



CORRESPONDENT

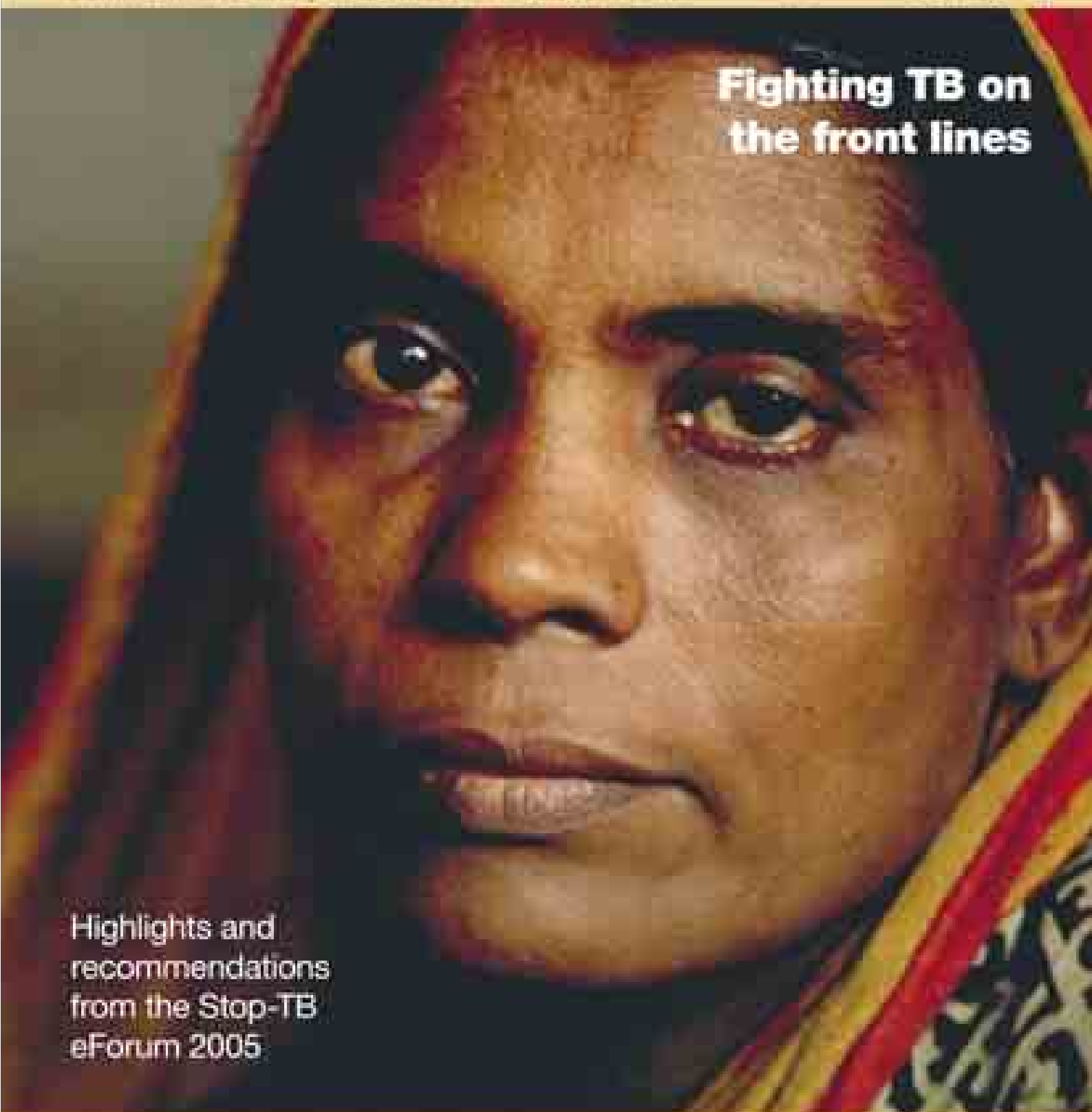
dialogues

Comment and analysis from the HDN KC Team

Issue No. 16

**Fighting TB on
the front lines**

Highlights and
recommendations
from the Stop-TB
eForum 2005



Fighting TB on the front lines

Highlights and recommendations from the Stop-TB eForum 2005

A joint publication of Health and Development Networks and
the AIDS-Care-Watch Campaign



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THE CORRESPONDENT

dialogues

contents

Acknowledgements	IV
Foreword	V
Introduction	VI
Executive Summary	VII
Findings and recommendations.....	IX
Key front line perspectives.....	XIII
Statement: World TB Day message, 24 March 2005.....	XIV
1. Front-line health workers and community engagement	1
Front-line health worker issues	2
<i>Front-line: Key issues related to front-line health workers</i>	<i>2</i>
<i>Unsung Heroes: in straining health systems.....</i>	<i>4</i>
<i>Key challenges facing individual TB healthcare workers</i>	<i>5</i>
<i>Front-line workers need training</i>	<i>6</i>
<i>Front-line health workers – crucial to tackling TB and HIV related stigma and discrimination.....</i>	<i>7</i>
<i>Study on front-line health workers in TB control (2).....</i>	<i>8</i>
<i>Study on front-line health workers in TB control (3).....</i>	<i>9</i>
The unsung heroes of TB control	10
<i>Unsung Heroes: Minds without fear and discrimination.....</i>	<i>10</i>
<i>Unsung Heroes: Peru.....</i>	<i>12</i>
<i>Unsung Heroes: TB health workers on the front lines in South Africa</i>	<i>13</i>
<i>Unsung Heroes: TB carers in Kenya</i>	<i>15</i>
Community engagement.....	16
<i>Front-line: Care about the community?</i>	<i>16</i>
<i>Unsung Heroes: Education and social mobilisation: The keys against TB in a Kenyan slum.....</i>	<i>18</i>
<i>Community partnerships against TB – Uganda and Nigeria.....</i>	<i>19</i>
<i>Front-line: Women volunteers as DOTS care providers in Myanmar</i>	<i>21</i>
<i>Spotlight: TB control at the local level in Pakistan.....</i>	<i>22</i>
<i>Community contribution to TB care: practice and policy</i>	<i>23</i>
<i>Comment: Community contribution to TB care: practice and policy</i>	<i>26</i>
2. TB patients and treatment.....	27
<i>Front-line: In one corner of Romania</i>	<i>28</i>
<i>Front-line: One family's struggle with TB.....</i>	<i>29</i>
<i>Comment: Lessons from the lost opportunities in TB control</i>	<i>30</i>
<i>Campaign: The Patients' Charter of the Tuberculosis Community</i>	<i>31</i>
<i>Spotlight: Complications of TB infection.....</i>	<i>32</i>
<i>Spotlight: DOTS in all districts of India: What next?.....</i>	<i>33</i>
<i>Spotlight: Improved TB case detection in Delhi (India)</i>	<i>35</i>
<i>Comment: The chase to meet DOTS targets – a few concerns.....</i>	<i>37</i>
<i>Front-line: Ground realities facing TB patients in China.....</i>	<i>38</i>
<i>TB diagnosis and treatment compliance – a challenge</i>	<i>39</i>
<i>Speak Your World: South Africa.....</i>	<i>40</i>

