

# **Vulnerable patients and the Public-Private Mix in tuberculosis**

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## Summary

Tuberculosis is a major cause of suffering and death affecting mostly the poor and disadvantaged in resource-poor countries. The majority of sufferers are not currently accessing public TB control programmes and are unlikely to do so in the future without major changes to social conditions and the programmes themselves. There are suggestions that a significant number of persons with active TB do not access any appropriate services. Private providers (PPs) are the main source of treatment for many TB sufferers, but there is evidence that the care they offer is often substandard. Public-Private Mix (PPM) DOTS represents an opportunity for extending the coverage of TB control programmes and improving the case management of TB by PPs by collaboration between public health services and PPs.

Looking at the most vulnerable groups by applying what is known or may be inferred about involving PPs in TB care, it would appear that there are likely to be net benefits for some vulnerable groups, such as the urban poor, from PPM DOTS, though each project will need to be evaluated according to the agreements made between the public sector and PPs, the capacity of countries to adequately monitor and regulate PPs and the individual circumstances of the project's area of influence. Some of the problems with PPM DOTS are more concerned with the acceptability to patients of directly observed treatment (DOT) than the private-for-profit aspect and the supervisory and regulatory capacities of the public sectors of resource poor countries will need to be strengthened in order for the implementation of PPM DOTS to be successful.

The size of the gains from PPM DOTS are yet to be seen and may turn out to be small and costly and the difficulties of implementation in resource-poor settings large. This is not a particular criticism of PPM DOTS - it is unlikely that any strategy, or combination of strategies, focusing solely on disease control will succeed in alleviating the burden of TB for the most vulnerable people. For that, multi-sectoral action, and a recognition that most of the countries where TB presents a significant problem will need greater resources in health, environmental and social care than they currently possess, is essential.

Overall, therefore, PPM DOTS should be welcomed as an initiative aimed at supporting expansion of DOTS. It should not, however, be seen as the over-arching solution to the current case-detection challenge faced by TB control globally. In addition the needs of vulnerable patients should be considered carefully as more and more PPM DOTS pilots are implemented and evaluated in different settings.

## **List of abbreviations used**

DOTS	Preferred strategy of WHO and IUATLD for tuberculosis control
HIV	Human Immuno-deficiency Virus
IUALTD	International Union Against Tuberculosis and Lung Disease
MDG	Millennium Development Goals
PP	Private provider
PPM	Public-private mix
TB	Tuberculosis
VHA	Vulnerability and Health Alliance
WHO	World Health Organisation

## Introduction

Tuberculosis (TB) is primarily a disease of poverty and overcrowding (and is increasingly associated with HIV) and its effects are felt disproportionately by the most vulnerable (Zumla and Grange, 1998). Eight to nine million new cases of tuberculosis occur in the world each year and nearly two million deaths due to this disease (WHO, 2002b). Most cases occur in middle and low income countries - the highest rates per head of population are in Sub-Saharan Africa, but the largest numbers of cases are in Asia, especially India and China (Trebucq, 2003). Tuberculosis is seen by international agencies as a major threat to human health and livelihoods and the reduction of the incidence of TB is hence included as a priority in the Millennium Development Goals (MDG, 2003). Tuberculosis is the leading cause of preventable illness worldwide and is thought to be more prevalent now than ever before (Gandy and Zumla, 2002). The modelling of TB carried out by Murphy and others (2003) suggests that strategies as they currently exist in developing countries are not going to be effective in significantly reducing the global burden of TB.

DOTS is currently the strategy favoured by the World Health Organisation (WHO) to control TB (WHO, 2002a). In 2001, only 45% of the estimated 8.5 million new tuberculosis cases were being notified to the WHO (WHO, 2002) and 29% of all estimated new cases were notified under DOTS. Analysing current trends, Dye and others (2003), predict that case detection rates (of tuberculosis sufferers with smear positive sputum) will stabilise around 40%, assuming that the case detection rate accelerates between 2001 and 2005. This outcome is likely to be similar in both high and low TB burden countries. If the assumed prevalence figures are reasonably accurate, then most TB sufferers are evidently either using non-public health services, or are unable to access any services.

Increasing coverage of tuberculosis sufferers with effective therapies is clearly vital and one possible step towards achieving this is through collaboration with private providers, who treat large numbers of TB sufferers. Public-Private Mix (PPM) DOTS is an initiative of the WHO to support the development of programmes of collaboration between public and private health sectors in the control of TB (WHO, 2003). This work is at an early stage, but initial feasibility studies have been carried out (Arora and others, 2002; CHRDMAAS, 2002; Mwaniki and others, 2002; Quy and others, 2002) which suggest that such an approach may be potentially useful. The questions which will be addressed here are: what effects on the most vulnerable people with TB may be expected from this approach; where do we lack knowledge; and how should PPM DOTS be designed and implemented in order to have maximum impact for vulnerable people with TB.

