of TB induced over a period of one year at a government clinic  
• 112 defaulters could be contacted  
• 60 TB patients  
• Defaulters from a total of 2,332 patients in controlled SCC trials  
• 796 TB patients, all age 15 or more  
• All the patients diagnosed on basis of radiography at the District TB center  
• 12,339 urban households and 6,354 rural households  
• Multistage stratified sampling  
• 256 cases of TB, newly diagnosed during 1986 and reporting at the New Delhi TB center | Treatment adherence  
Treatment adherence  
Awareness of chest symptoms and action taken by chest symptomatics  
Health care utilisation and expenditure patterns  
Care seeking behaviour between onset of symptoms and diagnosis                                                                 |
<p>| Madras city, Tamil Nadu; 1975-85 (21)                                                     |                                                                                                                                                                                                                  |                                                                                           |
| Madras city, Tamil Nadu; 1977 (8)                                                        |                                                                                                                                                                                                                  |                                                                                           |
| Nation-wide*, NCAER 1993 (12)                                                            |                                                                                                                                                                                                                  |                                                                                           |
| New Delhi; 1986 (15)                                                                     |                                                                                                                                                                                                                  |                                                                                           |</p>
<table>
<thead>
<tr>
<th>Study site, year, ref. no.</th>
<th>Sampling procedure</th>
<th>Focus</th>
</tr>
</thead>
</table>
| North Arcot District, Thiruvannamalai town and Madras, Tamil Nadu; 1990 (6) | - 18,395 rural subjects, 17,409 urban subjects and 37,290 metropolitan subjects  
- Cluster sampling | Awareness of chest symptoms and utilisation of health facilities by chest symptomatics |
| Pune and Bombay, Maharashtra; 1995 (11) | - 59 rural private providers from all 168 listed and contacted in 10 village towns chosen randomly;  
- 31 urban private providers from those listed in a big Bombay slum;  
- Only those who managed patients of TB and were willing to cooperate in the study  
- 100 rural patients from 59 private providers and 73 urban patients from 31 providers  
- Prospective study | Health-seeking behaviour of patients; behaviour of private providers of TB care |
| Pune, Maharashtra; 1991-94 (10) | - 6 rural Primary Health Centers selected by purposive sampling  
- 12 villages selected; two per PHC by stratified random sampling (two strata of villages—less than and more than 5 km distance from the PHC)  
- 605 households from 12 villages by systematic random sampling  
- 16 non-slum and two slum wards in Pune city by probability proportional to number of blocks; two blocks each from every ward by random sampling  
- 408 urban households from selected blocks by systematic random sampling  
- 299 cases of TB from six rural PHCs, two municipal clinics and DTC (patients registered at least three to six months earlier)  
- 61 newly registered patients at DTC and municipal clinic followed prospectively | Community knowledge and attitude towards TB; health-seeking behaviour of TB patients; behaviour of providers of TB care |
| Tumkur District, Karnataka (urban and rural); 1973 (7) | - 875 radiological TB cases and 877 radiologically normal controls, all aged 20 or more  
- All TB cases in 62 villages and four town blocks (randomly selected) of the district as detected by a epidemiological survey conducted four weeks back  
- Controls for age and sex randomly selected | Awareness of symptoms and action taking by persons with radiologically positive TB |
| Uttar Pradesh; 1992 (34) | - 488 private ‘doctors’ from 300 villages  
- Villages selected from the five distinct socio-cultural regions of the state  
- Stratified random sampling; villages in two population strata—less than and more than 2,000 inhabitants  
- ‘Doctors’ identified by asking village women where they sought professional help in case of illness | Profile of the rural private provider; practice patterns and interest in delivering family planning services |
| Wardha District, Maharashtra; 1988-89 (23) | - 52 adherent and 50 nonadherent TB patients from a short term biweekly chemotherapy project  
- Systematic random sampling from among participating patients  
- 12 patients of the nonadherent group were recruited from the District Tuberculosis Center | Treatment adherence |
| Wardha District, Maharashtra; 1988-89 (2) | - 200,000 urban residents  
- 490,000 rural residents  
- Population-based survey | Prevalence of TB in different socio-economic groups |

* Except Andaman and Nicobar, Jammu and Kashmir, Lakshadweep, Manipur, Mizoram, Nagaland, Sikkim, Tripura
Findings
**Who is the TB patient?**

The prevalence of TB is highest among adults and higher among men than women (1, 3). TB has been found relatively more frequently among the least well-off: those with low incomes, poor housing and little schooling (2). Figure 3 summarizes the findings on prevalence of TB among different socio-economic groups in a Wardha study.

The prevalence of TB among tribals has been found higher than among non-tribals (4). Figure 4 compares the prevalence of TB among tribals and non-tribals in one illustrative area.

**Health-seeking behaviour of TB patients**

**Stages in health seeking**

The health-seeking behaviour of TB patients is described in the following stages:

- development of symptoms
- help seeking
- “shopping” for diagnosis
- diagnosis
- evaluation of alternative providers
- choice of provider
- switching between providers
- treatment adherence
- treatment outcomes

The process of health seeking for a TB patient is often complex and may well last several years. It is a high involvement process on the part of the patient impinging on his/her physical well being and requiring the commitment of considerable time and money. It also places demands on family members and relatives. Continuous learning goes on during this process.

**Onset of symptoms, initial help seeking**

**Initial symptoms of TB resemble common chest symptoms**

The initial symptoms of TB — cough, chest pain and fever, make it virtually indistinguishable from other respiratory illnesses. Consequently it is reasonable to expect that the initial response to the onset of TB symptoms closely parallels the care seeking behaviour of chest symptomatics in general.

**Chest symptoms are commonly prevalent**

Studies indicate that the prevalence of chest symptoms in the general population could range from 5-10%. A
population-based survey in 55 villages in Bangalore district found that 12.1% of the surveyed population had chest symptoms: cough, chest pain, fever or haemoptysis, of seven days' duration or more (5).

A sample survey in rural, urban and metropolitan areas of Tamil Nadu revealed that 5.8% of rural, 5.5% of urban and 4.7% of the metropolitan population had chest symptoms: cough for two weeks or more, fever or chest pain for one month or more, or haemoptysis (6). Cough appears to be the most common chest symptom, followed by chest pain and fever (5, 7, 8).

**TB cases form a small proportion of chest symptomatics**

The proportion of TB cases among chest symptomatics is quite low. Table 2 shows the yield of sputum positives (culture) from chest symptomatics with increasing severity of symptoms (5).

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>% sputum + (culture)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough only</td>
<td>0.25%</td>
</tr>
<tr>
<td>Cough and chest pain</td>
<td>1.76%</td>
</tr>
<tr>
<td>Cough and fever</td>
<td></td>
</tr>
<tr>
<td>Cough, chest pain and fever</td>
<td>2.93%</td>
</tr>
<tr>
<td>Cough, chest pain, fever and haemoptysis</td>
<td>10.13%</td>
</tr>
</tbody>
</table>

**Most persons with illness choose private providers**

The private sector plays a predominant role in ambulatory curative care, where it dwarfs the government-run sector. A National Sample Survey (NSS 42nd round) showed that households first approached private providers in a majority of illness episodes (9).

Figure 5 shows that the majority of outpatient episodes are treated by private providers. Other surveys confirm this pattern. For minor illnesses rural household in Pune used a private provider in 78% of cases, followed by government-run services 19%, chemist 13% and self help 12% (multiple responses). For major illnesses, 88% of rural patients of private providers had first sought help at a private provider (10). Almost 75% of the rural patients at government-run facilities in Pune had first approached a private provider.

The urban scenario was similar. More than 60% of the urban households in Pune had utilised private providers for minor illness, 28% chemists, 24% self help and 10% government-run services (10). For major illnesses, 59% of urban TB patients with government-run services in Pune were found to have started off with private providers. Over 80% of patients with private providers in Bombay slums had started off with private providers (11).

Fewer than 30% of the short duration illness episodes in India are being treated at government-run facilities (11).

Remarkably, the private sector plays a major role even in the treatment of diseases such as malaria for which there is also a national control programme in place. For instance, 90% of the malaria cases in both rural and urban areas of Uttar Pradesh chose private providers (9).
**FIGURE 6**

Proportion of patients using private providers, according to expenditure quintile and urban/rural residence

*Population-based survey of 11,379 households. Source: 9*

**Rural Poor Choose Private Providers**

Percentage of outpatient episodes taken to private providers in rural areas

<table>
<thead>
<tr>
<th>Region</th>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
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<tbody>
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<td>Gujarat</td>
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<td>Tamil Nadu</td>
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</tr>
<tr>
<td>Uttar Pradesh</td>
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<tr>
<td>West Bengal</td>
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</table>

<table>
<thead>
<tr>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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<tr>
<td>20</td>
</tr>
<tr>
<td>40</td>
</tr>
<tr>
<td>60</td>
</tr>
<tr>
<td>80</td>
</tr>
<tr>
<td>100</td>
</tr>
</tbody>
</table>

**Urban Poor Choose Private Providers**

Percentage of outpatient episodes taken to private providers in urban areas

<table>
<thead>
<tr>
<th>Region</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maharashtra</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>West Bengal</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>20</td>
</tr>
<tr>
<td>40</td>
</tr>
<tr>
<td>60</td>
</tr>
<tr>
<td>80</td>
</tr>
<tr>
<td>100</td>
</tr>
</tbody>
</table>

**Private providers are utilised by all income groups**

The private sector is utilised in a big way by the lowest income quintiles (9). The pattern of utilisation of health facilities by 590 households in Jalgaon district in Maharashtra is summarised in Table 3.

Differences in income have only a marginal influence on the propensity to utilise different types of providers. Overall, there appears to be a small positive income elasticity in use of private providers: higher income groups are slightly more likely to seek treatment at a private provider. Figure 6 summarises the information.