THE CORRESPONDENT

dialogues

contents

<i>Spotlight: Delay in seeking TB treatment in Pakistan</i>	41
3. The 'twin epidemic': TB and HIV co-infection	43
<i>Unsung Heroes: Henminlun Gangte</i>	44
<i>Comment: Integrate TB and HIV treatment and care</i>	46
<i>Spotlight: Preventive TB therapy – the obvious HIV link</i>	47
<i>Comment: Preventive chemotherapy in TB-HIV and other co-infections</i>	48
<i>Spotlight: TB and HIV inextricably Linked</i>	48
<i>Looking back: Mandela – fight AIDS by fighting TB</i>	50
<i>Spotlight: HIV/TB co-infection and challenges</i>	51
<i>Speak Your World: HIV/AIDS opportunistic infections – a balancing act in clinical management</i>	52
<i>Spotlight: An uphill struggle against TB and HIV in South Africa</i>	54
<i>Spotlight: TB in HIV positive children – New opportunities and persistent challenges</i>	55
4. Policy, society and practice – other factors affecting TB control	57
TB and society	58
<i>Spotlight: TB and poverty</i>	58
<i>Comment: TB control in nomadic populations</i>	59
<i>Comment: TB control in nomadic populations (1)</i>	60
<i>Speak your World: Beating the odds, Akha woman shares her story</i>	60
<i>Front-line: Fighting TB in Senegal – a dead end for the marginalised</i>	62
Stigma and TB	63
<i>Spotlight: Stigma and TB in Tanzania</i>	63
<i>Unsung Heroes: Nun fights TB stigma with compassion</i>	64
<i>Spotlight: Stigma – lurking on the edge of the TB response</i>	65
Practice and policy	67
<i>Spotlight: Working towards a successful strategy in Pakistan: Interview with Dr Karam Ali Shah</i>	67
<i>Spotlight: Elusive targets and deteriorating public health service in Argentina</i>	69
<i>Spotlight: United Kingdom – immigrants' experience of TB health care</i>	70
<i>Speak Your World: Argentina</i>	71
<i>Vertical TB programming is a challenge</i>	72
<i>Drawing lessons from leprosy elimination campaigns</i>	73
<i>Comment: Debt forgiveness and TB</i>	74
<i>Private-public partnerships: a challenge</i>	74
<i>Comment: Private-Public partnerships: a challenge (2)</i>	75
<i>Comment: Private-Public partnerships: a challenge (3)</i>	75
<i>Comment: Private-Public partnerships: a challenge (6)</i>	76
<i>Comment: Private-Public partnerships: a challenge (8)</i>	77
Further reading	78
Glossary of terms	79
What is the Stop-TB eForum?	81



Acknowledgements

First and foremost, we would like to thank the members of the Stop-TB eForum for continuing to submit insightful, meaningful contributions coming from those countries where the realities of TB control are the most felt. Contributions came from so many countries including: Argentina, Bangladesh, Botswana, Canada, China, Ethiopia, Haiti, India, Indonesia, Iran, Italy, Japan, Kenya, Malawi, Mozambique, Myanmar, Nicaragua, Nigeria, Pakistan, Peru, the Philippines, Romania, Senegal, Somalia, South Africa, Switzerland, Tanzania, Thailand, Tibet, the United Kingdom, the United States, and Zambia.

We sincerely thank those individuals who acted as Key Resource People for this discussion and for sharing their experienced views with the eForum members:

Alfonso Gumucio-Dagron - Communication for Social Change Consortium, Brazil
Andy Seale - UNAIDS, Switzerland
Dermot Maher - World Health Organization, Switzerland
James Deane - Communication for Social Change Consortium, US
Lee B. Reichman - New Jersey Medical School National Tuberculosis Center, US
Silvio Waisbord - Academy for Educational Development (AED/Change)
Ted Torfoss - Norwegian Association of Heart and Lung Patients
Will Parks - JTA International

We are very grateful to the HDN Key Correspondents who took part in this project – for their ability to expertly and compellingly communicate the real issues felt by front-line health workers in high-burden TB countries:

Abigail Erikson - USA
Andrew Furber - UK
Bobby Ramakant - India
Claudia Catana - Romania
Colleen Jackson - South Africa
Dinesh Kumar Sharma - India
Elena Obieta - Argentina
Edwin Limo - Kenya
Eric Lugada - Uganda
Greg Manning - India
Gustave Gaye - Senegal
Henry Neondo - Kenya
Jamie Uhrig - Thailand
Lewis Ndlovu - South Africa
Lucien Chauvin - Peru
Milan Dinda - India
Monrueedee Laphimon - Thailand
Nanao Haobam - India
Nipaporn Intong - Thailand
Odilon Couzin - China
Rebecca Wanjiku - Kenya
Tumaini Mbibo - Tanzania
Zofeen T. Ebrahim - Pakistan

Our thanks also go to the dedicated team behind this initiative for their hard work: Bobby Ramakant, Dinesh Kumar Sharma, Duangkamol Donchaum, Evelyn Harvey, Kanako Mizuta, Nadine France, Owen Elias, Sehin Teferra, Sumadee Chaipanich, Tim France, and Warunee Kuthithamee.

We would lastly like to express our gratitude to the Stop-TB Partnership Secretariat for their financial support to this project and to Development Cooperation Ireland (DCI) for their ongoing support for HDN and its work.



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 workers, 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.

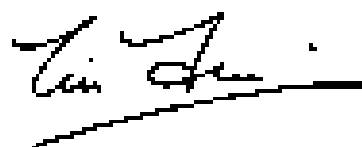
The overall aim of the discussion was to share information and assess the critical role that front-line health workers play in turning back the tide of TB. The discussion built upon the recognition that government services cannot defeat TB alone and that further improvements in case detection and cure 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 report, 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.



Tim France, PhD
Director, Health and Development Networks

Introduction

As a member of Stop TB Partnership, Health and Development Networks designed a communication and networking project around the theme of World TB Day 2005 – ‘The key roles and needs of front-line health workers in stopping tuberculosis’. The overall aim of the project was to acknowledge and document the crucial role and contribution that local health workers and other implementers play in the national and global responses to TB. The discussion built upon the recognition that government services cannot alone defeat TB and that further improvements in case detection and cure rates need the active and local engagement of people involved in daily care provision.

