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TB PRIMER

Fighting **TB** on the front lines

Key findings and
recommendations on
the crucial role played
by front-line health
workers in TB control



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Cover: Dhaka. Mother of Sahnas Khatoon, 18, newly diagnosed TB patient. Photo: WHO/TBP/Davenport

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Foreword

<< I have been involved with tuberculosis for the last three decades, first with the national TB programme and now with the revised national tuberculosis control programme. We have built up this programme brick by brick, person by person. We have put the systems in place, reached out to people from slums to the high society. >>

—Front-line health worker, India

The people fighting against tuberculosis (TB) are clearly the best-placed to talk about the challenges they face on a daily basis and how to improve the DOTS programmes so that they function at optimum level. They need a louder voice and more visibility—and those working at the health policy level need to learn from them.

As a member of Stop TB Partnership, Health and Development Networks moderated and managed a time-limited discussion on the Stop TB eforum on the theme of key roles and needs of front-line health workers in stopping tuberculosis.

The overall aim of the discussion was to share information and assess the critical role that front-line health workers play in turning back the tide of TB. The discussion built upon the recognition that government services cannot defeat TB alone and that further improvements in case detection and cure rates need the active and local engagement of people involved in care provision on a daily basis.

From various sectors and from different countries, including some with among the highest burdens of TB, many members of the eforum took this opportunity to 'speak their world'.

As well as generating the rich tapestry of experience and expertise you will read in this brief summary, it also provided a virtual forum for thousands to think about and discuss together the theme of World TB Day (WTBD)—over about a six month period.

This kind of open, inclusive discussion helps to broaden on-going discourses on TB and related issues, and hopefully encourages a greater sense of ownership of WTBD among all participants, especially among those whose voices, opinions and expertise have not been this widely recognised and acknowledged in the past.

We look forward to continuing to bring together key stakeholders and critical issues in TB control through the Stop-TB eforum.

A handwritten signature in black ink, appearing to read 'Tim France', with a long horizontal flourish underneath.

Tim France, PhD
Director, Health and Development Networks

Introduction

This year's World TB Day (WTBD) theme focused on the critical role played by front-line health workers in extending the reach of directly observed treatment short course (DOTS) services, a proven strategy for achieving tuberculosis (TB) control.

In March 2000, Ministers of Health, Planning and Finance from the 20 countries with the highest number of TB cases gathered in Amsterdam, the Netherlands to set targets for reducing the epidemic. They agreed to expand DOTS coverage to identify 70% of all infectious TB cases by the year 2005. In 2001 the First Stop TB Partners' Forum, held in Washington committed itself to intensify efforts to reach these global targets for tuberculosis control, setting the additional goal of successfully treating 85% of detected TB cases by 2005. These commitments culminated in the first 'Global Plan to Stop Tuberculosis' (2001–2005). The Stop-TB partners renewed their pledge to 'eliminate tuberculosis as a public health problem', in their second conclave held in New Delhi in 2004. Front-line health workers of the five continents play a defining role in pursuit of these goals by the global TB community.

Who really are the front-line health workers involved in delivering TB treatment services at the cutting edge? Traditionally, they are thought of as nurses and community health workers who have undergone at least a few

WHO/TB/Plavepoint



A TB patient in Guinea, West Africa, 1997

years of formal training. However, health care programmes in both poor and wealthy nations are experiencing a perpetual human resource shortage. Coupled with this, the growing needs of rapidly expanding national tuberculosis control programmes have given rise to a new class of TB front-line workers: community volunteers recruited through local channels, traditional healers, pharmacists and even shopkeepers. They largely represent the first ‘institutions’ that patients visit when they are sick.

Evidence is fast emerging from a number of countries that intelligent use of this novel health force can help improve case detection and treatment completion rates, particularly in difficult to reach rural and urban situations. This is achieved through health worker skills-building, to provide targeted information, identify chest symptomatic people, refer them to DOTS centres and help to ensure treatment compliance.

Another resource available are ‘TB-experienced’ people (cured TB patients or TB-affected individuals). Organised groups of such people are coming forward in some countries to help fight TB at local, regional, national and global levels. Thus the expression ‘front-line health workers’ portrays not only people working in an array of formal health facilities but also encompasses a range of individuals drawn from within the community that is being served.