There does not seem to be significant rural-urban difference in the utilization pattern for outpatient care. The private sector is the major source of care in rural as well as urban areas (9). In case of use patterns by sex, it appears that there is little difference except that in Tamil Nadu women in rural areas have a relatively lesser propensity to use private providers. More significantly, private providers do not predominantly serve the higher income groups. This survey showed that in Uttar Pradesh, 47% of the patients being treated by the private sector were from the poorest 40% of the population while only 37% of the care provided by government hospitals and 24% by government-run health clinics was for the poorest 40%. A study of poor households in Uttar Pradesh (14) has found that for cases of fever, private providers were consulted 77% of the time; for respiratory illness, private services were used in 63% of cases. This may be compared to gastrointestinal illness, where private care was sought 72% of the time; and for skin disease, where it was sought 57% of the time.

**Most TB patients will eventually seek professional help**

Many chest symptoms do not seek professional help before they heal themselves. The Bangalore survey found...
that less than half (47.7%) of the chest symptomatics had sought professional help (5). A Tamil Nadu survey found that around 75% of the chest symptomatics had sought professional help (6).

Most TB patients, however, will be forced to seek professional help since the symptoms worsen in the absence of treatment.

Most people with TB seek private care initially

As discussed above, initial help seeking behaviour of TB patients would closely parallel the general response to illness. Thus most people with TB symptoms would seek private health care at first. In one study of households in Pune who reported a chest symptomatic, over 60% of the symptomatics first went to a private health provider (10). A subsequent study in Pune and Bombay showed that 88% rural and 85% urban patients of private practitioners had started off with a private provider (11). Figure 7 shows that most TB patients first seek help from a private provider. This is in keeping with the general pattern of response to minor and major illnesses with 80% of householders preferring the private sector for minor illnesses and 75% for major ones (10). Table 4 and Table 5 summarize available information on initial choice of providers by chest symptomatics and TB patients.

Patients seek help when symptoms worsen

The early symptoms of TB are perceived as minor, and behaviour parallels response to other minor illness. Increasing weakness, chest pains and coughing up of blood are perceived as increased severity of illness and patients then seek medical help.

Table 6 summarises the action taken by a small sample of slum dwellers as the symptoms become increasingly severe. The first response to cough and fever was either to do nothing or try some self medication (16).

**FIGURE 7**

**The first help-seeking contact of TB patients in India**

*First help-seeking contact by TB patients is at a private provider*

**Among Patients Being Treated in the Private Sector**

<table>
<thead>
<tr>
<th>173 TB patients in Bombay and Pune, Source: 10, 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>88% of rural patients first sought help at a private provider</td>
</tr>
<tr>
<td>85% of urban patients first sought help at a private provider</td>
</tr>
</tbody>
</table>

**Among Patients Being Treated in the Public Sector**

<table>
<thead>
<tr>
<th>299 TB patients in Pune, Source: 10, 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>73% of rural patients</td>
</tr>
<tr>
<td>59% of urban patients</td>
</tr>
</tbody>
</table>

**TABLE 4**

First source of professional help for chest symptomatics and TB patients in rural areas

<table>
<thead>
<tr>
<th>Study site</th>
<th>Sample</th>
<th>Proportion to private providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangalore (5)</td>
<td>Chest symptomatics</td>
<td>53%</td>
</tr>
<tr>
<td>Chetpet Block, North Arcot District; Tamil Nadu (6)</td>
<td>Chest symptomatics</td>
<td>60%</td>
</tr>
<tr>
<td>Pune (11)</td>
<td>TB patients at private provider clinics</td>
<td>88%</td>
</tr>
<tr>
<td>Pune (10)</td>
<td>TB patients registered with government-run services</td>
<td>73%</td>
</tr>
</tbody>
</table>
**TABLE 5**

First source of professional help for chest symptoms and TB patients in urban areas

<table>
<thead>
<tr>
<th>Study site</th>
<th>Sample</th>
<th>Proportion to private providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thiruvannamalai town and Madras city; Tamil Nadu (6)</td>
<td>Chest symptoms</td>
<td>50%</td>
</tr>
<tr>
<td>Bombay (11)</td>
<td>TB patients at private provider clinics</td>
<td>85%</td>
</tr>
<tr>
<td>New Delhi (15)</td>
<td>TB patients registered with government-run clinic</td>
<td>60%</td>
</tr>
<tr>
<td>Pune (10)</td>
<td>TB patients registered with government-run services</td>
<td>59%</td>
</tr>
</tbody>
</table>

**TABLE 6**

Patients often seek medical help only when they start coughing up blood (Response of 16 slum dwellers in Bombay to the onset of TB symptoms) (16)

<table>
<thead>
<tr>
<th>Patient behaviour</th>
<th>Cough/Fever</th>
<th>Weakness</th>
<th>Haemoptysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did nothing</td>
<td>12</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Tried home remedies</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Bought drugs at drug retailer</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Sought medical help</td>
<td>1</td>
<td>2</td>
<td>16</td>
</tr>
</tbody>
</table>

*Medical help sought included unqualified and non-allopathic doctors*

**TABLE 7**

Source and nature of past treatment among sputum positive chest symptoms found in a population-based survey (7)

<table>
<thead>
<tr>
<th>Source</th>
<th>Number seeking professional help</th>
<th>No anti-TB treatment</th>
<th>Possible anti-TB treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous practitioners</td>
<td>10</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Private doctors</td>
<td>22</td>
<td>17</td>
<td>5</td>
</tr>
<tr>
<td>Government hospitals</td>
<td>26</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>TB hospitals</td>
<td>5</td>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>
There is a significant time gap between onset of symptoms and help seeking

Help-seeking is typically delayed. A survey of 796 patients at the government-run District Tuberculosis Center, Madras found that only 40% had sought professional help within a month of onset of symptoms while 16% delayed action for more than six months (8). The study found a statistically significant direct correlation between the number of symptoms and the time lag in months; apparently many patients ignore initial symptoms and report for treatment as the symptoms increase in number.

A study at the New Delhi Tuberculosis Center found a similar pattern of time lag between onset of symptoms and help seeking with only 41% of patients taking remedial action within a month and over 33% delaying for more than three months (15).

Studies in Pune and Bombay suggest a shorter delay. Most patients claimed to have sought help within a month of developing the symptoms (10).

Even if errors in recall are overlooked, it is possible that patients registered with private providers differ from their counterparts undergoing treatment in the government-run sector. Patients with government services are probably predominantly from the low-income groups who cannot afford private sector treatment and who also tend to delay treatment until their condition becomes unbearable.

Shopping for diagnosis

Significant delay between help seeking and eventual diagnosis, patients shop for diagnosis

There is a significant delay between help seeking and eventual diagnosis. The Pune study reported average gap of 41 days for rural patients (11). At least a third of the patients got diagnosed more than a month after seeking help. Only about half the patients get diagnosed at the first source of help.

The Bombay survey among patients in the slums found an average gap of 31 days between help seeking and diagnosis (11).

X-rays are usually used for diagnosis

Only a fifth of rural patients with private providers in the Pune based study were subjected to sputum examination (11). Fifty-six percent reported that they were diagnosed by X-ray alone (11). Ninety-six percent of Pune patients with government-run services reported X-rays while 79% reported sputum tests (10).

Only 10% of urban patients in Bombay said that they were subjected to a sputum test (11). Seventy-eight percent reported that they were diagnosed by X-ray alone (11). Ninety-three percent of urban patients with government-run services in Pune reported X-rays while 89% reported sputum tests (10).

Many TB cases (sputum positives) are not diagnosed as such, even in the government-run sector

Quality of diagnosing is generally poor, as suggested partly by the need to “shop” for diagnosis. This was confirmed by a study in Bangalore district which found that of 21 sputum culture positive TB cases who had gone to a modern medical facility (private allopath or government-run service), only nine could be confirmed as having received anti-TB treatment (5). The survey also reports that a large proportion of bacteriologically positive cases were not receiving anti-TB treatment (7). Table 7 summarises the nature of treatment undergone by sputum positive TB patients at different sources of help.

Diagnosis mainly in private sector

In Pune, even among rural patients registered with the government-run services, 64% had been diagnosed in the private sector (10). Forty percent of the urban patients registered with government-run services in Pune had been diagnosed by a private provider (10).

Diagnosis of TB often not revealed to patient

Only about half the newly diagnosed patients in one survey reported that the private practitioner had disclosed to them the diagnosis of their illness (11). About one-fourth had been told that they had been suffering from some illness other than TB and the rest were unaware of the disease for which they were taking treatment (11). The reluctance of patients to accept the diagnosis and the fear of losing a client because of the stigma attached to the disease have been cited as reasons why private providers conceal diagnosis of TB from the patient (10).

Despite the lack of information from providers, most (70-80%) patients interviewed in one study were aware that they were suffering from TB (10).

Shopping for treatment, evaluation of providers, choice of providers

Low profile of free government facilities for TB treatment

In rural areas of Pune nearly all (90%) of the households knew of the existence of government-run primary health care centers (PHCs) (10). Only 25% of the households aware of the PHCs knew that TB drugs were stocked at these clinics (10). This is not surprising, given the relative
FIGURE 8
Patients initially choose private providers

Overview of TB Patient Behavior

One survey during the first year after diagnosis

Continue private treatment

<table>
<thead>
<tr>
<th>6 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>70% cases opt for private sector</td>
<td></td>
</tr>
<tr>
<td>33% cases</td>
<td></td>
</tr>
<tr>
<td>16% cases</td>
<td></td>
</tr>
<tr>
<td>Private sector</td>
<td></td>
</tr>
<tr>
<td>100% new cases</td>
<td></td>
</tr>
<tr>
<td>20% cases</td>
<td></td>
</tr>
<tr>
<td>26% cases</td>
<td></td>
</tr>
<tr>
<td>Discontinue</td>
<td></td>
</tr>
<tr>
<td>17% cases</td>
<td></td>
</tr>
<tr>
<td>8% cases</td>
<td></td>
</tr>
<tr>
<td>Public sector</td>
<td></td>
</tr>
<tr>
<td>30% cases opt for public sector</td>
<td></td>
</tr>
</tbody>
</table>

Onset of symptoms

Discontinue* represents patients lost to analysis (stopped treatment, expired, migrated or refused to give information)

Source: Calculations based on 11.