Specific objectives of the project were to:

- Expand discussions around TB, in specific relation to the 2005 theme of World TB Day;
- Foster new partnerships;
- Promote a broadened discourse on TB, and a greater sense of ownership of World TB Day, by increasing the direct participation of a wide range of sectors and communities;
- Help to document and raise awareness about local and national priority issues in the context of TB, particularly regarding the experiences of front-line care providers;
- Improve public and political support for TB control by using the opportunity of World TB Day to involve more civil society organisations in TB-related discussions;
- To cross-link World TB Day discussions with on-going HIV/AIDS care-related discourses.

Project activities

Starting in March 2005, a focused discussion took place on the Stop-TB eForum for the following six months. Hundreds of members of the Stop-TB eForum contributed their viewpoints from different countries of the world and seized this opportunity to ‘speak their world’, on the following key themes:

- The vital contributions that front-line workers make to TB case detection and implementation of the directly observed treatment short course (DOTS) strategy;
- Local obstacles and needs in finding and curing cases of TB;
- How do ‘hidden heroes’ access hard-to-reach communities and go beyond the conventional health systems?
- What laboratory, diagnostic or treatment facilities/services would help to provide DOTS services to more TB patients at a local level?

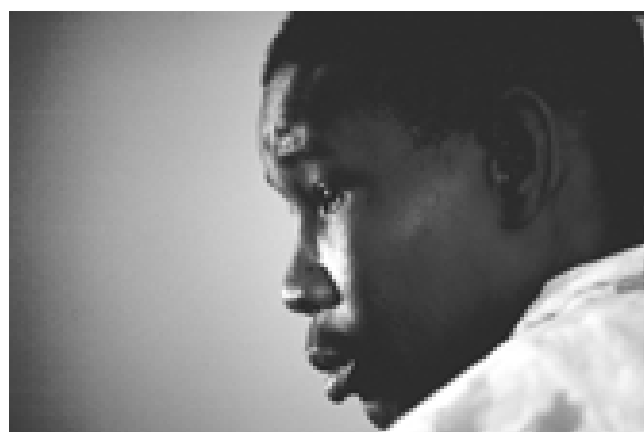
- Health workforce crisis: How is the brain-drain affecting our ability to stop TB locally?

The contributors to this structured discussion came from varied backgrounds, with most of them working in developing countries fighting tuberculosis every day, such as those infected with TB, front-line health workers, TB/HIV/AIDS service organisations, government officers, policy-makers, donor agencies, academics, researchers and teachers, and community- and faith-based organisations. Contributions to the discussion were received from: Argentina, Bangladesh, Botswana, Canada, China, Ethiopia, Haiti, India, Indonesia, Iran, Italy, Japan, Kenya, Malawi, Mozambique, Myanmar, Nicaragua, Nigeria, Pakistan, Peru, the Philippines, Romania, Senegal, Somalia, South Africa, Switzerland, Tanzania, Thailand, Tibet, the United Kingdom, the United States, and Zambia. A number Key Resource People, recognised experts and activists, were also invited to submit contributions on the various topics to help focus and guide the discussion.

In addition, the HDN Key Correspondent Team contributed 32 country-focused articles, mostly from high-burden TB countries, to further illustrate the real issues faced by front-line workers. These articles provide a unique perspective on the experiences of front-line health workers, caring for people affected by TB day-to-day and thus illuminate the crucial role they play in fighting TB and HIV/AIDS.

The complete Stop-TB eForum archives can be found at: www.healthdev.org/eforums/stop-tb

This document presents the key findings and recommendations drawn from the contributions received to the Stop-TB eForum. It also includes the most focused and illustrative postings submitted to the eForum as well as the series of country-based articles by the HDN Key Correspondent Team.



A TB patient in Guinea, West Africa

WHO/TBP/Davenport

Executive Summary

“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”

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.

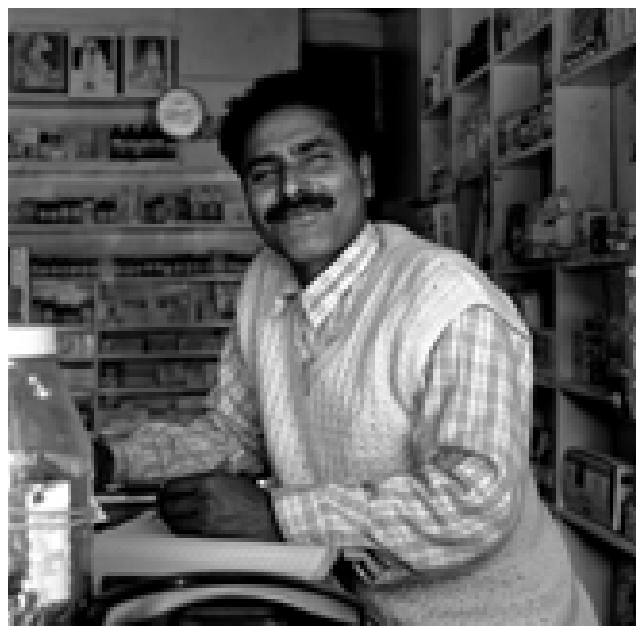
Who really are the front-line health workers involved in delivering TB treatment services at the cutting edge? Traditionally, they are thought of as nurses and community health workers who have undergone at least a few years of formal training. However, health care programmes in both poor and wealthy 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,



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

WHO/TBP/Gary Hampton

empowered with the ability to educate and provide information about TB, front-line health workers can 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 immune deficiency 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 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 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, a non-government organisation (NGO) working on public health issues, carried out a cross-sectional study in urban and sub-urban 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 micro-copy 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.

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 marginalisation. 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, synthesising 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

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 front lines 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 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 utilisation 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 utilised 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/TBP/Davenport
In Cuzco, Peru, nurse Elizabeth Quispe displays a TB flipchart she uses during educational talks

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 utilisation 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 sensitised 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.

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.



Ghanaian TB workers at one of their regular meetings

WHO/TBP/Pierre Viot

- 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.





Key front line perspectives

The following includes the most focused and illustrative postings submitted by eForum members during the discussion, as well as the complete series of country-based articles by the Key Correspondent Team.



Statement:

World TB Day message

24 March 2005

Kofi Annan

Five thousand people die from tuberculosis every day, although the disease is both preventable and curable. Clearly, we must work harder if we are to achieve, by 2015, the Millennium Development Goal of halting and beginning to reverse the spread of TB as one of the world's major diseases. Thanks to a massive scale-up of the DOTS strategy for TB control recommended by the World Health Organization, with 17 million persons treated in nine years, our prospects for reaching the goal have improved greatly.