The impediments faced by front-line health workers in the course of TB control programme delivery are innumerable. The foremost lies in overcoming the delay between the onset of the patient’s first symptoms and seeking treatment. One of the lessons learnt so far is that, empowered with the ability to educate and provide information about TB, front-line health workers can



WHO/TB/Barry Hampton

HIV-positive Betty Nyanzi puts on plays about HIV/AIDS and TB to sensitise the communities

bring patients into the DOTS scheme before they are too sick to be treated or have already spread the disease to other people in their community.

Stigma and discrimination associated with the disease combine to create an environment where people are less likely to confront TB. This calls for a communication strategy that helps front-line health workers overcome social and gender disparities, as well as myths and mystique associated with the disease. A sparse health infrastructure and paucity of resources, especially in isolated areas and congested urban slums, makes the challenges facing front-line health workers all the more daunting.

The advent of the HIV (human immunodeficiency virus) pandemic has made the lethal combination of AIDS (acquired immunodeficiency syndrome) and TB a worldwide problem. In countries with the highest rates of HIV/AIDS, TB is the most prevalent, serious infection people living with HIV/AIDS (PWHAs) develop. TB is the leading killer of PWHAs worldwide, with around one third of people who are reported as dying of AIDS actually succumbing to TB. The global community is beginning to accept that it is not possible to tackle HIV/AIDS in isolation from TB. Front-line health workers are required to put to use all their communication and social mobilization



WHO/TBPI/Isby Hampton

Raju, a local pharmacist in Bagar town in Shekawati, India

skills to meet this twin challenge successfully.

The stigma attributed to AIDS is extended to TB patients and in some areas of sub-Saharan Africa, TB is widely equated with HIV infection. This means that some people do not seek medical attention for fear of knowing their HIV status and others prefer to opt only for TB treatment and do not test for HIV. Health experts agree that curing or preventing TB increases or preserves immune function. In addition, TB treatment methods such as

DOTS are now being considered and studied for potential adaptation to more complex AIDS treatment regimens.

In a number of places, front-line health workers are now turning to tried-and-tested community-based approaches to HIV for TB control as well. A paradigm shift from reliance on a 'service provider approach' to a 'community-based approach' is emerging in countries of Asia and Africa. In many places, this is being done through home-based care programmes and the use of treatment supporters. A large number of high-TB burden countries in Africa also have high HIV prevalence rates but a less than optimal primary health care system. In such a disadvantaged situation, building partnerships with community is often the only effective solution.

Some of the examples of active community participation in TB control include the TB referral system being tried in Uganda, bottom-up initiated community programmes in Nigeria, tuberculosis health visitors to reach patients living in urban slums in India, and use of women volunteers as DOTS care providers in Myanmar. There are a number of inherent advantages associated with increasing the community contribution to TB control, whether countries are experiencing overwhelming case loads or



A TB health worker discusses treatment with a TB patient and her mother in New Delhi

WHO/DF/Gary Hampton

not. Community participation helps expand access to treatment for underserved patient groups and may further improve treatment outcomes.

National TB control programmes are now approaching private health care providers and seeking their active participation to improve TB case detection and treatment completion rates. In Pakistan, HOPE, an NGO working on public health issues, carried out a cross-sectional study in urban and suburban Karachi. The study discovered that following the onset of cough and

fever, most of the patients first engaged in self-medication. A vast majority of them visited various private practitioners a number of times, and not a single patient approached the TB control programme clinics directly. However, a study conducted in an industrial town of western India noted that when chest symptomatic patients visited private practitioners working in collaboration with DOTS services, two-thirds of them were diagnosed within three days of their first visit and were put on treatment two days following diagnosis.

These and other studies reveal that the immense potential of the private sector can be tapped to boost the performance of national tuberculosis programmes. In India, such public-private mix (PPM) projects are being implemented in fourteen cities. The project methodology provides for a number of options, which include private practitioners referring chest symptomatic patients to microscopy centres or providing DOTS-like services themselves. Early trends from these projects confirm the hypothesis that calls for wider participation of the private sector in TB control. Nevertheless, in order to make this concept operational on a larger scale, remaining barriers would have to be surmounted.

