

**Why Don't People Seek Treatment If They Suspect They Have TB?
What Factors Influence Their Decision And Who Is Responsible?**
Stop-TB e-Forum 2005

Pakistan ranks sixth in the world by number of estimated tuberculosis (TB) patients. 2.5 million people develop TB every year. To make matters worse, patients tend to reach the National Tuberculosis Control Programme (NTCP) health facilities at a late of the disease, leading to delay in diagnosis and, eventually, treatment. If the results from a study from Karachi are a pointer, the NTCP has to immediately rope in physicians from the private sector in order to improve case detection and treatment success rates. A communication strategy also needs to be evolved to overcome stigma and gender disparities that come in the way of patients seeking treatment for TB.

According to Dr Mubina Agboatwalla, chairperson of HOPE, an NGO working on public health issues including tuberculosis control, "The long gap between onset of symptoms and seeking treatment contributes to the spread of infection in the community. Despite the fact that the country now boasts of near total coverage with DOTS, case detection rate remains as low as 17% (2003) and the latter can only be improved by addressing the delay in case-finding."

HOPE has been working with the NTCP and the World Health Organization's (WHO) regional office to identify the factors that have led to low case detection rates. It is also extending help to design programme strategies to improve patient compliance as well as increase case detection rates. In this context, HOPE has worked on several research projects including gender perspectives on TB, pilot interventions to improve case detection rates and mobilizing community and other treatment supporters.

Why don't people seek treatment if they suspect they have TB? What factors influence their decision and who is responsible? To answer these questions Dr Mubina Agboatwalla, in collaboration with NTP and WHO, carried out a cross-sectional investigation in urban and suburban Karachi through three NTCP clinics from January to December 2003. It was part of a multi-centric study conducted in seven countries of the region. "We studied 844 patients, a majority (73.5%) of them were between of 15-35 years of age and nearly 55-57% of them were either illiterate or just able to read and write. Most of them were unable to accumulate any savings and 62% of them were in debt."

The study report reveals that following the onset of cough and fever, most patients started off with self-medication, followed by purchasing drugs from a neighbourhood medical store. A huge proportion (74.2%) sought homeopathic medicine.

Interestingly, the vast majority of patients (90.9%) had visited various private general practitioners (GPs), as many as five and even up to 12 times and not even a single patient had come directly to the NTCP facility initially.

And yet, even after so much running around, going from one private doctor to another, only 5.7% of them had successfully been diagnosed with TB. While average delay (the time period between the onset of symptoms and initiation of treatment) came to around 100 days, out of this 'patient delay' (i.e. the time period that the patient took from the onset of symptoms to seeking advice from a GP) contributed only 10% i.e. 9.9 days. Thus, the most important hurdle was at the level of GP, who wasted crucial time in diagnosing and initiating treatment.

Asked why they did not go to the NTCP clinics initially, the patients gave various reasons that included: the clinic is too far from their house; it is too crowded; they have to wait for a long time in the queue and some said they were discouraged by 'stories of unpleasant experiences' they had heard from persons who had visited these clinics.

"Fear of being diagnosed as a TB patient, social stigmatization (18.1%) and fear of social isolation, belief that the illness would be cured by itself (60.5%) and financial difficulties were some of the reasons that caused delay in patients accessing treatment," explains Dr Agboatwalla.

According to the report, a vast majority (85-95%), were ashamed about having developed TB and tried to hide their disease. Almost everyone feared (both male and female) that family and marital relations would be affected. More females, (96%) than males (90%) said that chances of a girl getting married are less if she has TB. Similarly, more females (91%) as opposed to males (80.8%) said they would be hesitant to initiate treatment for a young girl if she has TB, probably because of the stigma associated with visiting the chest clinic.

The report clearly identifies the 'unusually long delay' between onset of symptoms and diagnosis and initiation of treatment as a main barrier to control of TB. It recommends involvement of GPs in the NTCP so as to overcome this bottleneck. It also suggests that NTCP diagnostic centres be linked with the clinics of GPs where patients suspected of having TB could be referred for diagnostic tests. If these laboratory tests can be performed free of cost, it would help increase case detection rates since costs of these tests was an important determinant in diagnostic delay. Linkage with private practitioners, as well as increasing the number of DOTS treatment centres in the periphery will also help in reducing the delays, as distance to the health facility was also an important factor for the delay. The general practitioners also need to be made familiar with the NTCP's DOTS programme.

Stop-TB is an international eForum facilitating discussion of programmatic and policy aspects of TB control and TB/HIV integration.

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