TABLE 8
Shopping for treatment by patients in the first six months of treatment: 173 patients with private providers (11)

<table>
<thead>
<tr>
<th>Provider</th>
<th>Adherent patients (%)</th>
<th>Non adherent patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same doctor</td>
<td>54</td>
<td>57</td>
</tr>
<tr>
<td>Changed once</td>
<td>38</td>
<td>34</td>
</tr>
<tr>
<td>Changed twice</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Changed thrice</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Adherent patients are defined as those who reported taking at least 80% of the treatment during the period under report

rarity of TB. Only 15% of all households knew that government-run services offered free TB treatment.

About 60% of urban households in Pune were aware of PHC facilities (10).

Delay between diagnosis and treatment

Patients typically start treatment with the provider who diagnosed the illness. There is a relatively short delay reported in the start of treatment after diagnosis. Over 90% of the patients have been found to have started treatment within a fortnight of diagnosis (10, 11).

Shopping for treatment

Patients shop for effective private treatment and later switch to government services Over two-thirds of the patients privately diagnosed and started on treatment in the Pune-Bombay area continued treatment for at least six months (Figure 8). However, treatment was taken irregularly with only half the number of patients claiming to have been regular throughout the six months. Some switching occurred between private providers (11). In one study (Table 8) about 45% of the patients had changed providers at least once during the first six months of treatment.

Surveys of patients registered at government-run clinics (15) are revealing. Sixty percent of the patients registered at a New Delhi government-run clinic had first sought relief at a general practitioner or a provider of indigenous medicine. About half had sought professional help from two or more sources without adequate relief, before ending up at the TB clinic. Table 9 suggests that many patients switch to the government-run sector after pursuing ineffective treatment in the private sector. Half the patients switching to government-run services cited economic difficulties. Referral by the preceding treatment facility (private or public) was the other major reason for patients coming to government-run clinics.

TB patients switch from private to government-run services

The first contact of a TB patient with professional help is usually with a private provider. Over time there is a steady switching to the government-run facilities (Figure 9). The eventual steady switching from private to government-run services leads to an accumulation of TB patients in government-run services. Appendix 2 describes a simple model which explains how the flows probably lead to the observed cross-sectional picture.

Switching from private to government-run services occurs over time

Population-based cross-sectional information from five
states suggests that at any given time, roughly 50% of TB patients are under treatment with private providers. The 50% at government-run services comprises a large backlog of cases who have accumulated, whereas the 50% at private providers has a shorter duration of disease. Table 10 summarises the proportion of prevalent TB cases at private providers.

TB cases comprise roughly 10% of the hospitalization episodes in rural government hospitals and approximately 3% in urban government hospitals (9). From NSS data on number of TB cases treated in a hospital during the course of the preceding 365 days as well as TB cases seeking outpatient treatment in the course of the preceding 30 days, it has been estimated that about 7-8% of the TB cases under treatment in India at any given time are in hospital for treatment (Appendix 3).

Treatment adherence

Case holding weak in private sector

Case holding has long been recognized as the weakest component of TB services, both private and public. Among private sector patients in Pune and Bombay, adherence was reported high (70%) in the first two months and then declined to 54% by the end of six months (11).

Cohort analysis of 62 rural patients and 52 urban patients in the private sector showed treatment adherence rates of 53% (rural) and 57% (urban) in the first six months of treatment (11). For treatment extending to one year, adherence rates were reported to drop to 16% in both rural and urban areas.

Case holding rate low in NTP

Case holding has long been acknowledged as the weakest component of the national TB control program in India. A study in 1983 estimated that only 35% of the cases started on treatment in the government-run sector remain under treatment for an adequate length of time (17).

A relatively recent appraisal of the National Tuberculosis Programme (18) revealed that treatment completion rates were as low as 34% for patients on the standard regimen (18 months) in the cohort period 1.7.1990 to 30.6.1991 (based on reports from 152 district TB programmes).

Treatment completion rates averaged 51.3% for patients on short course chemotherapy in the cohort period 1.1.1991 to 31.12.1991 (based on analysis of annual reports from 119 DTPs).

Several studies have attempted to investigate the factors responsible for non-adherence (Table 11).

![Figure 9](image)

**FIGURE 9**

TB patients switch from private to public treatment

<table>
<thead>
<tr>
<th>Preference for private providers</th>
<th>70% cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public facility</td>
<td>30% cases</td>
</tr>
<tr>
<td>Private providers</td>
<td>100% new cases</td>
</tr>
<tr>
<td>Public facility</td>
<td>50% cases</td>
</tr>
</tbody>
</table>

**TABLE 9**

Number of visits to providers before reaching the government-run New Delhi TB clinic (256 patients at New Delhi TB clinic) (15)

<table>
<thead>
<tr>
<th>Number of preceding providers</th>
<th>% patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>12.1</td>
</tr>
<tr>
<td>1</td>
<td>40.2</td>
</tr>
<tr>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>3</td>
<td>14.8</td>
</tr>
<tr>
<td>4 or more</td>
<td>7.8</td>
</tr>
</tbody>
</table>

**TABLE 10**

The percentage of prevalent TB “episodes” under treatment at private providers (9)

<table>
<thead>
<tr>
<th>State</th>
<th>No. of TB episodes</th>
<th>Rural (%)</th>
<th>Urban (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td>58</td>
<td>44.3</td>
<td>60.2</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>98</td>
<td>32.3</td>
<td>34.2</td>
</tr>
<tr>
<td>UP</td>
<td>200</td>
<td>58.1</td>
<td>62.5</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>58</td>
<td>46.7</td>
<td>28.7</td>
</tr>
<tr>
<td>West Bengal</td>
<td>43</td>
<td>51.1</td>
<td>22.1</td>
</tr>
</tbody>
</table>
Summary: Factors shaping adherence

Treatment adherence is influenced by a multitude of factors. The socio-economic status of patients plays a role with poorer patients tending to be less adherent. The socio-economic status probably influences adherence through the financial means available to the patient and the perceived importance of regular treatment versus other tasks. Social support appears to help facilitate regular treatment. Patient-provider interaction seems to be yet another important factor, adherent patients are more likely to express faith in the doctors. The cultural context can play a role. Social obligations might take precedence over regular drug intake in traditional settings, patients would rather spend scarce time and money on family affairs. Clinic timings and distance also influence adherence. Side effects of the drugs are a relatively minor influence.

Adherent behaviour is also shaped by medication knowledge though there is evidence that patients are generally aware of required treatment duration. As stated above, nearly half the noncompliant patients in the Wardha study knew the correct treatment duration. Surveys in Pune and Bombay found patients to be knowledgeable about the treatment duration. Two-thirds could give the right answer (10). For patients the provider is often a key source of information. Patients appear to understand the need for regularity. Over 80% in the Pune

<table>
<thead>
<tr>
<th>Sample</th>
<th>Key factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>60 patients at a NGO TB clinic in West Bengal (19)</td>
<td>■ patient-provider interaction</td>
</tr>
<tr>
<td></td>
<td>■ change of residence</td>
</tr>
<tr>
<td></td>
<td>■ adverse reaction to drugs</td>
</tr>
<tr>
<td>400 defaulters at a government TB clinic in Lucknow (20)</td>
<td>■ careless and forgetful personality</td>
</tr>
<tr>
<td></td>
<td>■ family problems</td>
</tr>
<tr>
<td></td>
<td>■ failure to accept diagnosis</td>
</tr>
<tr>
<td></td>
<td>■ unsuitable clinic timings</td>
</tr>
<tr>
<td></td>
<td>■ long distances to clinic</td>
</tr>
<tr>
<td></td>
<td>■ symptomatic relief</td>
</tr>
<tr>
<td>60 defaulters in controlled SCC trials in Madras (21)</td>
<td>■ unwillingness for treatment</td>
</tr>
<tr>
<td></td>
<td>■ adverse reactions to drugs</td>
</tr>
<tr>
<td></td>
<td>■ pressure of work</td>
</tr>
<tr>
<td></td>
<td>■ outstation trips due to family</td>
</tr>
<tr>
<td></td>
<td>■ social or business obligations</td>
</tr>
<tr>
<td>150 defaulters and 150 adherents at government TB clinic in Agra (22)</td>
<td>■ socio-economic factors like caste, literacy, occupation, income</td>
</tr>
<tr>
<td></td>
<td>■ family affairs like births, marriages, functions</td>
</tr>
<tr>
<td></td>
<td>■ financial difficulties</td>
</tr>
<tr>
<td></td>
<td>■ transportation problems</td>
</tr>
<tr>
<td>50 nonadherent and 52 adherent patients at government clinics in</td>
<td>■ socio-economic factors</td>
</tr>
<tr>
<td>Wardha district (23)</td>
<td>■ health beliefs</td>
</tr>
<tr>
<td></td>
<td>■ social support</td>
</tr>
<tr>
<td></td>
<td>■ patient-provider relationship</td>
</tr>
<tr>
<td>299 patients on treatment in government clinics in Pune and Bombay (10)</td>
<td>■ feeling better (symptomatic relief)</td>
</tr>
<tr>
<td></td>
<td>■ economic constraints</td>
</tr>
<tr>
<td></td>
<td>■ unforeseen problems</td>
</tr>
<tr>
<td></td>
<td>■ health services related problems</td>
</tr>
<tr>
<td></td>
<td>■ adverse effects of drugs</td>
</tr>
</tbody>
</table>
survey (10) indicated that irregular treatment could lead to worsening of disease and possible death. Knowledge did not ensure adherence.

Factors influencing patient behaviour

List of main factors

The care seeking behaviour of TB patients is complex and dynamic — continuous learning takes place during the process. Several factors seem to shape this behaviour:

- the knowledge of, and attitude towards, TB in the community;
- the socio-economic status of the patients;
- gender as a special case of social status influencing patient behaviour;
- the personal motivation and health beliefs of the patient;
- patient perceptions of the various health providers and patient-provider interactions.

Community knowledge of, and attitudes towards, TB

A survey of households in Pune found that there was reasonable awareness of the disease. When the main symptoms of TB were enumerated over half the rural respondents and nearly three quarters of the urban respondents identified the condition as TB. A person with TB was visualized as being very weak, thin and with a persistent cough (10).