The Vulnerability Framework, developed by the Vulnerability and Health Alliance (VHA) at the Liverpool School of tropical Medicine (LSTM) is used as a basis for analysing the literature in this case study. In the framework, vulnerability is defined as, '*a set of factors that result in a reduction in well-being (decreased quality of life, increased morbidity/mortality) associated with infections such as malaria, TB and HIV*' (VHA, unpublished). This paper is an attempt to identify the potential effects of PPM DOTS on these factors and hence on the people most vulnerable to TB. It looks briefly at the Vulnerability framework and outlines PPM DOTS, before applying the framework to relevant knowledge. In the three main sections, the evidence will be presented according to the three levels of the Vulnerability Framework and important issues highlighted. Each of these sections will begin with relevant information summarised from earlier work done by the VHA on TB. The specific questions will be addressed in the discussion following this, case studies of public private collaboration are described and the findings discussed. Conclusions and general recommendations follow.

## Vulnerability perspective

The vulnerability framework developed at Liverpool School of Tropical Medicine\* aims to embrace a range of analytical lenses, such as poverty and gender analysis, which are sometimes applied in isolation. However it also focuses on the biological factors, such as age, sex, genetics and immunity that influence which individuals are affected within these social fault lines. Factors affecting vulnerability are categorised as shown below:

### **Vulnerability framework**

#### ***Individual level: biological and disease related factors***

Age, sex, immunity, genetics, interactions with other diseases

#### ***Household and community levels: social and economic factors***

Socio-economic status / poverty, nutritional status, livelihoods, gender, illness conceptualisation, education, religion, social exclusion, drug/alcohol use

#### ***Meso/Macro levels: environmental and institutional factors***

Physical / geographical, health services and policy, drug resistance, development policy

The *strength* of such a holistic and multi-disciplinary approach is that it provides a broad and inclusive framework for understanding the multiplicity of factors affecting vulnerability and it can be applied to individual diseases or groups of diseases. The framework can be used to identify potential links between different sectors and disciplines that are not apparent when a problem is viewed from a single perspective. It also provides a practical 'checklist' to make sure that important aspects of disease vulnerability are not overlooked.

With such a broad framework it may be easy to lose focus on priorities. Despite the breadth of the framework there may also still be gaps. In particular, emotional and psychological aspects of vulnerability may need more emphasis.

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\* The Vulnerability and Health Alliance which developed the framework is an interdisciplinary working group of LSTM staff with an interest in identifying and reaching groups who are particularly vulnerable in relation to infectious disease, with a focus on HIV/AIDS/STIs, malaria and tuberculosis. The work of the group has been supported by the UK Department for International Development (DFID) funded EQUI-TB, HIV/AIDS/STIs and Malaria Knowledge Programmes, together with the Malaria Consortium. More information can be found on the web pages at: <http://www.liv.ac.uk/lstm/vha.htm>.

## **PPM DOTS and vulnerable patients**

The Vulnerability Framework is primarily designed to identify which people are most vulnerable to a particular infectious disease, in this case TB. Since we are dealing here with health services, it would make little sense to use a vulnerability perspective to pinpoint those most at risk of TB as we are starting with the people who have already contracted TB. The point, then, is to use the framework to identify what opportunities and threats Public Private Mix represents for those people with TB who are most disadvantaged, and thus vulnerable in a more general sense. This leads to recommendations to guide the implementation of PPM which will help to promote the welfare of vulnerable people with TB.

There are currently few examples of Public Private Mix DOTS initiatives, and those which exist are mostly designed to assess the *feasibility* of collaboration between public and private providers in TB control. They therefore provide little information about impacts on vulnerable groups and so evidence needs to be sought from other sources. This will necessarily mean that judgements are generally speculative.

## Individual level: Biological and disease related factors

### Age and TB

Although TB principally affects people in the economically active age group (15-59 years), it is also an important cause of mortality for children. Furthermore, it is thought that the incidence of childhood TB is underestimated (by half or more) in official figures. Children with TB are neglected by health services, which concentrate on adults. Young children also carry the highest risk of developing disease after infection with *M. tuberculosis*.

### Sex and TB

Active case finding in several population-based studies from the 1960-80s show a male: female ratio that ranges between 1.2-4. Studies have found an equal prevalence of TB infection among boys and girls until the age of 15 years, after which the prevalence amongst males begins to exceed that amongst females. There are suggestions of a higher rate of progression from infection to disease among women than men and indications of an increased risk of development of disease for women during the post-partum period. New infections of HIV/AIDS are now occurring disproportionately in women and this is likely to alter TB prevalence and epidemiology

### Association of TB with HIV infection

HIV infection is among the strongest influences in the progression of latent TB infection to active disease and developing TB is associated with an increased likelihood of death in those with HIV infection. Complications of TB in HIV infected people include increased frequency of side effects of drug treatment and increased rates of relapse and re-infection

*Summary of information collated in Tolhurst and others, unpublished overview*

Age plays a further role because older people are more likely to have been infected with TB in their younger years and are therefore vulnerable to re-activation (active disease) with the natural physiological decline of the immune system in advanced age. Children are a vulnerable group and PPM DOTS will not improve this situation unless greater emphasis is placed on the treatment of children under DOTS. TB control programmes which do not address this will at best leave a reservoir from which new sputum smear positive cases will emerge in the future.

Though biological sex clearly affects the proportions of men and women with active TB, the most important influences related to this are social and are thus considered in the next section, as Gender falls under the Household/community level in the VHA framework.

Quality of care (including the attitudes of health staff) for those co-infected with HIV will have important consequences. If treatment in a particular sector is not satisfactory for HIV aspects then those providers are unlikely to have good case-holding for these patients. There is as yet little indication of how this might affect TB control.