WHO [World Health Organization] reports that eight in 10 patients are successfully treated under DOTS programmes, and that 45 per cent of infectious patients were treated in 2003 – up from 28 per cent in 2000. But huge obstacles remain, particularly in Africa – in the form of weak health systems, a depleted health workforce, and an HIV/AIDS epidemic that is driving TB. As Nelson Mandela said, “We cannot win the battle against AIDS if we do not also fight TB. TB is too often a death sentence for people with AIDS.” I urge African leaders to make the fight against both diseases a priority.

The Stop TB Partnership, with its 350 partner governments and organisations, is making a difference by forging consensus on strategies, coordinated responses, mechanisms for quality drug supply, and action for new diagnostics, drugs and vaccines. Governments, bilateral agencies, the Global Fund to Fight AIDS, TB and Malaria, and the World Bank are providing more resources. Still, to achieve worldwide impact, more is needed. And we must provide greater support for the increasingly wide range of care givers who help find people ill with TB and assist them with treatment. These providers include not just public health doctors and nurses, but also community leaders, former patients, women's groups, and many others.

Such broad mobilization is our strongest weapon in the fight against the disease. On this world TB Day, let us rededicate ourselves to that mission.



A health worker discusses treatment with a TB patient and her mother at a New Delhi clinic, India.

WHO/TBP/Gary Hampton

Kofi A. Annan
UN Secretary-General



1 Front-line health workers and community engagement



Front-line health workers issues

Front-line:

Key issues related to front-line health workers

Ted Torfoss

Front-line health workers can organise and encourage people to form peer-groups, invite them into planning and delivery of TB services or give them the task as advocates at all levels in society

In this article I will concentrate on a patient centred approach in the fight against tuberculosis (TB) and HIV/AIDS. I highlight three key issues related to the front-line health workers area of work. This may improve services and make it easier for the patients to reach and complete treatment:

1. Who really are the front-line health workers (FLHW)?

Traditionally we think of them as nurses and community health workers that have some kind of formal health education. Unfortunately, there is a human resource shortage facing the health challenge in many countries today. If we want to reach the people most in need, we must increase the number of FLHW on the ground and move the services out to where the people live. In many places this is being done when it comes to TB and HIV/AIDS, through home-based care (HBC) programmes and the use of treatment 'supporters' as they often are called, but scaling-up such services remains a major challenge. By involving and training volunteers from the communities, they can have an essential role in reaching the patients, securing compliance,

and spreading health education and knowledge on the ground. Since these are often voluntary inputs, it is important to recognise the crucial work such volunteers do. Different kinds of incentives have to be developed. Volunteers can be recruited through the local structure in the communities, through community-based organisations (CBOs) or faith-based groups.

Another group of FLHWs are traditional healers. They are often the first health provider a person with health problems will seek. If we want to improve detection and reach the people infected more effectively we need to build cooperation and partnership with this group locally and nationally. This is still a largely unexplored area.

Pharmacists and other shopkeepers in local communities are also often the first 'institution' that are visited when people feel sick, searching for some kind of remedies for their illness, like cough medicines, etc. They can be trained and given the responsibility to provide information and refer people to diagnostic centres. This is being tried out in an operational research project, with the TB Equity Knowledge

Programme in Malawi, to improve early diagnosis for TB and malaria in poor suburban communities.

2. How do the front-line health workers deal with the patients?

Patients with TB and HIV/AIDS face long and tough treatments. It is therefore important that the patients feel that they can trust the health services provided. The front-line health workers and medical personnel have to be well trained in how to meet the patients' needs. Here are a few areas that can be improved:

Take the patient seriously and treat him/her with dignity. In most countries the health services are very hierarchic, and the patients are always at the bottom. Patients tend to be just numbers and statistics in national programmes and strategies, and are often also treated that way. Give the patient a chance to take part in decisions that are linked to his/her illness and treatment.

Talk with the patient, not to the patient. It is important to establish a dialog with the patient. The health workers must learn to listen to the



patient, just not tell him/her what is 'best' for them. To achieve compliance and a successfully treated patient requires mutual respect and dialog between the health-worker and the patient. It is therefore very important that the patient's thoughts and feelings are heard. This can be a way to empower the patient and give him/her dignity.

Daily treatment, care and support should replace the expression 'directly observed treatment' since DOTS can be, and often is interpreted in a very authoritative way. To be placed on TB-treatment with a possible HIV diagnosis is a tough experience. It is therefore important to explore ways of giving the patient the proper care and support. The use of treatment supporters and peer educators are a couple of ways to solve this challenge.

Another issue related to care and support is lack of food and nutrition. Taking TB-drugs on an empty stomach is tough, but is the reality for many patients. Any initiative should be tried out here, from the World Food Programme to local initiatives. This is not only a responsibility for the FLHW, but should be considered as a National TB Programme policy. A lot can be done locally by developing partnerships with institutions, local businesses and organisations.

Start talking about HIV/AIDS. Health personnel must be taught how to bring up the issue of HIV/AIDS when they meet TB patients. The patient has the right to know what he/she might suffer from, and should be given correct information. Very often health workers – both professional and volunteers – think they know best on behalf of the patient, without asking the patient. They often want to protect themselves and the patient from the realities, not acknowledging the patient's ability to decide for him-/herself. Involve the patient in how they can deal with their own illness. FLHWs have an important task to fulfil here. To fight stigma attached to HIV/AIDS, we need to start talking about it.

Information and knowledge must be given in a proper way to the patient and their relatives, prepared for the individual. Very often patients themselves are blamed for non-compliance or defaulting. Of course, one should not take away the responsibility from the patient, but information given to the patient and the way the patient is treated is often not good enough. It is the health worker's responsibility to give the message in a way the patient can understand. What TB is, how it transmits, side effects, length of treatment and the importance of compliance are among issues that should be touched upon, not once, but several times. The patient may have received some of this information the day he/she got the diagnosis, but this is often not the right moment to give all this information. As said earlier, TB treatment policy is a very good setting for giving information, since you meet the patients several times over a long period. There are also other ways of providing further information to the patients and their family; support groups, peer education, meetings at health posts, community activities, etc.

3. How can the TB-experienced person (ex-TB patients/TB-affected) be a resource in the fight against TB, locally, nationally and globally?

This is an important issue for the whole community working with TB and HIV/AIDS.

It is because of the patients we are all involved in the fight against TB, so why don't we start listening to the patients and involve them where it is possible?