2005 is a landmark year in the history of the global fight against TB. The Washington Declaration, issued after the first meeting of the Stop TB Partnership 2001, vowed to achieve a DOTS case detection rate of at least 70%, whilst maintaining a treatment success rate of at least 85%; and to develop and scale up effective responses to TB-HIV and to multi drug-resistant TB (MDR-TB) by the end of this year. How close or how far we are from fulfilling these promises requires careful scrutiny.



WHO/TB/P/Peere Vroot

Ghanaian TB workers at one of their regular meetings

The involvement of cured TB patients and those living with HIV/AIDS with front-line health workers comes as a breath of fresh air. In Cubas, a poverty-stricken district of the Peruvian capital Lima, nearly 12,000 members of the 'Association of Tuberculosis Patients' work with fellow patients, assuring them that they are not alone, that they can beat the disease and its associated marginalization. An integral part of the association's work is collaborating with the health centres that form the backbone of the government's TB programme. The drafting of a 'patients' charter of the tuberculosis community, synthesizing values, principles and aspirations that are widely shared by people infected or affected by TB, TB/HIV or MDR-TB is a constant reminder to TB advocates and health workers to work for an equitable, sustainable and effective system of 'patient-centred' care. Front-line health workers are surely aware of this vital responsibility.

The future of TB control lies in the hands of front-line health workers. They befriend patients and establish a dialogue with them, and treat them with due dignity. This is essential to achieving compliance and successful treatment outcomes. It is heartening that while the four-hundred strong Stop-TB Partnership maintains a vigil over the progress of global TB control, another partnership is quietly emerging at the community level. A number of non-health partners have now extended a hand of cooperation towards the conventional health force staffing the health facilities, and there is a need for front-line health workers to develop skills in working with them. The expansion of the 'TB programme and community alliance' and its integration with HIV/AIDS responses at the peripheral level is a promising sign.

The establishment of a Global Network on TB and Poverty to further probe the complex connections between TB and poverty would also help in mainstreaming a pro-poor approach in TB programmes.

The world has awakened to the vital role that front-line health workers have played so far and appreciates the diligence of 'hidden-heroes' who have not allowed the lack of resources to curb their zeal, commitment and motivation. On their part, front-line health workers look forward to strengthening their alliance with the health care community, in order to help keep our shared date with global tuberculosis control targets.

Findings and recommendations

Specific findings and recommendations from the Stop-TB eforum structured discussion on front-line health workers:

During 2005, a structured discussion on front-line health workers in TB control was facilitated on the Stop TB eforum around World TB Day (WTBD) and the members were invited to express their opinion on the following questions:

1. What are the key challenges facing individual health care workers involved in the support and care of people with TB?
2. What additional support do front-line workers in this field need?
3. What comments, or experiences, can you share about the use of the DOTS strategy locally?
4. How much are TB-related stigma and discrimination local issues?
5. How can the lives of people living with TB and HIV be most effectively extended in district and community settings?

The eforum generated an overwhelming response from members. The following specific findings and recommendations are based on views expressed by members and personal accounts related to the vital contributions of the men and women working at the frontlines of TB control across the globe, particularly from developing countries. They are divided into eight areas of focus:

1. Front-line health workers
2. Community involvement in TB control
3. Health literacy and TB
4. Planning and implementation
5. Integrating TB and AIDS care
6. Communicating with patients
7. Public-private mix
8. MDR (multi-drug resistant) TB

1. Front-line health workers

- In the context of TB control programmes the scope of the expression 'front-line health workers' should be widened to include community volunteers recruited through local structures, private practitioners, TB-experienced people, traditional healers, pharmacists and even shopkeepers, in addition to health care providers staffing public health facilities.
- In a number of countries, cured TB patients or people affected by TB are coming forward and working as front-line health workers. They are the 'TB-experts', the ones who know what it is like to be infected with active tuberculosis, undergo treatment, live with the challenges, to live dually with HIV and TB, and they are the best ambassadors to communicate that TB is curable. Their voices need to be heard, to be accounted for and respected. They provide valuable



Traditional healers in Mpumalanga, South Africa

insight, and contribute significantly towards the success of programme implementation.