A number of genetic factors have been implicated in susceptibility and resistance to *M. tuberculosis* infection. PPM DOTS will not affect the genetic component of the disease. However, Murphy and others (2003) conclude from modelling that control of TB will be much more difficult in populations with a high proportion of genetically susceptible individuals and that more active case finding may be required than is currently encouraged under DOTS.

### Summary of points

- The issue of children with TB needs to be addressed
- There is a synergy between TB and HIV and the likely effect of this on PPM DOTS is unclear
- Active case finding may be necessary in some situations



## **Household/community level: socio-economic factors**

### **Poverty and TB**

The association between poverty and TB infection rates is well established and widespread, but the precise interactions between different aspects of poverty and the stages - vulnerability to infection, progression to disease, severe disease and mortality - are unclear. Identifying the relationship between poverty and TB infection is further complicated by the problems in defining poverty. The prevalence of TB is higher among poor countries and at a regional level, a positive relationship has been observed between the estimated incidence rate of sputum smear positive cases and the percentage of the population living below the poverty line.

Poverty is also associated with vulnerability to severe disease and death due to TB, especially through its effect on access to health care. Evidence is accumulating to suggest that the poor have greater difficulty overcoming barriers in accessing care and completing treatment than the less poor because they have fewer resources to use for direct costs, such as transport to health facilities and consultation fees, and indirect costs, such as childcare.

Delays in seeking treatment are longer amongst poor patients with a chronic cough, especially for poor female or aged people. Poverty is associated with low concordance with treatment, and therefore poor treatment outcomes. People constrained by the conditions of poverty who suffer from TB are more likely to default, especially between diagnosis, registration and completion of treatment. Poverty also leads to vulnerability to the negative effects of ill-health, such as further economic impoverishment.

### **Living conditions**

Poor living conditions are associated with vulnerability to infection with TB. The extent of overcrowding and lack of ventilation at home or in the workplace are factors in TB transmission - crowded institutions such as prisons, nursing homes, residential centres for HIV-infected persons and urban homeless centres are also sites for TB outbreaks.

### **Nutritional status**

Nutritional status is associated with vulnerability to progression from infection to TB disease. Associations have been established between nutritional status and immune response, particularly in regard to iron, vitamin D, and zinc deficiency.

### **Livelihoods**

Workers in industries where they are consistently exposed to dust are more at risk of developing TB. Suffering from TB affects the livelihoods of individuals and households. Daily wage based livelihoods, and occupations without sickness benefits or the possibility of flexible schedules are more likely to be disrupted by TB illness and treatment.

### **Illness conceptualisation**

TB is often perceived as a dangerous, infectious and incurable disease leading to stigmatisation and social isolation of TB patients and their families. Beliefs about TB are clearly affected by the quality of care available. Some traditional beliefs may contribute towards increased social isolation of TB sufferers and, related to this, delays in TB diagnosis.

### **Education**

Studies suggest that lack of education is associated with patient delays in seeking care for TB and with failure to complete treatment.

### **Age**

Age appears to interact with other factors such as income levels and education to produce vulnerability to severe disease. Old age may be associated with delays in seeking care for TB.

**Gender**

The extent to which differences in reported cases of TB between women and men reflect differences in prevalence or differences in access to healthcare remains unclear. There is evidence that gender does influence access to health care and therefore vulnerability to severe disease.

Perceptions of TB are affected by gender norms and stereotypes. The social and economic impact of being diagnosed with TB can differ for women and men of different ages and positions, affecting their vulnerability to effects of ill-health. Differences in anticipated impact of TB may translate into differences between women and men in seeking care and therefore vulnerability to severe disease.

Women and men often face different barriers to accessing care. Accessing and completing TB diagnosis and treatment is influenced by a complex interaction of contextual social, economic and institutional factors, which are all affected by gender. Women and men of different ages, marital and socio-economic status may have different vulnerabilities in relation to accessing care for TB. Gendered institutional norms and processes may also influence how women and men are treated by the health care system and therefore their vulnerability to severe disease.

**Social exclusion and marginalisation**

There is evidence that socially marginalized populations, such as the homeless, prisoners and the mentally ill, are particularly vulnerable to infection and to severe disease. Minority ethnicity is frequently a marker of marginalisation, and is associated with higher rates of TB. In addition, marginalised patients may receive poorer quality care in some contexts. Of itself, suffering with TB can contribute towards social marginalisation.

**Drug/alcohol use**

Both drug and alcohol use have been associated with an increased incidence of TB

*Summary of information collated in Tolhurst and others, unpublished overview*

Poverty is a very important and well recognised factor in TB. There is evidence that staff in some DOTS programmes select patients for DOT according to their perception of whether the patients are likely to default, in order to be able to report good treatment success rates (Balasubramaniam and others, 2000). In a study in India (Singh and others, 2002) the patients who were excluded were those in absolute poverty, who were socially marginalised, itinerant labourers or had reduced social contacts. The issue of stigmatization is critical in this context and the extent to which this occurs will vary significantly from place to place. Impoverished people with TB are doubly stigmatized, through their poverty and through having TB. Little is known about how successful PPs are at case holding with these particular groups relative to public services as they rarely maintain records (Uplekar and others, 2001a). Aspects of what advantages and disadvantages PPs have compared with public services generally are considered in the next section, under Health Services.