However, widespread misconceptions on the cause of the disease continue to persist. In Pune some households were found to attribute TB to behavioral causes such as physical stress, drinking alcohol, smoking and sexual activity (10). The researchers found that significant proportions (about 20%) of households and patients appeared to believe that socially unacceptable behaviour contributes to TB. Respondents mentioned sex with prostitutes and elderly women, wrong types of food and alcoholism as possible causes of TB (10). A study in rural areas of 24 Paragans in W. Bengal found that close to 70% of the respondents agreed that TB was a hereditary disease (24).

The Pune survey revealed that a majority of the households believed that TB was curable (10). Yet the disease remains stigmatized. The researchers found people reluctant to talk about the disease. The TB patient was often considered "impure" and stigmatized by the community. Patients contacted at the clinics were found to give wrong names and addresses to keep their identity confidential.

The W. Bengal survey found that almost 80% of the respondents would not negotiate the marriage of their son/daughter to an ex-TB patient. The researchers concluded that social attitudes towards TB have survived through the ages. Manu, the ancient Hindu Law giver, had opined that TB was unclean, incurable and an impediment to marriage (24).

Information for households came from personal experiences and the community, more than the media and the health services. This was more so in the case of rural households. Even among urban households, slum dwellers depended for information on their own experiences and the community (10).

Stigmatisation of the patient has obvious consequences for the success of treatment. Patients would be reluctant to come forward for medical help and reveal their condition. The stigma also translates into a lack of social support during treatment. Social support has been found to be a critical factor in treatment adherence.

Socio-economic status of patients

The socio-economic status of the patients determines their access to information about the disease and the diagnostic and treatment facilities available. It influences their choice of the provider and their ability to meet the demands involved in regular treatment.

A study in Jalipur on the awareness about TB in the general population found significant differences in the knowledge about the disease among different socio-economic groups (25). Eighty to ninety percent of the illiterate respondents were either unaware or had misconceptions about different aspects of TB. In contrast 70-80% of the literate respondents gave correct answers to most of the questions about the disease ($\chi^2=202.76$, $p<0.001$, for questions relating to general aspects of TB).

In general, the researchers found that the people with higher socio-economic status had a greater awareness about the disease.

Evidence of the link between socio-economic conditions and treatment adherence emerges from the Wardha survey (23). Adherent and nonadherent patients were found to differ sharply on three counts — the monthly per capita income of the patient, the type of house in the patient lived and the monthly income of the patients’ family. The average monthly family income of the adherent group was USD 60 (range USD 21-143) while of the nonadherent group was USD 48 (range USD 14-114) (F-value 4.34, $p<0.05$). The average monthly per capita income in the family of the adherent patient was USD 12 while for the nonadherent patient it was USD 9 (F-value 6.77, $p<0.01$). Seventy percent of the nonadherent patients lived in an improvised structure compared to 48% of the adherents.

The Agra study found even stronger association between socio-economic status and adherence to
treatment (22). There was significantly higher default among scheduled ("backward") castes as compared to other Hindu castes. There was a higher proportion of defaulters among patients earning up to USD 3 per month than among those earning USD 3 or more per month ($\chi^2 = 14.28$, df = 1, p < 0.001). Illiterates formed the majority among defaulters, while there were comparatively more literates among the non-defaulters. The difference was highly significant ($\chi^2 = 27.3$, df = 1, p < 0.001).

For poor patients who live in harsh conditions it is very difficult to continue chemotherapy when symptomatic relief is obtained. It is especially difficult to justify expenditure on drugs when there are other pressing demands on meager finances.

**Women face special constraints**

The women of India have been described as reluctant patients (26). Women, because of household responsibilities, and out of ignorance, tend to neglect their illness until they become too sick to move around and attend to their normal chores. They are often dependent on others to get them needed medical attention (26).

A study of TB patients in Bombay slums revealed sharp gender-based differences in patients’ response to the disease (31). Women and men were found to experience differing amounts of family support which was expressed in terms of rest and lighter work loads for men. Family support also manifested itself in early contact with a care provider and regularity in treatment. More support was experienced by men, and by unmarried women who were staying with their parents.

Another study has suggested that women’s inability to control their own movements, and concerns about family expenditure are major factors in treatment non-adherence (20). The study also suggested that married women with TB were more likely to be divorced as a result, while unmarried girls with the disease would sometimes find it difficult or impossible to get married.

**Personal motivation and health beliefs**

The Wardha study on treatment compliance has closely examined the health beliefs of the adherent and non-adherent groups (23). Adherent patients were more likely to think that TB could become life threatening and that the disease reduces one’s working capacity. Adherent patients tended to eat good foods, clean their body and visit a primary Health Center. Nonadherent patients tended to isolate themselves and pray to God for cure. Adherent patients perceived the benefits of treatment—recovery from illness and the prevention of hospitalization—as more positive than nonadherents.
Treatment of TB requires numerous patient-provider interactions. These represent opportunities to educate and counsel the patient. The health worker’s pessimism about the patient’s ability to change may serve as a barrier in the relationship between providers and patients (28).

Out-of-pocket costs to the patient

Diagnosis

In the private sector the cost of diagnosis ranges from USD 3-7 which is the cost of an X-ray and three sputum tests (16). In addition there is the cost of treatment prior to diagnosis. This appears to be an average USD 10-13 as revealed by patients who registered for treatment with government-run services after help seeking at other sources (10). Thus the average cost to the patient of diagnosis and the treatment preceding diagnosis is about USD 17.

Treatment

Cost of treatment runs at USD 0.4 average per day for the drugs and USD 115 for a nine month course (16). Excessive prescriptions can result in much higher costs. In addition consultation fees per visit range from USD 0.5 to as much as USD 7 (16). These figures show that a patient receiving treatment in the private sector is paying at least USD 110-140 as out-of-pocket expenses, if treatment is actually taken. This does not include opportunity costs, nor payment for superfluous nutritional supplements. Over half the money spent at drug retailers, for over-the-counter preparations, goes on vitamin, protein or carbohydrate supplements (29).

The figure of about USD 100 to 150 for required treatment may be compared to the USD 200 per year which a daily wage labourer in India can hope to earn. When the costs of daily living and the costs of superfluous treatment are considered, together with the lost wages and time due to illness and treatment, indebtedness is predicted and observed. Twenty percent of rural patients and 40% of urban patients in one survey (11) became indebted as a result of TB.

The cost figures for patients who underwent regular treatment in the private sector are shown in Table 12. In practice, patients often discontinue treatment after paying for not only the correct drugs but also superfluous nutritional supplements. This leads to temporary palliation of symptoms, followed by recurrence and re-treatment. After a few cycles of temporary relief and re-treatment, the patient is sometimes left ill and indebted. Some patients simply die (estimated at up to 10% per year in one study) (11).

<table>
<thead>
<tr>
<th></th>
<th>1-6 months</th>
<th>1-12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>USD 115</td>
<td>USD 182</td>
</tr>
<tr>
<td></td>
<td>(46 - 401)</td>
<td>(50 - 435)</td>
</tr>
<tr>
<td>Urban</td>
<td>USD 95</td>
<td>USD 164</td>
</tr>
<tr>
<td></td>
<td>(52 - 435)</td>
<td>(72 - 330)</td>
</tr>
</tbody>
</table>

1 USD = Rs. 32

Table 13

Money spent on earlier treatment related to monthly income (15)

<table>
<thead>
<tr>
<th>Monthly Income*</th>
<th>No. of patients</th>
<th>Average cumulative expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; USD 15</td>
<td>40</td>
<td>USD 14</td>
</tr>
<tr>
<td>USD 16 - 30</td>
<td>97</td>
<td>USD 16</td>
</tr>
<tr>
<td>USD 31 - 45</td>
<td>62</td>
<td>USD 16</td>
</tr>
<tr>
<td>USD 46 - 75</td>
<td>46</td>
<td>USD 23</td>
</tr>
<tr>
<td>&gt; USD 76</td>
<td>11</td>
<td>USD 17</td>
</tr>
</tbody>
</table>

*The 1986 rupee prices were adjusted for inflation (at 10% p.a) to get 1995 prices which were converted to USD at 1 USD = Rs. 32.

Expenses of patients in the government-run sector

A 1986 survey from Delhi (15) investigated the financial burden imposed on TB patients by diagnosis and treatment expenses prior to registering at a government-run TB clinic. The results are summarised in Table 13.

It is clear that a majority of the patients on the register of the government-run clinic at New Delhi are from the lower income groups and that they end up spending a large chunk of their income on fruitless treatment.

The prime reason for the switch from private providers to government-run services appears to be the cost involved. Many patients are no longer able to afford the consultation fees and the expense of drugs. Many patients may simply discontinue treatment instead of changing to a government-run facility.

It has been suggested that patients struggle to continue treatment with private providers under great financial hardship (27). When they feel better, they drop out. Repeated cycles of relapse and palliation exhaust the
financial resources of the patient who then seeks treatment at a government-run facility.

A survey of TB patients in Bombay found that 66% of the sample belonged to the lower socio-economic class (30). Further, the mean monthly per capita income of a patient in the sample was found to be about USD 7. But on average, a patient had been found to spend USD 26 on prior treatment attempts. Also a third of the patients were spending at least USD 0.3 on each visit to the clinic to collect drugs. Thus a patient could end up spending nearly 10% of income only on traveling to the clinic twice a month to collect drugs.

TB patients pay significantly lesser amounts than in the private sector once they have registered with the government-run urban TB clinics. Urban patients reported an average expenditure of USD 1.5 after registration (10). In rural areas, further costs are imposed by transportation. More than a third of the patients at government-run clinics were found to have spent between USD 30 and USD 230 on their illness (10). Given that most patients in the government-run sector started treatment in the private sector, this is not surprising. Patients at government-run clinics were sometimes found indebted from past unsuccessful treatment attempts.

### Purchase of health care in India

Health care in India is mostly privately financed. The estimated household share of total Indian health expenditure in 1987 was 60% (31). Another estimate puts the national health expenditure at about 6% of the GDP (approximately USD 13 per capita at 1990-91 exchange rates), of which 75% is spent by households (9). Insurance plays a minor role; only the four percent of the population working in the organised government-run and private sector are covered by insurance schemes (9). Figure 10 summarises the distribution of health expenditure in India.

On average five percent and two-and-one-third percent of total household expenditure in rural and urban areas respectively were for health expenses. This proportion is higher in case of the households with lowest overall expenditure (9).