I believe involving the patient is essential to improving TB-control and reaching the ones infected and sick with tuberculosis. Treat the patients with dignity, empower them and see them as a resource and a partner. They are the 'TB-experts', the ones that know what it is like to suffer from tuberculosis, the ones that live with

HIV and TB, the ones that know what stigma is about. They are the ones that can help identify needs and barriers when it comes to reaching diagnosis and treatment, and they are the best ambassadors to communicate that TB is curable.

For many FLHWs, involving the patients requires a new way of thinking. People affected by TB are often seen as poor, shy and not very outspoken, which in many cases is correct. BUT, among the thousands and millions of TB-patients every year, there are always some patients that are more outspoken, and can play an important role, who again can encourage others. It involves identifying these persons and inviting them on board, training them and recognising their experience. This should be the tasks for the FLHWs. I have heard from treatment supporters, who have experienced TB themselves, and who say how this has been very useful when encouraging other patients to continue their treatment.

FLHW can organise and encourage people to form peer-groups, invite them into in planning and delivery of TB services or give them the role of advocates at all levels in society. But DO NOT only use them as tokens that only have their value at conferences and celebrations. Take them on board as real partners and recognise their experience as a resource for the improvement of TB services.

I work in LHL, the Norwegian Association of Heart and Lung Patients, a patient organisation started by TB-patients more than 60 years ago. In addition LHL has been involved in the international fight against TB for the past 20 years. Our main aim is to secure access to proper diagnosis and treatment for everybody, which we see as an important human rights issue.

Ted Torfoss

*Deputy Manager International Cooperation
Norwegian Association of Heart and Lung
Patients - LHL*

Email: tt@lhl.no

Unsung Heroes: in straining health systems

Abigail Erikson and Bobby Ramakant

“My area of operations should have at least seven medical officers but I have been provided with just one”



In Ghana, a TB patient is examined by his doctor

WHO/TBP/Pierre Viot

Stopping tuberculosis is a daunting task and it takes more than just the DOTS strategy to succeed. It also takes the efforts of hidden heroes - the men and women who work in TB centres every day, oftentimes underpaid, overworked and unrecognised.

The moment we entered the New Delhi-based DOTS clinic, it was immediately clear that the centre is run by a well-trained staff that care deeply about the men, women and children that are treated for TB there. The clinic is spotless and despite limited resources, is well-organised and well cared for. It is also very busy. A display board shows the number of clients visiting the centre each month, and the catchment area served by the centre - 2 million residents in the densely populated city of Delhi.

Behind the well-trained staff and the well-kept clinic, is the doctor in charge, who has been working in TB control for over 30 years. Initially, he was reluctant to speak with our group of five having just identified ourselves as participants of the Stop TB Partners Forum taking place in the city. He was unaware there was a Stop TB Partners Forum happening. In fact, he was unaware that there was a Stop TB campaign at all. But he was aware that 30% of all TB cases are found in India and he was also aware of the programmatic deficits and resource shortages that are preventing the clinic from operating at an optimum level. His frustration was palpable. He lamented that he has been working in TB control in the capital city of Delhi for three decades yet no one bothered to inform him or the hundreds of health workers who are working with DOTS in TB clinics about the campaign.

As his anger subsided, he relaxed a bit and began to talk - not as a doctor, not as a manager, but as a hidden hero working in the fight against TB. He told us about the thirty-five DOTS clinics he manages and proudly showed us the notice board displaying statistical details of the clinics' performance during the past few years.

The cure rate of 82% in 2003 achieved by his facility is impressive and should be recognised. He also explained why he is frustrated and at times feels helpless. The gap between those working on the ground and those making policy decisions is ever-widening and the power imbalance is increasing. These people who are fighting against TB are the best people to talk about the challenges they face on daily basis and how to improve the DOTS programme so that it functions at an optimum level.

These are just a few of the problems he described. “My area of operations should have at least seven Medical Officers but I have been provided with just one. Even the number of senior treatment supervisors and senior laboratory supervisors is far from adequate. How do I do the monitoring and supervision without these people?” He also stated that while the doctors are well paid, his staff is not. Living on just 6,000 rupees a month (roughly US\$4 a day), the health workers are barely getting by. And despite the reality that working in a TB clinic is hazardous, the government tacks on a measly 100 rupees a month (US\$2) to compensate. Most difficult he says, is the geographic area, plus the population of 2 million his TB clinics cover with meagre resources, one vehicle and inadequate staff.

“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 [the DOTS strategy for India]. 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 high society. But no one even sends out an announcement about an international TB meeting to inform the people who are the closest in the fight against TB.”

Touring the facility, we found that systems are very much in place. The laboratory is simple, only a handful of equipment but lab technicians are well-versed in their work. They keep up-to-date and detailed

records of their work with simple hand-drawn bar graphs drawn to scale (one inch equals 100 patients) depicting the monthly incidence of new TB cases and smear positive patients being treated in their centre.

The nursing staff at the TB ward were caring, compassionate and appeared to take excellent care of the patients and their needs. Some patients in the ward had been there for months, for many reasons. Some were very sick and needed to have around the clock care and nutritious meals. Some lived far away, in areas that DOTS does not reach and were unable to make the daily/weekly trips, and therefore had to remain on site to be treated. Some were homeless, migrant workers who had no where else to turn. But all were well cared for - not just because of the effective drug treatment but also because of the emotional support given by fellow patients and staff.

During the Stop TB Partners Forum the lack of community to advocate for better treatment and medications at the global level was a recurring theme - but here in Delhi, just a few kilometres from the conference venue, TB-infected patients were supporting each other in the daily struggle.

There is no doubt the critical role the Stop TB Partnership has in the fight against TB. Since the creation of the Partnership, governments, donor agencies, NGOs and others have organised to streamline a more concerted, strategic effort towards achieving the objectives of the Global Plan to Stop Tuberculosis. To truly ‘keep the pledge’ the unavoidable conclusion from this site visit is that the ‘hidden heroes’, who have dedicated their lives to improving those of people infected and affected by TB, must be brought on board and given a more meaningful role in the partnership.

Abigail Erikson and Bobby Ramakant
HDN Key Correspondents
United States of America and India
Email: correspondents@hdnet.org



Key challenges facing individual TB healthcare workers

Muherman Harun

In our programme no incentive or enhancers have been provided. Not for our diligent patients, nor for our very dedicated healthcare workers

All health care workers caring for TB patients need constant and regular guidance/motivation from their supervisors. If available, they need someone as their role-model or example, a spiritual leader or symbol, which can inspire them to achieve the highest possible cure-rate - more than 85% - each and every year.

Just as TB patients have to strictly comply with their treatment, the health care workers also have to strictly comply with the National/WHO TB programme guidelines. The health care workers have to do their utmost to always keep every patient on regular treatment. In the course of time, health care workers may become fatigued and their performance dwindle.