With passive case finding (as is usual in DOTS), a low proportion of women with TB are found, in contrast to active case finding where roughly equal numbers of men and women with TB are detected (Uplekar and others, 2001b). The factors which bring about this differential access have included self-image, status, access to resources, manifestation and expression of symptoms and the stigma of having TB. Once detected with TB, women are more likely to be adherent to therapy and be cured of TB than men. The ratio of male to female TB patients in the PPM project in Hyderabad (which was approaching 1:1) suggests that women find private more acceptable than public providers (Murthy and others, 2001), though the data do not in themselves tell us why this might be.

Brugha and Zwi (1998) summarise the findings on patients' preferences for private providers (see table, page 15) and possibly the relative importance of these factors varies according to gender. A study in Vietnam (Johansson and others, 2000) found that stigma, poor quality of services and staff attitudes had more negative effects on women than on men and so the

perception of superiority of PPs may be stronger for women. In Bombay, Nair and others (1997) found that female TB patients were more worried about social isolation (likely to occur through stigma) than their male counterparts. They also found that married men and single women had more social support during treatment than married women. The stigma of TB for women can mean increased economic vulnerability, especially where marriage is an important part of survival in resource poor communities (for example, see Khan and others, 2000). This stigma can affect families (with unmarriageable daughters) as well as the women themselves. There appears to be potential here for improved services to women, both through the use of more acceptable PPs and through improvements to public services using the lessons learned from PPs in this regard. This conclusion is a cautious one, however, and is further discussed in the next section.

Measurement of the equity of outcome of health care has proved difficult. The WHO emphasise equity of access in the indicators they use. Currently, these equity data are not sufficiently disaggregated to show whether equity by socio-economic status is equivalent to equity by gender. Reviewing different programmatic approaches to dealing with equity and gender issues, Standing (1997) observed that they frequently have outcomes which are not predictable and require investigation. This means that PPM projects can only be properly evaluated with an examination of their specific contractual requirements and their actual implementation in each individual context.

The impoverishment which can be caused by suffering from TB (through the negative effect on livelihoods) is not necessarily reversible through successful TB treatment alone. Sufferers may find themselves indebted and with reduced resources as a result of prolonged illness. Livelihoods may be lost or severely constrained. In so far as PPM DOTS can reduce negative impacts on livelihoods (through reducing the time from symptoms to cure - see next section) it will mitigate the effects for vulnerable people, though persons in these circumstances will often find it difficult to complete treatment.

State institutions such as prisons will vary from country to country in their capacity (and willingness) to collaborate with PPs in TB control. The improvement of conditions contributing to the spread of TB, in addition to treatment in prisons and workplaces is unlikely to be directly affected by PPs, but their involvement could potentially highlight such issues and provide extra impetus towards this. Any PPM DOTS projects in these areas will be highly dependant upon local political considerations and intersectoral collaboration.

#### **Summary of points**

- There is insufficient information about the case holding of vulnerable TB patients by PPs
- There is evidence that some of the most vulnerable TB patients are deliberately excluded from DOTS in some public programmes
- Stigma remains a large problem in TB control and in some circumstances PPs may be more acceptable to disadvantaged groups, for example women
- TB control programmes will need to be supplemented by broader poverty alleviation strategies in order to reduce the impact of the disease on vulnerable patients and their families
- Context is important in devising TB control strategies for and within countries

## **Meso/macro level: environmental and institutional factors**

### **Geographical location**

Segregation of groups of people may create geographic pockets where factors such as poverty, overcrowding and poor housing are more concentrated and therefore result in a higher spread of TB. Living in a rural area has been significantly associated with a higher risk of delays in seeking TB care in a number of contexts.

### **Drug resistance**

Multi-drug resistant (MDR) TB has been identified in over 100 countries and the incidence is rising.

### **Migration and complex emergencies**

Immigration rates are significantly correlated with TB mortality. TB always arises as a clinical management and control problem in the later stages of complex emergencies.

### **Policy**

Historical analyses of the trends in TB prevalence in industrialised countries have shown that tuberculosis started to decrease during the second half of the 19th century before the discovery of tubercle bacillus in 1882 and the subsequent widespread use of chemotherapy. It is therefore likely that such developments will have an important part to play in influencing the efforts to reduce TB prevalence in countries where it is currently high. Since chemotherapy became available for TB there have been no studies on the relationship between socio-economic development and TB prevalence. Such studies would enable an analysis of the relative contributions of TB control programmes and levels of socio-economic development to changes in TB incidence and prevalence.

### **Access to healthcare**

Lack of access to appropriate, good quality healthcare increases the vulnerability to severe disease for an individual suffering from disease, and also the vulnerability to infection for those living or working in close proximity to them. The currently recommended strategy for TB treatment - the DOTS strategy - is only available to around half the world's population and it is estimated that as many as half of all cases of active TB are not diagnosed. According to the WHO, at least 70% of cases need to be detected and 85% of these treated in order to make control effective.

Access to health care is affected by both 'demand side' and 'supply side' factors. 'Demand side' factors such as lack of resources and fear of social consequences have been discussed above. 'Supply side' factors include the geographical distribution of facilities, and staff, levels of formal and informal fees, and (perceptions of) the quality of care offered.