About 65% and 60% of household health care spending in rural and urban areas goes towards non-hospital treatment (9). Since private providers account for 70-90% of ambulatory treatment, about 50% of out-of-pocket household health expenditure is payment for treatment under private ambulatory care providers.

Most illness contacts for people, regardless of income, are with private providers. These contacts cost on an average one-and-one-half to two times more than contacts with government providers.

Out-of-pocket household health spending accounts for most of the health expenditure in India, it accrues mostly to private providers and it imposes a disproportionate burden on poor households.

### Aggregate private expenditure on TB treatment in India

The National Sample Survey provides cross-sectional data on the treatment expenses incurred by households during the 30 days preceding the survey. Average payment per month for TB treatment in the private sector was roughly RS 200. Adjusted for inflation (10% p.a.) this amount to RS 472 per month at current prices. The prevalence of TB in India has been estimated at 422 per 100,000 (11). Thus there are roughly 4 million (3.8 million) cases of TB in India. Even if we assume that just half the cases are in private care, and half again of the private sector cases are spending on TB treatment at any given time, out-of-pocket expenditure on private sector TB treatment in India works out to at least USD 150 million per year. Details of the calculation are given in Appendix 4.

### Private providers

#### General characteristics

**Private health care providers abound**

The private for-profit health care sector plays a major role in the health care system in India. In 1989, there were about 242,650 qualified allopathic physicians practising privately, as compared to 88,105 in the government services (32). The distribution of providers is summarized in Figure 11.

The actual number of private providers is in fact much greater. Health statistics typically under-report the size of the private health care sector. Many private providers have no formal qualifications and are not registered with either the medical council or the ISM (Indigenous System of Medicine) registry. One survey revealed that 62% of the private providers identified by respondents had no formal qualifications (33). A survey of 488 rural private health care providers in 300 villages in the state of Uttar Pradesh found that only about half had any formal qualifications (34). This study put the number of private providers in the rural areas of Uttar Pradesh at 80,000 and went on to estimate that there are 1.25 million providers in India or one for every 600 people in rural areas. In contrast, government figures indicate a national average of one privately practising physician for every 3,500 people (9). Government data usually relate only to qualified allopathic doctors. There exist large numbers of "registered"
providers with lower qualifications as well as unregistered and unauthorised providers with no formal qualifications.

The private sector is growing rapidly
Private providers operate through private hospitals, nursing homes and clinics. There is a large number of such institutions which typically have not been recorded in health statistics (35). Such centers have been proliferating rapidly. The number of recognized hospitals in the private sector grew from 2,764 in 1983 to 4,488 in 1987 (35).

Private providers are present in small villages, more accessible than government-run centers
Private providers are often present even in remote areas where there are no government services. The survey of rural “doctors” in 300 villages of Uttar Pradesh found private allopathic doctors in 37% of the smaller villages (population less than 2,000) while PHCs (Primary Health Centers) were found only in 1% of those villages. Private allopathic doctors were found in 81% of the villages with a population greater than 2,000 while only 12% of these villages had PHCs and 19% had Sub-centers (34).

Private providers are a heterogeneous mix
The private providers are a heterogeneous mix of qualified and unqualified allopaths, homeopaths, “vaidyas,” “hakims” and “tantriks.” The Indigenous Systems of Medicines (ayurveda, siddha, naturopathy, unani, amchi) are practiced widely alongside Western medicine (34). Most ISM doctors in the UP survey were also prescribing allopathic medicines.

Profile of a typical rural private provider in Uttar Pradesh
The survey of nearly 500 rural providers in Uttar Pradesh found that the typical rural private provider in Uttar Pradesh was a 38 year old male with about 10 to 12 years of schooling, in practice for about 11 years (34). He practiced a mix of Western and professional medicines. Only seven percent had any professional training in Western medicine and techniques. Yet two out of three providers said that their main practice was allopathy. The remaining one-third of rural providers mainly practiced homeopathy and ayurveda. Almost 80% of the ISM doctors occasionally use Western medicines.

Half the providers have no formal qualifications
Only about half the providers have any formal training. Significantly, less than half (45%) of the providers practising allopathy had any professional training, and of those who did, it was mostly in ISM or homeopathic schools. A mere 7% of the providers mainly practising allopathy had received training in a college or university of allopathic medicine (34).

Unqualified providers learn as compounders or assistants
Ninety percent of the untrained doctors practising allopathy learn their skills from family members, or as a compounding, pharmacist or doctor’s assistant (34).

To sum up, most rural doctors are not trained in allopathy; they are either trained in ISM or homeopathy...
or have no formal training. Yet they are primarily practising allopathy and distributing modern medicines.

**Earnings of rural providers are low**

The rural doctor in Uttar Pradesh was found to be earning RS 11,000 (USD 400) per year which is less than the wages of low level employees at government-run health facilities. Not surprisingly, about 45% of the rural doctors worked part-time; they had alternate sources of income, primarily agriculture. Full time trained doctors practising Western Medicine were found to earn the most (34).

**Rural providers sell medicine; often repackaged store-bought medicine**

Nearly all the rural doctors charged patients on the basis of a margin added to the medications (34). About 93% earned income solely through sale of medicine, 3% charged for both medicine and consultation and 4% charged for consultation alone (34). Thus it appears that patients expect to receive medicines when they go to a doctor; considerable value is attached to the relief and cure through medicine. Repackaging of store-bought medicine was found to be common — 40% of the rural providers compounded medicines at their clinic or repackaged store-bought ones (34).

The average rural provider in Uttar Pradesh was seeing about 10 patients a day. Allopathic doctors tend to see more patients a day than other providers (34). About a fifth of all the providers were seeing at least 16 patients a day. The case load appears to be positively correlated with professional training and full time practice.

**About half the rural private providers belong to a professional association**

More than half of the rural private providers were found to be registered with some medical association (34). However, these are self-reported memberships and might not fully reflect reality. Professionally trained providers were more likely to be members of a medical association (65% vs 42% for unqualified providers) (34).

**Private providers are keen on joining a medical association**

Nearly 95% of the providers expressed interest in joining a rural medical practitioner’s association (34). The main reasons given for this interest were:

- to exchange ideas;
- to learn about new medicines and techniques.

**Urban areas have high concentrations of private providers**

Urban areas have a relatively higher concentration of private physicians than rural areas. In Bombay, there are an estimated 14,000 qualified allopaths practising privately as compared to 6,000 in government services (36). There would also be a large number of ISM doctors as well as providers with no formal qualifications whatsoever.

**Profile of private providers in Pune, Bombay survey**

The Pune survey contacted all the private medical practitioners in the study sites (10). All of the 81 rural providers contacted were qualified though a majority had non-allopathic qualifications. However, the Uttar Pradesh survey revealed that only half the private providers in rural areas were qualified (34). Regional differences are unlikely to account for this big difference. It appears that unqualified and unregistered providers might have been excluded from the Pune sample of rural medical practitioners.

The Pune and Bombay surveys find that non-allopaths outnumber allopaths among the medical practitioners surveyed. Interestingly, there was a higher proportion of allopaths in villages (45%) than in urban slums (33%).

**Preferred first source of help for TB patients**

Private providers are the preferred source of help for curative ambulatory treatment. Seventy percent of ambulatory curative care in India is being delivered by private providers (12). The initial care seeking behaviour by chest symptoms appears to follow the general pattern. Evidence from surveys in Pune, Bombay, Delhi, Bangalore and Madras shows that a majority of the TB patients first seek help from private providers. In the absence of information from other parts of the country, it can be reasonably assumed that initial help care seeking for TB is similar to the general pattern for other illnesses. Thus private providers are likely to be the first source of professional medical help for 50-80% of TB cases in India, depending on the region.

Figure 5 shows that in the five states of Uttar Pradesh, Gujarat, Maharashtra, Tamil Nadu and W. Bengal, the private sector share of outpatient care ranged from 70-90%. The utilisation of government-run facilities for short duration illnesses is less than 30% for the country as a whole (12). There are regional variations, with the proportion of short duration illness episodes being treated at government-run facilities ranging from a high of 66% in Orissa to a low of 10% in Punjab (12). The hilly North Eastern regions, Orissa and the hill state of Himachal
Pradesh appear to have a relatively greater reliance on government-run health facilities (12). This may be partly due to private providers' preference for densely populated zones, such as urban areas. Even in the hilly regions, however, the private sector treats 40-50% of the short duration illness episodes.

**TB patients do not form an important part of the case load of an average private provider**

In one study, about half the private providers were treating between one to five cases of TB patients (10). A significantly large proportion (34%) of the non-allopaths was not treating any TB case. Table 14 shows the distribution of the number of patients under treatment of private providers. Elsewhere, a multi-site study found that fewer than 1% of patients consulting a private provider were possibly TB cases (29).

**Quality of private health care is variable even in cities**

Modern sophisticated hospitals in metropolitan areas serve an affluent clientele and offer world class facilities. In slums and in many villages, clinics are operating in dilapidated rooms, run by semi-qualified or unqualified people.

A study of private health facilities in Bombay alleged that the "private sector provided substandard medical services in every respect" (36). Private facilities were found to lack proper physical infrastructure and manpower, and negligence was claimed to be rampant. This despite the impressive regulations that exist on paper.

**Dubious practices in the private sector**

General providers, consultants, nursing home owners and investigation centers were found to collude with one another to "squeeze the patients" (36). Patients were sometimes referred to several consultants and investigation centers, and the fees charged were then shared by the consultants and laboratory owners. The patient can be subjected to unnecessary expense and treatment delayed (36).

One survey of 2,400 patients found that private doctors prescribe a large number of drugs. Combinations/preparations containing hidden classes of drugs were often suggested and anti-infectives were widely, and often inappropriately, used (29).

A survey in Jalgaon district of Maharashtra found that physicians in the private sector use more injections and medicines than their counterparts in government-run services (13).

**Diagnostic practices**

Almost all private providers surveyed in Bombay and Pune seem to be advising possibly superfluous or incorrect tests for diagnosis (11). X-ray is by far the most popular tool to diagnose possible TB suspects. About 75% of private providers used X-ray plus sputum while 15% used X-rays only (11). Another study found that X-rays were advised by 95% of the private providers, 85% advised blood tests and 65% advised sputum microscopy (10).