- Just as TB patients must comply with their treatment, health care workers also have to comply with the programme guidelines. Over time, they may become fatigued and their performance dwindles. Constant motivation of all health care workers and retention of their interest and commitment is therefore a persistent challenge and needs to be addressed since this can impact programme success significantly.
- Problems faced by front-line health workers have to be attended to urgently. Provision of transport (depending on the geographic area) and other logistic facilities increase work performance, geographic coverage and as a result, patient compliance and programme outcomes.
- Communication and motivational skills-building should be part of curriculum of health schools and this process also needs to be carried forward as on-the-job training.
- Incentives should be provided to reward and motivate front-line health workers with good track records of accomplishment.
- The good work done by front-line health workers should be publicly recognised. In case of salaried workers, the system must ensure adequate and regular flow of their salaries.

2. Community involvement in TB control

- TB policy planners and programme managers should reconsider their usual reliance on a 'service provider approach' and reposition to a 'community-based approach'. The lessons learnt from rewarding results obtained through active community participation in HIV/AIDS prevention and control may be replicated and appropriately adapted for TB control.
- Community-based TB models are more likely to be sustainable and are cost effective in the face of poorly functioning primary health care infrastructures in a number of developing countries.

- Community leaders and volunteers can be invited to participate in the planning process and actual delivery of TB treatment services at the local level. Community participants should be taken on board as real partners and their experience should be recognised as a resource for the improvement of TB control services.
- Non-government organisations (NGOs) that enjoy good reputations owing to their work in society may also be involved to improve utilization of services provided by TB control programmes.
- All available human resources (of health and non-health sectors) at village/ community level have to be efficiently utilized to screen for symptomatic people.
- Engaging communities can result in an effective response to the TB-HIV co-epidemics. Although at the policy level, the two programme interventions (TB and HIV control) are coming closer, more needs to be done to effectively integrate TB and HIV control programmes at the ground level.

3. Health literacy and TB

- Lack of health (tuberculosis)-related information leads to delay in diagnosis and initiation of treatment among chest symptomatic patients. Poorly educated patients also tend to skip drugs or drop out of treatment.
- Health education messages should be simple and appropriate—the story method often carries some weight.
- Skills/capacity building of non-medical or non-health professionals who volunteer and contribute effectively to TB control programmes should be supported.



WHO/TFB/Gary Hampton

In Cuzco, Peru, nurse Elizabeth Quispe displays a TB flip chart she uses during educational

4. Planning and implementation

- Due to the shortage of human resources available for health care programmes, rapidly expanding TB control programmes face an acute shortage of skilled workers to man these initiatives effectively. More people must be recruited and given the necessary training.
- Rigid operational guidelines and targets result in data manipulation, over or under reporting, and loss of interest on the part of health workers or volunteers and should be avoided.
- Flexible targets based on ground realities need to be developed and adopted locally.
- National guidelines must leave scope for innovative approaches at the local level.
- Decision-making must be decentralised and transferred to district level whenever possible.
- Tuberculosis cannot be treated with drugs alone. The issues of poverty, lack of food and nutrition, which create the ideal conditions for infectious diseases, also have to be addressed.
- Experience has established that integration of research into health programme planning and implementation can improve the utilization and coverage of health services. Health system research should be an integral part of national tuberculosis control programmes.

5. Integrating TB and AIDS care

- As HIV/AIDS organisations and the TB sector work more closely together in addressing the dual epidemics raging in many countries and communities, they should give due emphasis, attention and involvement to front-line TB health workers and service providers. The dual epidemics are addressed at a local level every day, more often than not by the same teams and individuals. At the grassroots level the slogan ‘Two diseases. One patient. One local health worker’ summarises this reality.

- Front-line health care workers are uniquely placed to remind people that TB and HIV/AIDS treatment, support and care regimens require a dignified and professional response.
- Stigma within health care settings is one of the foremost deterrents to seeking treatment from available services. Providing sensitized health care staff and increased access to treatment and care services for people living with HIV and active TB will go a long way to encouraging people to test for TB/HIV and seek appropriate comprehensive care and support services in their communities.
- One way to manage dual HIV/TB infection—and deliver TB preventive therapy as well as DOTS for those presenting with active TB—is to establish comprehensive HIV care clinics. In such clinics voluntary counselling and testing (VCT), DOTS, antiretroviral drugs (ARVs), prevention of mother-to-child HIV transmission services (PMTCT), as well as prevention and treatment of other opportunistic infections, are offered as a total package.
- Improved communication strategies should be designed and implemented for combating stigma and discrimination, and raising awareness of the challenge of TB-HIV, so that people living with HIV can access TB treatment without facing stigma and discrimination within health care settings.
- Every effort should be made to effectively integrate TB-HIV programmes at the ground level.