### **Quality of health care**

There are numerous examples of poor quality of TB services from around the world - this poor quality may be due to staff attitudes and lack of skilled human resources and equipment. Poor quality of health services leads to poor outcomes for patients and can reinforce the belief that TB is incurable.

Poor regulation of the private sector and poor co-ordination with the public sector are important factors influencing poor quality services and delays in diagnosis.

*Summary of information collated in Tolhurst and others, unpublished overview*

Population movements in developing countries are common, whether due to conflict, disasters or economic hardship and can reduce the ability of families and individuals to cope with the costs of illness through the weakening of kinship ties and geographic separation from normal sources of support. Migration due to economic hardship and drought is reducing TB treatment completion and cure rates in India (Anonymous, 2002). It is debatable to what extent people affected by these issues would be seen as potential defaulters by DOTS programmes (and therefore excluded). Patient held records may help in these situations.

In addition to the comments on policy by Tolhurst and others (above), some commentators have argued that many of these analyses ignore the historical context in which the improvements in living conditions for the poor came about, pointing to the campaigns for social justice and lobbying for welfare-oriented legislation which influenced the process (see, for example, Link and Phelan, 1995). Currently, there is little sign of effective, concerted lobbying by major organisations involved in TB control for improved social justice.

Adherence to therapy is a difficult area, but the main factors identified in TB control are outlined below:

**Compliance with therapy decreases with increases in:**

Poverty  
Cost to patient  
Travel time  
Unstable Social/family situation  
Poor living conditions  
Concurrent illnesses  
Substance abuse  
Mental health problems  
Lack of information  
Lack of family support  
Staff attitudes and behaviour  
Societal stigmatization of the disease

*from Pope and Chaisson, 2003*

By far the largest number of these are social factors which need to be addressed outside the remit of health services, though the relative influence of each factor may vary from place to place and action on a single factor may have a significant effect in some situations. Among the factors which can be influenced by health services is staff attitudes and behaviour and there are a number of studies which indicate that patients generally are choosing PPs partly because of better interaction with staff, suggesting that the presence of this factor may assist in case holding for PPs as well as attracting patients in the first instance.

Private providers are the first choice for allopathic health care for TB patients in many parts of the world - examples are India (Nair and others, 1997), Nigeria (Enwuru and others, 2002), Phillipines (Auer and others, 2000), Vietnam (Lönnroth and others, 2001). Traditional practitioners are also used extensively (especially by women) and are very diverse (Standing, 1997). Some of the reasons commonly identified for patient preference for private practitioners is given below:

**Reasons for preference for PPs**

Ease of access  
Shorter waiting times  
Longer or more flexible opening hours  
Better availability of staff and drugs  
Better staff-client relationships  
Greater confidentiality in stigmatising diseases

*from Brugha and Zwi, 1998*

This question is not straightforward, however. As Standing (1997) notes, the issue of choice is difficult to disentangle from socio-economic and cultural constraints. Poor and marginalised people will have fewer options and this is most likely to be true of women.

There is also some evidence that some patients choose PPs in preference to the public TB services because of the DOTS strategy (see below). It is not clear precisely which patient group this represents.

**Some characteristics of private TB care which seem attractive to patients which contrast sharply with the structure of the Vietnamese NTP strategy; Ho Chi Minh City**

Flexible diagnostic procedures

No administrative procedures to establish eligibility for treatment

Flexible choices of drug regimens

Non-supervised treatment (no DOT)

No tracing of defaulters in the household

No official registration of TB cases and thus less threat to personal integrity

The possibility to demand individualised service through the use of fee-for-service payments directly to physicians

*from Lönnroth and others, 2001*

Access to health care obviously depends on the availability of suitably trained staff. The public health sectors in developing countries are hemorrhaging qualified staff, both to the private sector and to developed countries (Martineau and others, 2002). Currently there is much overlap between the public and private sectors, that is, staff may work in both and public hospitals may have private beds or wards (Mills and others, 2002). If working practices change through PPM DOTS, what will the result be for general public services? The effects on vulnerable people will be negative if health workers are drawn away from public services without safeguards being built into welfare systems to ensure they can still afford to access care. Currently, it is not clear what effects PPM will have on staff allocation.

The delay experienced (by those patients who are diagnosed) between the development of symptoms and eventual diagnosis appears to have two different components: time from the onset of symptoms to contact with allopathic health services, and the time from contact to diagnosis. Here again, we have little data with which to form an opinion about the relative effects on vulnerable and less vulnerable groups. Reducing the health service delay (contact to diagnosis) would benefit all groups of patients, but potentially the improvement for vulnerable groups would be relatively greater as they stand to lose a larger portion of their incomes during the delay. The patient bears most of the costs from onset of symptoms to cure, even where treatment is provided free (Jaramillo, 1999).

**Factors in delay to treatment for TB**

Stigma/fear of social isolation

Poverty

Poor quality of health services

*Johansson and others, 2000*

A review by Uplekar and others (2001a) found that, generally, the delay from contact to diagnosis is longer than the delay from symptoms to contact. Without active case finding, the route by which patients enter care is usually the primary care services and until these are strengthened sufficiently, vulnerable patients will continue to suffer disproportionately. Work in Zambia suggests that different factors are at work in the two stages (Needham and others,

2001; Godfrey-Faussett and others, 2002; Needham and others, in press) and it is unclear whether these are universal or local factors. PPM DOTS has the potential to reduce the delay from contact to diagnosis through improved links and improved use of diagnostic facilities between public and private providers (Uplekar and others, 2001a).