About 70% of the private providers surveyed in Pune singled out X-ray as the preferred test for diagnosing pulmonary TB (10). Seventy-five percent of the urban providers referred patients to private labs for diagnosis (10). Poor patients were typically referred to government hospitals and TB clinics (10).

About 60% of the providers sought a consultant's advice for confirming diagnosis (10).

**Treatment practices**

Most (e.g., 90%) providers prescribe but typically do not dispense anti-TB drugs (11). However, supplements such as vitamins, analgesics and tonics are dispensed at profit. Private providers dispense expensive nutritional supplements to more than 50% of all their patients (29). This imposes unnecessary expense on the poorer patients. In general nutritional supplements account for a quarter of the drugs prescribed by private providers (29).

More than half the providers were prescribing four and five drug regimens in the intensive (first two to three months) phase of treatment (11). There were considerable inappropriate practices such as the use of pyrazinamide for over three months (61%). Only 24% of allopaths and 16% of non-allopaths reported a total duration of chemotherapy as short as six months. Most recommend six to nine months (Figure 12).

**Table 14**

Adult patients under treatment with private providers: Survey of 177 private providers in Pune (10)

<table>
<thead>
<tr>
<th>No. of patients</th>
<th>Allopaths (%)</th>
<th>Non-allopaths (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No patient</td>
<td>18</td>
<td>34</td>
</tr>
<tr>
<td>1 - 5</td>
<td>60</td>
<td>40</td>
</tr>
<tr>
<td>6 - 10</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>11 - 20</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Can't Say</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>No response</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
**FIGURE 12**

Prescriptions for anti-TB treatment among private providers

*Most providers prescribe four to five drugs in the intensive phase*

Regimens prescribed by 105 private providers in Pune and Bombay. Source: 11

```
| Providers | 23
| 3
| 13 | 53
| 4
| 2
| 2
| 5
```

Total Duration of Regimen

- < 6 months
- 6-12 months
- 12 months

No significant difference was observed between the prescribing practices of allopaths and non-allopaths. This may be due to the fact that drug manufacturers’ representatives form the predominant source of continuing information on drugs, for all drug prescribers in India.

**Case holding practices**

Three quarters of the rural and 68% of the urban providers in one survey asked their patients to report for a refilled prescription at intervals ranging from one week to one month (11). There was no direct supervision of drug ingestion. Interestingly, a third of the allopaths surveyed believed that weekly X-rays were desirable during treatment (10).

Private providers typically keep no case records (29). When a TB patient on treatment failed to report back more than half the providers admitted to taking no corrective action (11), while about 40% claimed to have sent a reminder to the patient through someone.

**Treatment outcomes**

**Completion of treatment**

Overall case holding is poor: treatment completion rates higher than 50% were claimed by only 2% of providers surveyed (10). Very few private providers in Pune and Bombay were found to be using sputum microscopy to verify cure. Eighty percent of urban and 60% of rural providers indicated that completion of course was a criterion to stop treatment. Only 15% of urban and 10% of rural providers volunteered that three consecutive negative sputum specimens were desirable as evidence of cure (10).

**Mortality among rural private sector patients**

In a study of 100 rural patients followed prospectively for one year after commencing treatment in the private sector, at least six died of TB during the year (11). This translates to a case fatality rate of at least 1.3% to 10.7% per year (95% confidence interval) for this group of patients.

**Cure rates in NTP are low**

A 1983 study estimated overall success in case holding and chemotherapy in the national TB programme at 35% and 75% respectively (17). These figures imply an overall cure rate of 26-27% within the government-run sector.

**A promising innovation among private providers**

In South Bombay, a group of private providers came together in an initiative to help the poor TB patients in the area (30). Though the diagnostic expenses were borne by the patient, treatment was free of charge for the non-affording smear positive patients. A TB clinic was created where patient records were kept and drugs dispensed by an appointed social worker. The social worker also identified defaulters and contacted the referring doctor for follow up action. The Bombay Municipal corporation supported the scheme from the start and supplied 10% of the drug requirement free. Unfortunately, cure rates were not consistently measured. It is often not possible to do a sputum test at the end of the treatment period. Drug collection rates of 50-60% have been reported. This experience is not ideal, but it offers some pointers for the design of private/public DOTS programmes.

**Drug retailers**

Prescription and dispensing of drugs in India appears well regulated on paper, but fairly unregulated in practice. Drug retailers consistently sell restricted drugs without requiring prescriptions. Self medication is very common — nearly two-thirds of patients buying medicines over the counter did so without a prescription (29). When patients could not afford all the drugs on a prescription, it was typically left to the discretion of the pharmacist to decide which ones to omit. Post-graduate training in clinical pharmacology was generally found only among representatives from the pharmaceutical industry.
Discussion  The evidence available suggests that private individuals in India are spending at least USD 150 million per year on private TB treatment. This usually buys them temporary relief from symptoms, but not cure. Besides, it increases the risk of multi-drug resistant TB. Most TB patients first approach private for-profit providers rather than government-run services. The haphazard practices among private for-profit providers in India may be compared to the tried and tested 5-point DOTS strategy recommended by WHO. Consistent documented cure relies on diagnosis and monitoring by sputum microscopy, ensuring regular and complete treatment, and a standardized recording system.
It is not surprising that ill TB patients accumulate in India, and several hundred thousand patients unnecessarily die each year.

The picture that emerges is not that different from other countries where private medical practice thrives. Patients usually choose the nearest trusted provider for health care. In many countries, this is usually a private for-profit provider. TB is most frequent among the least well-off people. Therefore, financial problems form one of the main reasons for discontinuing treatment. Repeated cycles of inadequate treatment and temporary relief make the patient increasingly ill and poorer. Government-run services steadily receive the poorest and least healthy patients.

The initial symptoms of pulmonary TB are practically indistinguishable from general chest symptoms. Both TB patients and private providers therefore approach the disease as they would any other chest symptoms. This could have important implications for the design of interventions. Chest symptoms vastly outnumber TB patients, and represent an important source of income for private providers.

Prescription and dispensing of drugs in India is well regulated on paper but fairly unregulated in practice. It has been found that drugs which have a high incidence of side effects or a significant risk of fatal idiosyncrasy are being sold over the counter and prescribed by doctors for trivial complaints (29). Almost two-thirds of patients were found to be buying medicines over the counter without a prescription (29). Explanations cited include loopholes and inertia in the legal system, the lack of effective administrative infrastructure, and the commercial persistence of drug manufacturers (29). Existing regulations seem ineffectively applied, and it is not clear what the prospects of implementation are for any additional legislation.

Recently the Consumer Protection Councils (CPC) have been taking an active role in pursuing possible cases of medical malpractice. Interviews with knowledgeable members of the Indian Medical Association (IMA) reveal that the IMA has been raising questions regarding the CPC's competence and role in judging medical practice. The IMA has a membership of nearly 100,000 qualified practitioners and has traditionally been one of the strongest opponents of medical practice by unqualified practitioners.

Questions have been steadily raised about the prescription of modern allopathic medicines by health care providers trained in other systems of medicine. A recent ruling by the Indian Supreme Court confines doctors to the system of medicine in which they were trained.

**Options considered**

Several options for intervention have been identified partly through the global email discussion group on private providers, started by GTB in October 1995. These options are not mutually exclusive.

**Exclusion of private providers**

**Excluding TB drugs from private channels**

Some countries such as Algeria and Chile have legislation which bans the sale of anti-TB drugs through private channels. This has worked effectively in the two countries, and patients are consistently referred to the government-run services which provide anti-TB drugs. Special circumstances in Algeria (political transformation in the 1960s) may have facilitated the legislation.

**Mandatory referral of TB patients to government-run services**

Oman has successfully implemented mandatory referral of TB patients to government-run services. However, there might remain some skepticism about the potential effectiveness of such legislation in large developing countries, where enforcement is more challenging. TB is a notifiable disease in many countries.

Incentives for referral of TB suspects to government-run microscopy and treatment services have been shown to work. In China, incentives for referral were used to confirm diagnosis, with confirmed TB patients being returned to the referring private provider for DOTS supervision.

**Exclusion of private providers through price and quality competition from government-run services**

Some developing countries such as Peru have government-run TB services of perceived high quality and perceived low costs/inconveniences to patients. Private providers can effectively compete for only those patients who value privacy and convenience above the additional cost of private treatment.

**Potential limitations and difficulties of exclusion**

All the options for exclusion of private providers presuppose that government-run services offer high quality and low inconvenience to patients; apart from having sufficient resources and ability to cope with the entire load of TB cases. This optimal state of government-run services might take some considerable time to achieve, in large
Delegation of responsibilities to private providers: Individuals and organisations

Delegation of TB control responsibilities to a private voluntary organisation — The norms and guidelines for producing consistent documented TB cure can be set out clearly, and a memorandum of understanding signed between the government and a private voluntary organisation (PVO or NGO). Such an agreement between the Government of Bangladesh and BRAC is working well, with TB cures being produced within a defined geographical area according to agreed norms and guidelines. Initial training used the standard WHO modules. Although private voluntary organisations in India have not played a prominent role in TB control, there seems to be no reason why they should not start now. Some private voluntary organisations in India have been demonstrated to achieve high rates of treatment completion (37). Organisations with an established widespread network (e.g., leprosy control organisations) seem the most promising.

Private/Public collaboration for delivery of documented TB cures — Individual private providers or groups of providers can be enrolled with DOTS centers which undertake to produce documented TB cures. DOTS centers might be managed by the government or by an authorized public-spirited agency, such as a voluntary organisation or an association of private providers.

Such centers would rely on the supply of inputs such as standardized training, standardized practice, public information and strict quality control. Drug supply and supervision of treatment would be the responsibility of the DOTS center. A brand name might prove useful to differentiate the participating providers from others, and to help certify quality. Payments to the DOTS center would be based only partly on inputs and processes, but largely on clearly defined outputs (documented TB cure). Fraud control needs specific design. Working models of such “franchising” arrangements exist outside the TB control field.

It is worth noting that private health care providers are concerned more with the chest symptoms than with TB patients, since the market for quality chest care is much larger than that for TB treatment.