I developed the TB Programme of the St. Carolus hospital, Jakarta 23 years ago. Each TB centre (there are 5 of them) is integrated with a community health centre. Our source of inspiration is St. Carolus, our patron, who gave up everything to serve the poorest people who could not flee and were left helplessly stricken by the 'black scourge' - pestilence (by the way, TB is also known as the 'white scourge').

The TB nurses also have other time-consuming tasks at the community health centre with its many public health programmes. These nurses are the very ones to constantly guide and motivate the TB patients. They have to see to it that patients always come to the centre on time. They keep very meticulous administration records on the performance of each patient, conscientiously calculating patients' drug intake every month.

Special control systems have been invented to detect defaulters early and to notify the home-visitor at once.

Whenever guidance/motivation has not been up to par, very poor, under-

educated patients may skip treatment from the start, especially when there is no treatment observer (preferably, the nearest kin). The more remote the patient lives from the centre, the more intensive the motivation process should be, because, the administration and management of many defaulting patients makes work very difficult. The programme achievement, in terms of cure rate, may drop to below 85%. Poor programme performance leads not only to increasing numbers of multi-drug resistant TB cases, but also adds to the number of respiratory cripples. They are the crux of every TB centre as these patients can not be cured but keep on visiting our centres.

Before embarking on treatment, the patient would be conditioned to declare that (s)he has a full understanding of the disease and is now ready and eager to undergo treatment until complete cure. On that very occasion, the TB nurse and home visitor would express their commitment also to see to it that (s)he completes full treatment. In a situation of mutual respect, trust and understanding, our centre never needed any contract to be signed by the patient.

The home visitor would consult the TB nurse, if after several home-visits and personal motivations he still failed to get the defaulting patient back to treatment. The problem that arises is whether to finally let the patient go (hence to be reported as 'drop out'). After consultation and counselling, the decision would be put upon the home visitor's shoulders, whilst considering what his belief would dictate ('to forgive', even if patients default).

This is an enormous strain on the part of the home visitor. In our programme, there are no patients who can not be found, even if the data on their ID cards was false or obsolete. Patients' address registration is very accurate, even if they live in unregistered, impoverished,

self-made huts along riversides, under bridges or at railway platforms.

And there is no patient 'too far' to be visited (if patients were able to visit our centre, why should the home visitor with his motorbike not be able to visit defaulters?). Furthermore, the compliance rate (of at least 90%) for every patient, as calculated by the nurse, has to be maintained, hence defaulting patients should be visited without delay (usually within 24 hours).

Before our TB centres came into being, all health workers who in some way or other have contact with TB patients would receive extra meals: bread, eggs, vitamins and milk. This has since been abandoned. There has been not a single TB case amongst our TB workers. Ironically, TB cases have just been found among the general health workers, who had only incidentally contacted TB patients.

In our programme no incentives or enhancers have been provided. Not for our diligent patients, nor for our very dedicated health care workers. Looking back at our programme in a developing country with high TB prevalence and meagre income, I feel now, that it would perhaps be better if (financial) arrangements could be made as a reward to those (TB nurses and home visitors) who were carrying out enormous tasks towards achieving a successful TB Programme.

Our key targets are:

1. A patient is declared cured, if the drug intake was at least 90% of the treatment plan.
2. A TB programme is successful, if more than 85% of the treated patients were cured.

Muherman Harun
Email: mhjkt@attglobal.net

Front-line workers need training

Dr Will Parks

There is a need for front-line health workers to develop skills in working with non-health partners.

In an effort to respond to the most needy, many countries have decentralised their health systems with a strong focus on the district level. The district level focus offers a comprehensive overview of local community problems and constraints. At the same time, the district level accommodates significant public sector infrastructure for service delivery. Moreover, districts are usually managed by a small group of key officers and this facilitates interaction and coordination between different government departments, community-based organisations, non-government organisations (NGOs), and other local stakeholders.

Decentralisation is important in reducing delay to diagnosis and treatment for HIV/AIDS and TB, but is also creating a need for new skills among health workers and their district-level implementation partners. For example, there is a need to rectify poor public and private health worker practices (especially diagnosis, counselling, and drug dispensing). There is a need for district staff to

know how to advocate for (e.g., use local media, call for greater district budget allocation, etc.), manage, monitor and evaluate programmes. There is a need for front-line health workers to develop skills in working with non-health partners. There is a need for front-line health workers to understand and implement gender-sensitive and pro-poor interventions. There is a need for district health workers to understand how to involve private practitioners and traditional healers where research with these groups indicates such collaboration is beneficial. There is a need to establish local occupational health and safety regulations and monitor their implementation. There is a need for district level staff to develop good communication skills both in health facility and community-settings as well as with special groups such as immigrants, refugees, drug users, the homeless, and so on.

Despite these often quoted district-level needs, national/central level staff are usually the only ones who have access to skill-building opportunities

and very few learning outcomes from national workshops “trickle down”. Evidence and experience to date strongly suggest that the scarcity of skills at the district level contributes substantially to most programme implementation failures. Unless we address the lack of skill-building opportunities for front-line health workers, nationally devised HIV/AIDS and TB programs will not deliver results where they matter: at district and community levels. Training activities could be innovated by the revolution in information and communication technologies. Front-line worker capacity-building initiatives must become a high priority.

Dr Will Parks

Senior Adviser Public Health and Health Promotion,

JTA International, Brisbane, Australia and Member of the Advocacy,

Communication and Social Mobilization Working Group, Stop TB Partnership

Email: Will.parks@jta.com.au



WHO/TBP/Gary Hampton

HIV-positive Betty Nanyazi puts on plays about HIV/AIDS and TB to sensitise communities, Uganda



Front-line health workers – crucial to tackling TB and HIV related stigma and discrimination

Andy Seale

The role of health care workers throughout the world is crucial to an effective AIDS response for a number of reasons. Health care workers not only contribute in the obvious way through staffing essential health services that directly save and prolong lives but they are also critical in challenging the stigma and discrimination that still violently threatens an effective response to AIDS.

The impact of stigma and discrimination has long been documented - ignorance and fear around HIV and AIDS can lead to communities stigmatising those most associated with the epidemic. Stigma and discrimination combine to create an environment where people are less likely to confront HIV. As we know, inaction – whether it is from governments or individuals – can be fatal.

Stigma and discrimination present a complex challenge because we know that when there is a greater uptake of HIV and AIDS services communities often start to break down the cycle of fear, denial, stigma and discrimination. This helps to create the kind of environment where stigma is less likely to take hold in the first place. It is therefore absolutely crucial that the health care environment is free of stigma and discrimination – placing considerable responsibility on the shoulders of health care workers.