Adherence is known to be a large problem in TB control, but more than half of all active TB cases are thought to go undiagnosed (even in countries where DOTS coverage approaches 100% of the population), so, while significant, poor patient adherence cannot currently be the main problem preventing adequate TB control (Farmer, 1997). Patient agency is limited by structure, that is, for the most vulnerable patients their capacity to act is constrained by their social position and the socio-economic problems of their communities (Link and Phelan, 1995). Farmer (1997) argues that in different contexts, different structural factors limiting patient behaviour may be significant (for example racism and poverty in one case, gender and poverty in another), but poverty is the overridingly important factor. Strategies with a biomedical focus which do not address social issues (such as DOTS and therefore PPM DOTS) are thus unlikely to succeed in completely controlling TB, though they may be very successful with individual patients, a conclusion also reached by Jaramillo (1999).

Health education of patients is an unclear area. In Nepal, Hurtig and others (2002) found that pharmaceutical companies selling anti-TB drugs to PPs were not interested in providing health education for patients. Generally, it is not something which PPs are good at (Uplekar and others, 2001a) and will need to be strongly promoted by the public service part of the PPM, though often health education in the public sector is inadequate.

In most cases, the poor quality of public health services has come about through political and economic processes, leaving them short of resources and staff. Many developing countries are faced with declining funding for public health services and increasing calls for privatisation and private sector involvement (Alubo, 2001). Public Private Mix DOTS implies greater control of PPs and increased resources for the public sector (M. Uplekar, private communication), which may improve the situation. The extent to which this can combat the poor quality is of necessity indeterminate as no examples yet exist.

The involvement of PPs in TB control will require intensive and extensive input (Caminero, 2003). The increased regulatory arrangements necessary to monitor PPs is likely to have cost implications, and a part of those costs will almost certainly need to be found from extra funding in the public sector. If these costs are passed on to patients then utilisation will probably fall. In the opinion of Brugha and Zwi (1998), low income countries currently lack the resources and capacity to enforce regulatory controls on the private sector. However, the benefits of this regulation should result in improved adherence of PPs to protocols and hence to cure rates. In some cases, it may be possible to improve treatment in the public sector if resources are improved through increased efficiency, as a side effect of increased resources involved in PPM DOTS or alternatively, if the burden on public services is reduced by PPM DOTS moving some patients into the private sector.

**Summary of points**

- TB control is linked to social justice
- PPs may offer more acceptable care, though in some cases vulnerable patients may be using them through *lack* of choice or poor quality of public services
- There is an opportunity for the public sector to learn from the PPs what they can do to make their services more acceptable
- In some cases, patients may be choosing PPs over public in order to avoid DOTS
- The effects on staffing and use of public health services need to be determined
- Better links between public and PPs can reduce the delay (and hopefully costs) experienced by vulnerable TB patients
- PPs are generally poor at health education, though public providers have often also been less than good
- If PPM DOTS brings increased resources (and/or reduces the burden on public services), this could have a positive effect on public services as well
- The increased regulatory needs may be beyond the capacity of some developing countries



## **Experiences with Public-Private Mix in TB so far**

### **General points**

The first four examples (Delhi, Pune, Nairobi, Ho Chi Minh City) are projects linked with the Stop TB working Group of the WHO. Their intent is to assess the feasibility of collaborations between public and private providers in TB control (M Uplekar, private communication). They are here described only briefly. The outcomes are very mixed, though it should be pointed out that most were at a very early stage when evaluated. The overriding factors for essential success seem to be a strong government sector and a capable mediating body between the public and private sectors. But it would appear that these will not guarantee success. The cost effectiveness of putting the same resources into the public sector has not been assessed and it is not possible to draw positive conclusions about the overall effect on the most vulnerable groups.

### **Delhi, India (urban)**

From Arora and others, 2002.

#### ***Description***

Three models of collaboration were tested in three areas of New Delhi: I - PPs referred suspected and diagnosed TB cases; II - private clinics provided sputum collection and DOT treatment services according to national TB treatment protocols; III - private clinics acted as diagnostic and treatment centres.

#### ***Results***

Model I was slow to start and was therefore not evaluated. Total yearly case detection rates (private + public) for model III increased by 131% compared with the year before the start of the project, the data was not analysed for model II. Cure rates for Model III were acceptable according to DOTS criteria (90%), but not for model II (61%). Approximately half of the sputum smear positive patients were not put on DOT by the PPs - reasons given by PPs and patients were: inconvenience; disbelief in effectiveness of the regimen (by patients); disbelief in the effectiveness of free government drugs (by patients); choice not offered to patients who the PPs feel are rich enough to pay for the drugs.

Costs for patients were not compared with the previous, wholly public, model. The most disadvantaged groups of patients did not enter DOT through the project. Models I and II catered mainly for people in the middle income group.

No cost analysis was made comparing the effectiveness of the project with a similar input of resources into the public sector.

#### ***Observations by the paper authors***

Sufficient managerial and training capacity in the government sector is essential.

An intensive, ongoing mutual exchange and learning programme between the public and private stakeholders was and is necessary for the continuation and development of the programme.