Incentives to individual private providers — Many people, especially in rural areas, first seek care from less-than-fully qualified private providers. Incentives for referral of TB suspects (based on confirmed sputum positivity) and for supervision of the intensive phase of treatment have been demonstrated to work. In China,
the former “barefoot doctors” have become private providers of health care. They were paid for treatment completion of patients supervised. In Massachusetts, USA, fully qualified private providers are contracted to produce TB cures (alongside treatment of STDs and AIDS) and are required to take a pro-active approach if a patient misses an appointment. In New York City, private providers were offered the incentive of free medicines, plus direct observation of treatment, in exchange for reporting on follow-up of cases. It is doubtful whether qualified urban private providers in India can themselves become interested in the time-consuming and unrenumerative aspects of the DOTS strategy.

Gaps in information

Some important gaps in information persist. There is no reliable estimate of the number, density and distribution of specialist chest clinics, where TB might form a more important part of the case-load than in general clinics.

There are also no reliable estimates of the projected marginal cost per cure in the successful sites of the Revised National TB Programme. Any financing schemes proposed for new interventions will need to use the marginal cost per cure in the RNTCP as a benchmark.

Successful experiences from other areas of the world require careful examination. The innovative community financing schemes of BRAC, Bangladesh, and the incentive/disincentive schemes used to modify private provider behaviour in other countries will probably have useful lessons for the design of interventions in India.

References


27. Krieger L. Visit Report, India, Consultancy July 3-August 11, 1995. (Social assessment study of TB in India, on behalf of ODA; unpublished)


Appendix 1:
Research methods in the studies reviewed

1. A prospective survey (1981-83) was carried out in four villages of North Arcot Ambedkar district in Tamil Nadu to determine the prevalence and incidence of smear-positive TB (1). The entire population of 22,847 was covered prospectively; the prevalence survey of 1981 was conducted through house to house interviews followed by collecting and examining sputum specimens from symptoms (cough for more than two weeks duration or other respiratory or systemic symptoms compatible with TB). The prevalence survey was followed by monthly visits for two consecutive years to obtain an accurate estimate of incidence.

2. A study (2) was designed to observe the relationship between socio-economic status of the population and TB. The study covered an urban population of 200,000 and a rural population of 490,000, aged 5 years or more, in Wardha district, and it provides estimates of prevalence of bacillary positive pulmonary cases detected by smear/culture of at least two sputum samples. The study was completed in 1989.

3. A survey in 1991-92 by the Regional Medical Research Center (RMRC), Jabalpur (4) looked for tuberculosis among 22,250 individuals in the Karhal block of Morena district in the state of Madhya Pradesh. It provides estimates of prevalence of sputum smear and/or culture positive TB. The 120 villages of the area were stratified according to population size and the proportion of tribal population in each village. A sample of 37 villages was drawn, such that the final sample contained a population of 23,000. The age group 9-14 were excluded since the researchers expected a low yield of cases from this age group. Forty-nine and one-half percent of the study population were members of an indigenous tribe. The tribals live in colonies adjoining the main villages inhabited by non-tribals.

4. A population-based study of prevalence of chest symptoms and action taken by symptomatics was carried out by the National Tuberculosis Institute, Bangalore in 55 randomly selected villages of Nelamangala taluk in Bangalore district (5). 21,316 subjects were interviewed (98.8% of the eligible population). The study findings were published in 1976.

5. Tuberculosis Research Center, Madras carried out a sample survey of awareness of symptoms and utilisation of health facilities by chest symptomatics in rural, urban and metropolitan areas of Tamil Nadu (6). A 20% sample from rural areas of North Arcot district, 20% sample from Thiru-

vannamalai town and 10% sample from Madras city were chosen, based on cluster sampling. In all three areas, a census was taken and chest symptomatics were identified. The study was confined to persons aged 15 years or more. The survey findings were published in 1990.

6. A sociological study of awareness of symptoms and actions of persons with pulmonary TB was conducted by NTI, Bangalore in 62 villages and four town blocks of Tumkur district in 1973 (7). The study was carried out within four weeks of an epidemiological survey in the area. All persons aged over 20 years with X-ray evidence as confirmed by at least one of two independent readers were eligible. An equal number of randomly selected non-cases controlled for age and sex to match the cases were also interviewed. In all 1,752 persons were selected for interview — 875 radiological cases and 877 controls. About 88% of the former and 91.1% of the latter were satisfactorily interviewed. The study area has been the site of special ad hoc programmes of the State Health Services. In 1965 a TB pilot project had been established under the aegis of the district TB association which involved follow-up of TB patients by volunteers. As such, the area might have a higher awareness of the disease as well as government-run TB services.

7. A sociological study of awareness of symptoms of pulmonary TB and action taken by the patients to seek relief was carried out at the District Tuberculosis center for Madras city (8). A total of 796 patients, all aged 15 years or more, diagnosed in the course of six months on radiographic evidence were selected for the study. The study findings were published in 1977.

8. The 42nd round of the National Sample Survey (NSS 1986-87) was devoted to health care utilisation and financing (9). The survey was carried out in five states—Gujarat, Maharashtra, West Bengal, Tamil Nadu and Uttar Pradesh. The survey covered 11,379 rural and 7,912 urban households. Households in which a person had received hospital care during the previous year or non-hospital care during the 30 days prior to the survey were asked to indicate the nature of ailment, the type of treatment taken and the associated expenditure. Four hundred fourteen cases of hospital based treatment and 360 cases of non-hospital treatment were reported for TB.

9. Surveys of users and providers of TB care were carried out during 1991-94 in the urban and rural parts of Pune district in Maharashtra (10).

A pilot study of 22 PHCs in the district was carried out and all the PHCs in the district were stratified according to:

- number of TB patients on the register (less than 15 and 15 or more)
The only PHC with X-ray facilities was deleted from the sampling frame and from each of the other groups, one PHC was selected purposively (to cover all parts of the district and to ensure that all key functionaries are in position). Two PHCs were selected from the largest group — PHCs with less than 15 patients and no investigation facilities.

Two villages with average population were randomly selected from each PHC, one within five km distance from the PHC and the other beyond five km. Six hundred five households were selected by systematic random sampling from these 12 villages.

Four hundred eight urban households were chosen so as to represent the slum and non-slum populations of Pune city. For this purpose, 16 of the 76 non-slum wards (slum population less than 50%) were selected with a probability proportional to the number of census blocks in the ward. Two of the nine slum wards with the highest slum population were selected. Two blocks from each of the 16 non-slum wards and five from each of the two slum wards were selected randomly. From each block 10 households were selected for interviews.

The researchers also interviewed retrospectively 299 patients of pulmonary TB (sputum positives and negatives) who had registered three to six months prior to the survey at six rural primary health centers (PHCs), the district TB clinic and two municipal TB clinics in Pune city.

Sixty-one newly registered urban patients at the district TB clinic and the two municipal clinics were followed prospectively for a period of eight months.

Data on the rural government-employed health functionaries (Medical Officers, health workers and pharmacists) were collected from 24 PHCs through semi-structured questionnaires and interviews. In-depth studies of the urban TB clinics were also carried out using participatory observation methods, secondary data and group discussion with key personnel.

All the private practitioners in the selected PHC areas and urban blocks were contacted and asked to complete semi-structured questionnaires—a total of 177 private practitioners formed the respondents.

The patient samples were taken from among patients already registered with the government-run health services—the results cannot be said to hold for patients who continue treatment in the private sector or discontinue treatment.

Further it is not clear how the private practitioners were identified. All the private practitioners in the sample were qualified though many had non-allopathic (Ayurveda, Unani, Homeopathy etc.) qualifications. A large number of unqualified but practising physicians may have been missed.

10. A study of private practitioners and the TB patients under their care was conducted in 1995 in the rural areas of Pune district and a big urban slum in Bombay city (11). The study included qualified allopathic and non-allopathic private providers. Private providers who managed patients of TB in their clinics and were cooperative were included. Fifty-nine rural private practitioners were interviewed from a total of 168 who were listed and contacted in 10 village towns.

Adult patients newly diagnosed as cases of lung tuberculosis and being managed in the clinics of practicing private providers were recruited. The private doctors' diagnosis of TB was assumed to be correct. A rural sample of 100 patients was drawn from 59 private practitioners spread over 10 village towns, while 73 patients from 31 urban private providers were recruited for the study. The patients were followed prospectively at intervals of two months for 12 months.

The assumption that villages have few resident private doctors is debatable. A survey of rural doctors in 300 villages of Uttar Pradesh found private allopathic doctors in 37% of the villages with population less than 2,000. Eighty-one of the villages with population more than 2,000 were found to have private providers (34). It is likely that rural patients would first seek relief from symptoms at the nearest available provider who would typically be the village doctor, qualified or otherwise. As such the survey might not have captured some of the initial care seeking behaviour.

11. The National Council for Applied Economic Research (NCAER) conducted a household survey of health care utilisation and expenditure covering all the states and union territories of the country except Manipur, Mizoram, Nagaland, Sikkim, Tripura, Andaman and Nicobar Islands, Lakshadweep and Jammu and Kashmir (12). The study used a multistage stratified sample design. In all 18,693 households were selected of which 12,339 were from the urban areas and the remaining 6,354 from the rural areas. The survey was carried out during the summer months of May-June 1993 and a recall period of one month was used.

12. A study was conducted at the New Delhi TB center to analyse the care seeking pattern between appearance of symptoms and diagnosis (15). The study covered 256 cases of respiratory TB, newly diagnosed during 1986 and reporting at the New Delhi TB center.
13. A 1993-94 study explored the health-seeking behaviour of poor patients in Bombay (16). Sixteen patients attending a TB clinic run by a NGO in a Bombay slum were interviewed in-depth. While the sample size is small and hence the findings cannot be generalised, the interviews yielded qualitatively useful information especially on the influence of gender on care seeking behaviour.

14. The case holding and treatment failures in a TB clinic operating in a rural area of the 24 Parganas district of West Bengal were examined to identify the underlying causes (19). Nine hundred ninety-six cases of TB, all the patients diagnosed and placed on treatment at the rural clinic between 1st January, 1986 and 28th February, 1987 were included in the study. One hundred fourteen patients from the project area had failed to complete treatment and were interviewed to find out the reasons for dropping out. It is important to note that the project area cases receive free treatment, and get home visits and counseling in the event of default.

