

## Editorial: Delays to tuberculosis treatment: shall we continue to blame the victim?

M. L. Lambert and P. Van der Stuyft

*Department of Public Health, Unit of Epidemiology and Disease Control, Institute of Tropical Medicine, Antwerp, Belgium*

**keywords** tuberculosis, tuberculosis control, treatment delay, health services, health education

Delayed diagnosis and treatment of pulmonary tuberculosis (PTB) entail increased transmission, since patients are contagious until effective chemotherapy is started (Rieder 1999). Health education on 'TB signs and symptoms' is often advocated in order to reduce delays and increase case detection, under the hypothesis that 'lack of knowledge about TB' determines care seeking among patients. The only published literature review on the subject of delays to TB treatment is based on qualitative studies (Thomas 2002) and concludes that 'the main reasons for delayed presentation of TB are a lack of understanding about TB, the stigma associated with the disease, the inaccessibility of treatment, and a preference for private practitioners' (in that order). Quantitative studies to measure delays to TB treatment rely on interviews of diagnosed patients. Of 13 such studies, published between 1995 and 2004 in the *International Journal of Tuberculosis and Lung Diseases*, a leading journal in the field of tuberculosis, 10 include 'improving awareness of TB in the community' amongst their recommendations for reducing long delays to TB treatment. Does patients' 'lack of knowledge of TB' indeed substantially contribute to long delays to TB treatment, compared to other factors, and should 'awareness of the disease be increased in the community', for more effective and successful tuberculosis control? The evidence for this is actually rather weak.

The TB control strategy currently promoted by WHO in high prevalence countries is to identify tuberculosis cases among people with symptoms (most importantly, prolonged cough) attending general health services (WHO 2003). The unchallenged assumption behind this approach is that symptoms of TB are so severe that cases will seek treatment soon after they develop (Newell 2002). From a TB control point of view, the target for patient delay – the time from the onset of symptoms to the first contact with a qualified health provider – is 2 or 3 weeks. Not only patient factors, but also health services factors, such as accessibility or quality of services, can contribute to patient delay. As for provider delay – the time elapsed from a first contact to the start of treatment – it could in theory be only a few days, if a sputum test is requested and processed in

due time for all eligible patients. In an ideal world, total delay to TB treatment (the sum of patient and provider delay) would hence be no more than 3–4 weeks for the majority of smear-positive TB patients.

Reported delays to TB treatment vary widely across studies, and are mainly meaningful in their own context. Differences in study methods, not least the definition of health care provider, also preclude comparisons. In fact, few of the studies with recommendations to 'educate the population' in order to reduce delays do actually investigate 'knowledge of TB' among TB patients. Even fewer measure 'knowledge of TB' in relation to delays to diagnosis. Those which do are hardly convincing. In India (Rajeswari *et al.* 2002), 'lack of awareness about TB' was cited by 40% of patients with long patient delays as a reason for delayed care seeking, but this 'lack of awareness about TB' was not investigated among patients reporting short patient delays. In Nigeria (Enwuru *et al.* 2002), 'lack of knowledge about TB' was associated with longer patient delays, but no other possible reason for patient delay was investigated and the association was not adjusted for level of education or other confounding factors. Also, many studies emphasize patient factors over provider factors when analysing reasons for delays or commenting on their findings – even when the data suggest otherwise. For instance, median provider (doctor) delay exceeded its target much more than median patient delay in studies from Malaysia (Liam & Tang 1997), The Gambia (Lienhardt *et al.* 2001), or India (Rajeswari *et al.* 2002), but in these studies the recommendations to 'educate communities' come first, before recommendations to 'educate providers'. The exhaustive list of similar examples would be long (and boring).

Cultural patient factors like stigma or consulting a traditional healer may indeed play a role in delayed care-seeking, but their importance compared with health services factors should be properly evaluated. In Botswana delays were longer among patients who had consulted a traditional healer, but in this study median provider (doctor) delay in itself was 5 weeks (Steen & Mazonde 1998). This is the priority problem: total delay to TB

treatment for patients consulting a traditional healer necessarily includes doctor's delay. TB carries a strong stigma in many communities, and qualitative studies have reported that fear of being diagnosed with TB might prevent some patients from seeking this diagnosis (Liefoghe *et al.* 1995; Jaramillo 1998; Johansson *et al.* 2000). However, to our knowledge, only one study measured the impact of stigma on patient delay. In urban Zambia (Godfrey-Faussett *et al.* 2002), TB and HIV were felt to be closely linked and indeed highly stigmatized, but stigmatizing was *not* associated with delays in seeking care for chronic cough. This study focused on patients with chronic cough (those targeted for TB screening), rather than on patients already diagnosed with TB, hence avoiding the bias that could arise from patients' knowledge of their diagnosis. It also found that long patient delay was related to accessibility problems, and to a poor perception of the quality of health services, but not associated with socio-economic status and knowledge on tuberculosis.

To date no study has persuasively demonstrated that 'lack of knowledge about TB' plays a significant role in patient delay. There is even less evidence that 'educating the population' would be the right way forward for improving case-detection and reducing overall delays to diagnosis. The major constraints to reaching the global TB targets, as identified by WHO, include the lack of qualified human resources, the lack of health infrastructure, poor decentralization of the health system and little coordination with the private sector (WHO 2004). Still, what emerges from the literature on delays to TB treatment is to 'blame the victim', with conclusions and/or recommendations – in the absence of supporting evidence – biased towards patients' factors rather than factors related to the health services. In fact, the solutions to long delays to TB treatment – including long patient delays – are to be sought on the providers', not on the patients' side.

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## Authors

M. L. Lambert and P. Van der Stuyft, Department of Public Health, Unit of Epidemiology and Disease Control, Institute of Tropical Medicine, Nationalestraat 155, 2000 Antwerp, Belgium. E-mail: PVDS@itg.be