### **Pune, India (rural)**

From CHRDMAAS, 2002.

### ***Description***

PPs were able to refer suspected TB patients to government centres for diagnosis and management and acted as DOT centres. The project was initially for one year.

### ***Results***

No change in total yearly case detection rates (private + public) were detected as a result of the project, suggesting that the 51 cases (out of a total of 449) referred by the PPs may have found their way into the government system. PPs appeared willing and interested in the issue of TB control. By the end of the project, a cumulative total of 30 PPs were referring patients and 7 were acting as DOT providers, out of a total of 113 PPs approached. The outcome of three cases was available by the end of the project period. Two had been cured and the other had completed treatment. Under pressure from the public providers, two PPs had falsified referral records for cases which they had not referred. No assessment was made of the socio-demographic characteristics of the patients.

### ***Observations by the paper authors***

The PPs and public sector both tended to use the project staff as intermediaries, despite the intention that communication would be direct.

Relevant government staff need to be involved and motivated from the beginning of a PPM project.

## **Nairobi**

From Mwaniki and others, 2002.

### ***Description***

Eight private chest physicians were recruited to treat TB patients according to national guidelines, but providing subsidised drugs at a set cost (KSH 4800 = US\$ 64, excluding consultation and diagnosis), to be paid in advance by the patient. Normal equivalent drug costs available privately would cost KSH 30000 - 36000. The scheme began in November 2000 and was evaluated in October 2001.

### ***Results***

110 patients were registered under the scheme. Cure rates were 84% for patients being treated under PPM compared with 70% among other private TB patients. Example costs were around KSH 17900 per patient for the PPM patients and KSH 7300 for patients treated in the public sector. Because of slow uptake of the project amongst PPs, the revenue generated from the drugs had not reached a level where it could become self-sustaining. The patients in PPM appeared to be from middle and high income groups.

### ***Observations by the paper authors***

The model used may free capacity in the public sector by moving some patients into the private sector.

Drug costs for the patients should be kept as low as possible.

## **Ho Chi Minh City**

From Quy and others, 2002.

### ***Description***

PPs were involved in referral, diagnosis, and treatment of people with TB. An evaluation was carried out after 12 months.

### ***Results***

335 out of 508 PPs (physicians and pharmacies) in the area participated. There was an increase of 17% in the detection of sputum smear positive cases compared to other areas of Ho Chi Minh City. The cure rate in cases treated by PPs was 7.9% and the default rate of sputum positive cases was 42%. Initial default rate for sputum positive cases referred by PPs was 58%. DOT was not used by the PPs, defaulter tracing was not carried out and health education was limited. Patients financed the private treatment out of pocket - only 40% were aware that treatment in the public sector was free.

### ***Observations by the paper authors***

More effective control over diagnostic procedures and case management is needed, requiring additional resources for the public national TB programme.

## **Hyderabad**

From Murthy and others, 2001.

### ***Description***

A non profit hospital provided diagnostic facilities and supervision to PPs, who referred suspected TB patients. A number of the PPs also functioned as DOT centres. There was no cost to the patient after initial consultation.

### ***Results***

Case detection increased fourfold in three years of the project. The cure rate for sputum positives was 90%. Patients paid less for diagnosis (\$5 vs \$20) and for treatment (\$1 vs \$11) compared to patients in the public sector, mostly due to reduced transport costs. The proportion of female patients was higher than that of neighbouring government TB services.

### ***Observations by the paper authors***

The non-profit hospital served as a useful intermediary between the government TB programme and the PPs.

Clearly defined roles and frequent communication were essential for success.

## **Kathmandu**

From Hurtig and others, 2002.

### ***Description***

PPs in a rural area could refer patients for diagnosis and treatment to a Non-Governmental Organisation and were encouraged to monitor the progress of their patients.

### ***Results***

Links with PPs were informal and sporadic. Most PPs did not want to comply with a uniform system of referrals or recording. No suspected pulmonary TB patients were referred by the PPs for diagnosis. There was no increase in registration of TB patients compared with the period before the project. 39 of the patients (8.6 %) were referred for treatment by the PPs.

### ***Observations by the paper authors***

There was a lack of human resources and managerial capacity in the government TB programme to sustain the collaboration. The institutional capacity at a local level was insufficient to form working relationships with the PPs. Any linkage between private and public sectors in Nepal would require a mediating body such as a Non-Governmental Organisation.

## Discussion

Vulnerable people with TB can potentially be reached in two broad ways, universal coverage or targeting. There are different implications for equity - findings from a review are shown below:

### **Targeting and universal coverage to reach vulnerable people with TB**

#### ***Targeted programmes***

may be difficult to administer

may be stigmatising

can be inappropriate as the only response (for example it would be pointless to provide TB treatment only to people who have less than a certain level of income, though it may be possible to provide *extra* services in certain localities)

often effective

#### ***Universal coverage***

potentially provides equal service quality to all groups

vulnerable people are harder to reach and programmes may lose momentum, producing greater inequalities

*(from Victora and others, 2003)*

There are essentially two issues to be considered - case detection and treatment. Approaches can of course be combined. In the case of TB, there needs to be universal coverage because there will not be control without it. But targeting could be a strategy for finding the most appropriate measures of treating the most vulnerable people. As part of a drive to increased coverage PPM DOTS has the potential to provide equitable outcomes, but this needs to be part of a concerted effort of TB programmes to reach all groups. Will PPM DOTS encourage the identification of all people with TB disease? Since active outreach has never been incorporated into the DOTS framework this is unlikely. It is probable that vulnerable people, especially women, are the least likely to present voluntarily. Although a general improvement in the clinical ability and practices of PPs in dealing with suspected and confirmed TB cases, as well as the possibility that some of the most vulnerable people will find PPs more acceptable, will increase case detection to a degree, PPM DOTS by itself is unlikely to resolve this problem.