15. A study of default during treatment was carried out at the Kasurba TB clinic in Lucknow (20). The treatment cards of 400 cases of pulmonary TB inducted during a period of one year were analysed. This clinic is a peripheral unit of the Government TB clinic, Lucknow. The clinic has a defaulter retrieval mechanism in place. The researchers managed to interrogate 112 defaulters while they failed to trace 82 cases. The study findings were published in 1977.

16. Tuberculosis Research Center, Madras conducted a retrospective study of 60 noncompliant patients who had received less than 75% of the prescribed treatment (21). The study aimed to find out the reasons for their default. These patients were from among a group of 2,332 patients admitted to three different short course chemotherapy studies conducted during 1975-85. TRC has very stringent criteria for selection of patients for their studies, a system of motivation for their patients and effective defaulter retrieval. As such, these 60 defaulters represent special cases who could not be kept on treatment despite the best efforts of TRC.

17. A study of defaulters was carried out at the TB Demonstration and Training Center, Agra from July 1973 to December 1973 (22). A defaulter was defined as a TB patient who had a discontinuity of more than a month in his treatment schedule. An equal number of control cases were taken from among the regular patients. Defaulter and non-defaulters numbering 150 each, were drawn randomly from the daily attendance of the clinic where patients came to collect their monthly quota of drugs.

18. A study attempted to identify the factors responsible for noncompliance among TB patients in Wardha District in 1988-89 (23). Fifty-two compliant and 50 noncompliant patients were interviewed and the two groups were compared to determine which socio-economic and health belief factors could be responsible for the difference in behaviour. This study was a part of a tuberculosis control programme using short term biweekly chemotherapy which was carried out by the Mahatma Gandhi Institute of Medical Sciences, Wardha. The overall compliance rate among patients in this field trial was 80% as compared to an estimated 35% in the rest of the country. Thus this study is useful in highlighting the critical factors related to treatment nonadherence.

19. A survey was carried out in Bispapur Block I and II in the South 24 Parganas district of West Bengal. The objectives were to evaluate the general knowledge and awareness about TB and also to examine the prevalent social attitudes (24). The researchers are attached to a NGO working in the area and they interviewed 213 people from five villages in the project area, picked at random. They also selected three villages at random outside the project area and interviewed 50 people at random. In addition, they interviewed 60 patients (30 newly diagnosed and 30 who had been on treatment for six months or more) from the patients attending the NGO clinic. The survey findings were published in 1988.

20. A survey was carried out to test the awareness of tuberculosis among the general population in and around Jaipur city (25). A total of 1,000 persons from different walks of life were interviewed during the period January-June 1986.

21. A study of the drug prescription and self medication patterns in India was conducted in 1994 (29). Data was collected on prescription to 600 patients at the out-patient departments of large urban hospitals in Calcutta, Delhi, Bangalore, Trivandrum and Vellore. Six hundred patients were also followed at rural PHCs which were all connected to the large referral hospitals mentioned above. Twenty-six private practitioners and 12 pharmacies were randomly selected in Calcutta, Trivandrum, Delhi, Bangalore, Vellore, Ahmedabad, Patna, Hyderabad and Mussorie. Prescription patterns as well as the over the counter sales without prescription were observed. Six hundred patients each were followed at the private practitioner clinics and at the pharmacies.

22. A study was carried out in an urban TB clinic in 1992. It involved in-depth interviews of 60 patients of TB registered with one of the Area TB Clinics (ATC) under the City TB Programme (CTP) in Bombay city (30).
23. A survey of 488 private doctors in 300 villages was conducted by a team of researchers from The Urban Institute and Indian Market Research Bureau in May-June 1992 (34). Private doctors were identified in a novel fashion. Rural women were approached and asked to name the doctor they went to when they were ill. The villages were randomly selected from the five distinct socio-cultural regions of Uttar Pradesh—Uttarkhand, Rohilkhand, Brij, Oudh and Bhojpur.

Appendix 2:
A model to explain the initial preferences and eventual private/public distribution of TB patients

A model reconciling the public/private distribution of newly incident and prevalent TB cases

\[
\begin{align*}
\text{Patients} & \xrightarrow{r} R \xrightarrow{\lambda_1} \text{Losses from death, cure or default} \\
& \xrightarrow{\tau} U \xrightarrow{\lambda_2} \text{Losses from death, cure or default}
\end{align*}
\]

- \( r \): proportion of incident cases first going to private providers
- \( 1-r \): proportion of incident cases first going to public providers
- \( \tau \): rate of transfer from private to public
- \( \phi \): rate of transfer from public to private
- \( U \): stock of patients in the public sector
- \( R \): stock of patients in the private sector
- \( \lambda_1 \): Rate of losses from private sector due to death and cure and default
- \( \lambda_2 \): Rate of losses from public sector due to death and cure and default

Formally at equilibrium (steady state):
\[
U/R = (r + \lambda_1(1-r))/((\lambda_2 + \phi)) \ldots \ldots 1
\]

The left hand side of the above equation represents a ratio of stocks (prevalent cases) while the right hand side represents flows (incident cases).

We can simplify this equation by assuming that \( \phi \) is small and, treatment outcomes in the private and the public sectors are similar i.e. \( \lambda_1 = \lambda_2 = \lambda \).

We get, \( U/R = (r + \lambda(1-r))/((\lambda + \tau)) \ldots \ldots 2 \)

Now we can try to reconcile the two independent estimates of the public/private distribution of prevalent and newly incident cases in Maharashtra.

We know from the cross-sectional National Sample Survey (NSS, 9) that about two-thirds of the TB cases were being treated in the public sector.

Thus, \( U/R = 2 \)

Surveys in Bombay and Pune (11) indicate that roughly 70% of the first contacts of TB patients are with private providers i.e. \( r = 0.7 \).

Substituting for \( U/R \) and \( r \) in equation 2,
\[
1.1 \lambda = \tau
\]

Thus if patients in the private sector are at least as likely to switch to the public sector as they are to stopping treatment due to default, death or cure, then the independent estimates of public/private distribution among newly incident and prevalent TB cases respectively, are consistent.

Appendix 3:
Proportion of prevalent TB cases being treated as inpatients in hospitals

The National Sample Survey (1987) reported the following distribution of TB cases under treatment:

<table>
<thead>
<tr>
<th>State</th>
<th>In hospital for TB treatment (during preceding 365 days)</th>
<th>Treated outside a hospital (during preceding 30 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td>72</td>
<td>59</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>89</td>
<td>88</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>78</td>
<td>58</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>113</td>
<td>201</td>
</tr>
<tr>
<td>West Bengal</td>
<td>62</td>
<td>43</td>
</tr>
</tbody>
</table>
Thus the survey found that a total of 414 cases of TB had undergone treatment in a hospital at some point in the 365 days preceding the survey, while 449 TB patients had reported outpatient treatment in the 30 days preceding the survey. It is possible to estimate the approximate proportion of TB cases in hospital for treatment.

Percent in hospital for treatment = 
\[ \frac{414}{449} \times \frac{30}{365} \times 100 = 7.5\% \]

About 7 to 8% of the TB cases under treatment at any given time in India are being treated in a hospital.

Appendix 4:
Aggregate private out-of-pocket expenditure on private TB treatment in India

1. The National Sample Survey provides cross-sectional data on the treatment expenses incurred by households during the 30 days preceding the survey (9). For non-hospitalised cases of TB being treated by private providers, the treatment expense data is summarised below.

Average total payment for outpatient TB treatment in the private sector (Rupees at 1986-87 prices)

<table>
<thead>
<tr>
<th>State</th>
<th>Rural</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gujarat</td>
<td>198</td>
<td>176</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>287</td>
<td>185</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>120</td>
<td>76</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>307</td>
<td>242</td>
</tr>
<tr>
<td>West Bengal</td>
<td>212</td>
<td>2,107*</td>
</tr>
</tbody>
</table>

* outlier, disregarded

Based on the above, average payment per month for TB treatment in the private sector has been assumed to be RS 200. Adjusted for inflation (10% p.a.) this amounts to RS 472 per month at current (1996) prices.

2. The prevalence of TB in India by the 1993 NCAER survey has been estimated at 422 per 100,000 (12). Thus there are roughly 4 million (3.8 million) cases of TB in India.

3. Data from the National Sample Survey indicates that approximately 50% of the prevalent TB cases are in the care of private providers, at any given time.

Hence, the aggregate annual expenditure on private sector TB treatment is estimated at:

\[ \text{RS } 472 \times 12 \text{ months} \times 1,900,000 \text{ TB patients} = \text{RS } 10,760 \text{ million} \]

\[ \text{(USD } 300 \text{ million per year)} \]

It is likely that many prevalent cases are not under any form of treatment (default etc.). Even if we assume that just half of the private sector cases are spending on TB treatment at any given time, out-of-pocket expenditure on private sector TB treatment in India would be approximately USD 150 million per year.

List of Abbreviations

ATC  Area Tuberculosis Clinic
BRAC Bangladesh Rural Advancement Committee
CPC  Consumer Protection Council
CTP  City Tuberculosis Programme
DOTS Directly Observed Treatment, Short-course
DTC District Tuberculosis Center
DTP  District Tuberculosis Programme
GDP  Gross Domestic Product
IMA  Indian Medical Association
ISM  Indigenous System of Medicine
NCAER National Council of Applied Economic Research
NGO  Non-government Organisation (PVO)
NSS  National Sample Survey
NTI  National Tuberculosis Institute, Bangalore
NTP  National Tuberculosis Programme
PFC Primary Health Center (government-run)
PVO  Private Voluntary Organisation (NGO)
RS  Indian Rupees
SCC  Short-course Chemotherapy
STD  Sexually Transmitted Disease
TB  Tuberculosis
TRC  Tuberculosis Research Center, Madras
WHO World Health Organisation
UP  Uttar Pradesh
USD United States Dollars
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Authors:
Vikram Pahlawan, Joel Almeida, Arata Kochi
Creative Director:
Victoria Bracewell Short
Design:
Winge & Associates, Inc., Chicago, Illinois, USA
Printer:
French-Bray, USA
Photographer:
© 1997, Jim Erickson, USA

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