Sadly, and despite the awe-inspiring work of many health care workers around the world, surveys from a wide range of countries have shown a significant number of health care workers admitting to having refused to care for an AIDS patient, or had denied HIV positive patients admission to a hospital. People all over the world have experienced discrimination at the hands of health care workers with many denied medicine because of their HIV status – yet ironically we know that greater access to care and treatment is a key factor to undermining stigma.

Health care workers play a crucial role at every level in ensuring that services are stigma-free and non-discriminating. And when they interact within their communities outside of work they are also

We all owe it to health care workers around the world to think creatively of how we can best capture and document the positive impact they have on influencing attitudes and challenging stigma and discrimination.

in a strong position to enlighten others about the realities of HIV and AIDS and challenge stigma.

Who is better placed to talk candidly about the challenges and realities of people living with HIV and AIDS outside the infected and affected communities themselves? Surely it must be the people who work most directly with people living with HIV and AIDS? The role of health care workers must not be underestimated.

Increasing access to treatment is one of the most powerful incentives for individuals to discover their HIV status and the prospect of a longer, more productive life for individuals encourages communities to reassess the way they relate to people living with HIV, creating a sense of hope and reducing the feelings of threat and burden which can trigger stigma in the first place.

Other powerful efforts to curb HIV-and AIDS-related stigma and discrimination are driven by the involvement of people living with, or affected by, HIV or AIDS. Where health care workers nurture close relationships with their clients there is always less stigma – both in the health care setting itself and often in wider communities. HIV and AIDS-related stigma and discrimination often builds on pre-existing social inequalities, prejudices and patterns of exclusion, and further marginalises people who are already most vulnerable to HIV. These groups, depending on the national context, can include women and girls, men who have sex with men, sex workers and their clients, injection drug users and sexually active young people. It is essential that health care workers are supported to interact effectively with marginalised groups and to reflect on how they can work with them to combat stigma and discrimination.

The stigma around death and AIDS remains high in many contexts and is one area familiar to those also working in TB. Families often prefer to record the death of a loved one as TB-related rather than AIDS-related as they perceive there is less taboo around dying of TB compared to AIDS. When we look at the reasons for this stigma we can see it is usually driven by ill-informed concepts of 'innocence' and 'guilt' around modes of transmission. We can then understand why TB can be more 'acceptable' to some people. Health care workers are uniquely placed to be able to remind people that these are both 'diseases' that require a dignified and professional response.

Much can be done to improve health systems and country-level capacity to deal with both AIDS and TB but as we all rally and advocate for improved health infrastructures and scaling up of interventions – let us not lose sight of the crucial role health care workers also play in fighting stigma and discrimination.

We all need to do more to acknowledge and support this vital role. But this is not easy. The negative consequences are all too obvious when stigma and discrimination occur in health settings but it is hard to measure how health care workers contribute to positively changing attitudes and challenging stigma. Yet it is not impossible. We all owe it to health care workers around the world to think creatively of how we can best capture and document the positive impact they have on influencing attitudes and challenging stigma and discrimination. Their work in this field is truly invaluable.

Andy Seale
Advocacy Adviser
UNAIDS
Email: sealea@unaids.org



Study on front-line health workers in TB control (2)

Dr A A Kameswa Rao,

The main question/problem with regard to TB control in India is how to improve the grass roots level situation. To achieve this, we have to answer and find solutions to several questions, such as:

- How can we improve case finding as a whole and particularly outreach?
- How can we improve case holding and how can we reduce defaulting?
- How can we make direct observation perfect?
- How can we improve DOTS as a whole and make it qualitative and quantitative?
- What type of operational research is needed at present?
- What type of control policy is needed now?
- How can we reduce multi-drug resistant TB (MDRTB)?

The study revealed the following problems.

- Outreach problems
- Diagnostic problems
- Side effects of drugs
- Transport problems
- Financial problems
- Community insensitivity
- Lack of self referral

- Quacks (unqualified medical practitioners) problem
- Lack of incentives
- Overburdened staff

The study also provided the following solutions and suggestions.

- Door-to-door search for patients with chest symptoms
- Health education - approached through the village leaders for confidence building
- Removal of fear of side effects
- Group meetings to increase compliance
- Frequent house visits
- Lab technicians at local level, sub centre level/Lab technicians in villages with large numbers of cases
- Village TB clubs with leaders and patients

Discussion will be continued part 3

With regards

Dr AA Kameswarao, MD
India
Email: avasara@yahoo.com



WHO/TBP/Davenport

Careful record keeping prevents infectious patients from vanishing, Dhaka, Bangladesh



Study on front-line health workers in TB control (3)

Dr AA Kameswara Rao

How can we improve case finding?

Screening for chest symptomatics by health team: Almost every village in India has chest symptomatics who complain of chronic coughs or chest pains or hemoptysis. A feasible mechanism has to be developed to find these patients, among whom some will be sputum positive for acid-fast bacilli (AFB). All the human resources (of health and non-health sectors) available at village level have to be efficiently utilised to screen for sputum positive cases. This can not be done by the health sector alone without the cooperation of agricultural assistants, village leaders, teachers, anganwadi workers etc. A health team has to be formed by including all these people, whose ultimate concern is also nothing but the welfare of the people. Our national health policy strongly recommends health turnover by health teams.

The question is how to make this practical and feasible. This can be achieved by strong motivation at personal, family and community levels through intensive health education using television, radio, cinema, sportsmen, film stars etc plus some incentives. This should be done on a war footing basis. A planned approach with measurable targets and inbuilt evaluation to improve case finding at sub centre level (sub centre action plan) is urgently needed. Mothers' leaders, youth clubs, and agricultural assistants, and non-governmental organisations have to be utilised. School children and college students have to be involved for motivation and propaganda, particularly with their family members.

Solving the problems of front-line workers: Problems faced by the front-

line workers have to be attended to urgently. Surveys need to be regularly conducted to discover the lapses and for corrective action to be initiated. In this study, most of the front-line workers asked for lab technicians at sub centre level to improve case finding and complained that lab technicians located presently at primary health centres are not easily accessible for sputum examination. This additional input is worth considering as it has several advantages. The advantage is that the patient himself, without any motivation, may come for sputum examination as the facility is within reach (in his own village or nearer than the public health centre) and without any travel. He need not be absent from his daily work. Moreover some poor and old TB patients who are left in the house without help can come for testing if the facility is within their reach and they can get there without any expense. This is the reason why some poor patients first get treatment from quacks, who go to their houses and dupe them.

Next is the outreach problem: Urban slums and tribal areas are particularly lagging behind in case finding activities. Our front-line workers face lot of problems regarding transport, geographical terrain etc.