Treatment of TB patients can take place in a vertical, targeted program, a public general service or in the private sector. The way in which options for treatment are presented to patients at the time of diagnosis is clearly important. There is a need for systems to offer the flexibility to suit all patient groups and for incentives to be provided for PPs to present a balanced view of treatment options.

The issue of profit for PPs and how this is managed within individual PPM DOTS projects will have a large impact. What will the physicians have to gain from directing patients to private care apart from benefits gained from participating in a TB programme? Will it undermine patient confidence in public treatment and strengthen the move to commodify health services within the dynamic of another supply/demand framework? The desire of private physicians to protect their profits (which is often framed as personal need or "protecting the interests of their patients") and their autonomy and traditional role in many societies as authority figures worthy of deference and respect will to be a strong influence on the shape of PPM DOTS projects.

## Conclusions

Public health services of developing countries are operating with limited levels of funding and face continuing crises, particularly in relation to human resources. Implementing DOTS, which is about finding and treating TB cases, in this context is a challenge. In addition, as Uplekar and others (2001a) point out, the continued growth of the private sector with current TB treatment problems will reduce the effectiveness of TB control programmes. The issue of alternative responses to this situation is an important one, but here only PPM DOTS has been considered. As a component of a strategy addressing the needs of vulnerable people globally it has certain things to offer the most vulnerable people with TB. PPM DOTS offers the possibility of improving the situation in the following ways:

- ❖ The urban poor are likely to be helped to some extent with better coverage;
- ❖ Better treatment outcomes for patients in the private sector through improved diagnostic and prescribing practices of PPs;
- ❖ With the identification of factors important in people's preference for PPs some lessons may be applied in public sector with corresponding increase in acceptability/utilisation;
- ❖ There is an opportunity for strengthening these same public health services by bringing in extra resources and improved management practices through PPM;
- ❖ There is a synergy between TB and HIV. Quality of care (including attitudes) for those co-infected with HIV will have important consequences. If treatment is not satisfactory for HIV aspects then PPs unlikely to have good case-holding for these patients.
- ❖ Compliance with therapy is a difficult area. Economic factors and social support can have a significant effect on treatment adherence. Some of the negative factors may be offset by using PPs who are often perceived to have better attitudes and behaviour and by reducing the travel and opportunity costs through improved linkages in diagnosis and referrals for treatment. Reducing costs in this way will potentially benefit the most vulnerable people proportionately more than others.

There are also a number of problems and unknowns:

- ❖ The rural poor remain difficult to reach. PPs are reluctant to provide services in rural areas - will the incentives needed to tempt PPs into rural areas be more costly than provision of public services? There are a lot of Traditional Practitioners in rural areas and if PPM is to extend into rural areas then partnerships with these practitioners need to be explored;
- ❖ Some of the factors with which patients explain their preference for PPs may be incompatible with National TB Programmes policies and the implementation of these policies by PPs may cause some patients to avoid the programmes. It is not clear which patients these are likely to be - the poor? women? others?. No study shows clear socio-economic differences between those who utilise PPs and those who do not, at least not in the initial phases of health seeking.
- ❖ Increased regulatory requirements are likely to increase costs for the public sector and there is a risk that this may divert funds from other programmes and diminish the resources available for developing already weak health systems.

Overall, therefore, PPM DOTS should be welcomed as an initiative aimed at supporting expansion of DOTS. It should not, however, be seen as the over-arching solution to the current case-detection challenge faced by TB control globally. In addition the needs of vulnerable patients should be considered carefully as more and more PPM DOTS pilots are implemented and evaluated in different settings.

# Recommendations

## Implementation

- ❖ Data on case-finding and treatment outcomes In PPM DOTS pilots should be disaggregated to show differences by sex, age and social classification (this last point is likely to prove extremely difficult).
- ❖ Context is an important factor in individual situations. Innovation based on local knowledge rather than global templates should provide the basis for PPM DOTS projects.
- ❖ Countries implementing PPM DOTS should ensure that they have a strong regulatory framework and the capacity to enforce it. Funding agencies should factor the recurrent costs of providing this regulation into the cost of supporting PPM DOTS where governments are currently unable to do so themselves.
- ❖ Incentives may be needed to ensure PPs give education about TB

## Research needed

- ❖ Factors affecting choice of provider have been discovered, but are generally retrospective. Theories of how to improve access and acceptability for vulnerable groups, especially poor women, need to be formulated and tested. In doing this, wider social forces affecting personal behaviour need to be acknowledged.
- ❖ The effects of PPM DOTS projects on vulnerable groups needs to be investigated.
- ❖ An economic analysis of the costs of PPM, including the potentially unintended costs to public sector institutions would be very useful, with a comparison of the effects of allocating the necessary extra resources solely to public sector TB control programmes.

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