6. Communicating with TB patients

- Patients must be treated fairly and with dignity, and their needs and concerns taken seriously.
- In most countries, health services are very hierarchical, and patients are invariably at the bottom. Patients tend to be subjectified as numbers and statistics in national TB programmes and strategies, and as a result are often treated that way in health care settings.
- Patients should have opportunities to take part in decisions that are linked to their illness and treatment/management.

- Health care workers should talk with the patients, not to the patients. It is essential that the thoughts and feelings of each patient are heard. This can be a way to empower the patient and help protect their dignity.
- To be diagnosed and placed on TB-treatment is a tough experience. It is therefore important to explore ways of giving patients optimum care and support. The use of treatment supporters and peer educators are possible ways to help address this need.
- The role of cured TB patients or TB-affected people in advocacy and TB control initiatives, and in patient communication and support in particular, should be expanded wherever possible.



WHO/TB/Pere Viet

In Ghana, a TB patient is examined by his doctor

7. Public-private mix

- Effective engagement and participation of private health care providers and other 'first contact points' for people with a cough and fever, like pharmacies, faith-based healers, etc should be promoted.
- Private practitioners are often, sometimes inadvertently, labelled as poorly qualified profit-makers who wrongly diagnose and incorrectly treat patients. Policy-makers and health workers should adopt a more positive attitude towards private practitioners.
- National Tuberculosis Programmes should be open to criticisms from practitioners and patients and should give space to fact-based views, rather than evade criticism.

- Before enrolling private clinics as drug-distribution centres or DOTS-providers, it must be ensured that these centres can provide satisfactory record-keeping and defaulter retrieval services.

8. MDR (multi-drug resistant) TB

- Many countries in the global south are facing huge potential burdens of MDR TB. Effective steps must be taken to reduce new cases of MDR TB, and to help people comply with DOTS more effectively.

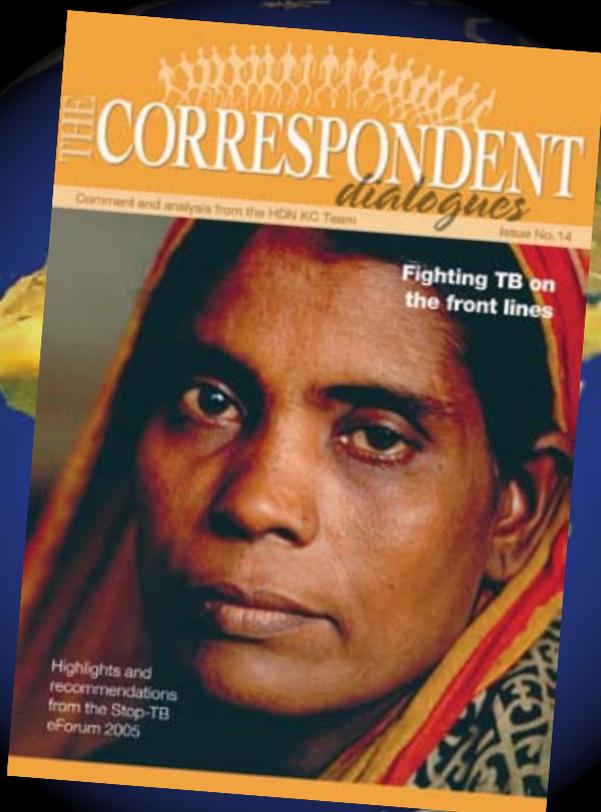


WHO/TB/09/Hampton

Ugandan children outside a community health centre

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Highlights and recommendations from the Stop TB eforum 2005, including over 50 articles from HDN Key Correspondents and other experts in the field of TB

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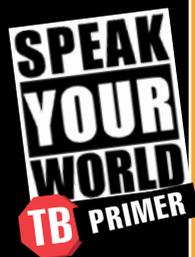
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