The urban slum problem: Urban slums with poor illiterate people, unemployed youth, and poor availability of health facilities pose a great challenge for case finding. These settlement colonies contribute to the spread of TB particularly in cities. The urban TB control units are now over-loaded with work.

Most front-line workers stressed the need for strong motivation. Here the

problem is un-organised community. Here best solution is to utilise non-governmental organisations (NGO) in TB control. These NGOs have a good reputation in these areas.

The tribal area problem is peculiar. People are not only illiterate but also strongly believe in superstitions. They believe their priests only. We have to first motivate and change these influencers, as these are strong advocates of supernatural theory of disease and source of all superstitions. Here under reporting is the rule. Very often, these people believe in plant juices, and roots etc. to cure the disease. They have less faith in allopathy. The other main problem here is difficult geographical terrain and lack of transport for both the patients and health workers.

Most of the front-line workers do not have enough skills and evidence to motivate these priests and hence fail in their work. They need intensive special training to face these problems. Community sensitisation is difficult here. Additional inputs, akin to drug distribution centres and fever treatment depots in malaria control, have to be established. Visits by front-line workers to these areas are very infrequent. They have to be given some extra incentives while they are working in tribal areas. Usually the teachers in tribal areas are a good resource to be utilised, frequently they are the healers also. They have to be taken into confidence and utilised in case finding activities.

Dr AA Kameswarao, MD

India

Email: avasara@yahoo.com



The unsung heroes of TB control

Unsung Heroes: Minds without fear and discrimination

Milan Dinda

Primary care-givers in India may be living on the edge themselves but still find the resources to help those with TB

Primary care-givers in India may be living on the edge themselves, but still find the resources to help those with TB. We look at a few personal stories

More adults in India die from Tuberculosis (TB) than from any other infectious disease. Although the number of men who are diagnosed with and die from TB is higher than that of women, it is still a leading cause of death amongst females. It kills more women of reproductive age than all other causes of maternal mortality combined. As tuberculosis affects women mainly in their economically and reproductively active years, the impact of the disease is also felt strongly by their children and families.

Indian women who suffer from TB face special constraints. They tend to neglect their illness due to household responsibilities until they become too sick to attend to their normal duties. They are often dependent on others to get necessary medical attention (Source: Revised National TB Control Programme document). Here we highlight some of the 'Hidden Heroes' of rural healthcare, both men and women, who are working to improve their community's access to treatment.

Peer educators at Bangalpur Women's Credit Cooperative, Howrah

Bangalpur Women's Credit Cooperative has mobilised and organised around 8,000 women to participate in savings and income generation activities. The cooperative is committed to providing accurate information on TB as well as DOTS, a method of peer-observed treatment that helps ensure adherence to regular drug regimens.

The cooperative achieves this aim by using peer education, and has now created forty trained educators with the support of CARE India (West Bengal), an international NGO.

Focusing on community mobilisation, the credit cooperative has paid special attention to removing the many myths and misconceptions related to TB and its treatment. And there is practical help too; all forty-peer educators are also working as community based DOTS providers to help TB patients. As a result of patient confidentiality assured by the team, more and more women are coming forward for the treatment, and in the last 11 months the team has helped 90 women become free from the disease.

Lilima Begum, wife of a migrant jute mill worker

Lili, as she is affectionately known, is a 35-year-old woman who lives with her children and in-laws in a small, ramshackle house in the interior of Howrah district, West Bengal. Hers is a migrant family from Bihar, and her husband is a jute worker, presently jobless from the sudden closure of his mill. This has left Lili as the sole breadwinner, earning a meagre 100 rupees (US \$2.2) per month as a 'community volunteer' for Jhumjhum TB Unit.

Despite these hardships Lili is an inspiration in her dedication to her community. Spirited and dynamic, she has an ability to be both inspiring and convincing. She has become well respected in the seven villages, including her own, in which she works, catering to a population of over 15,000.

In her first year, Lili worked as DOTS provider for 11 TB patients, and all of them have since successfully completed their treatment. Her competence with the technical facets of DOTS is notable, but her success also rests on her sincerity and meticulous effort.



WHO/TBP/Arnold

Local nurse with TB drugs, Mandalay, Burma

Women like Lili live behind the shadows of poverty, their service to the community seldom recognised by state healthcare providers. But the blessings and thanks of the sick and dying remain unfettered.

In the face of severe economic hardship, some might say this is not compensation enough. Yet given the socio-cultural realities in Indian communities, Lili represents a real effort to reach out to rural women suffering from TB.

Ekramul Haque, a 'bare-foot doctor' in Malda

From dawn to dusk, Ekramul Haque tries to convince clients with three weeks or more of persistent cough to report to their nearest state microscopy centre for sputum test. He also motivates imams to follow up on those who are put on DOTS regimes.

Ekramul has been helping people with TB since the beginning of 2003, following training provided by CARE. He has become very popular in 13 villages, where he is known as the "TB Doctor". Since starting his work, Ekramul has provided care to 81 TB patients, 59 of whom have now been

cured. The remainder continue to benefit from his support with DOTS, with a hope that they, too, will soon be free of the disease thanks to the TB Doctor.

Becharam Malik and Kumkum, Howrah

Twenty-nine-year-old Becharam Malik, a carpenter in Howrah, helps dispell the myths and misconceptions relating to TB, and provides a similar service to Ekramul.

Right now he is referring those with chest symptoms to their nearest microscopy centre, acting as a community DOTS provider and declaring those who have been successfully treated as cured. So far Becharam has helped 24 TB patients successfully complete their treatment.

Kumkum, a 19-year-old housewife

Wife of a migratory jewellery worker, Kumkum dedicated herself to TB healthcare with conviction. Her own experience of the disease is a motivation, since she and her one-year-old daughter were discriminated against by the community because of her husband's TB.

Kumkum has turned this experience on its head, and now disseminates scientific knowledge regarding TB and its treatment using the example of her now-cured husband. She has become well accepted thanks to her dedication to breaking the cultural silence about TB. And thanks to her efforts 15 TB patients have been successfully treated through DOTS.

Thanks to the work of Kumkum and people like her, basic healthcare services like DOTS are being provided to the doorsteps of people who would otherwise be unreachable. Only in this way will the tide of TB be turned in areas where committed 'Unsung Heroes' are the only available resource to fight the disease.

Milan Dinda
HDN Key Correspondent
India
Email: correspondents@hdnet.org



Unsung Heroes: Peru

Lucien Chauvin

Health Minister Fernando Carbone says the DOTS programme – started in 1990 – is successful for one reason – its personnel.

Elena Cubas' life changed dramatically one dreary winter day four years ago when a doctor told her she had multi-drug resistant tuberculosis (TB). Her husband left her. She lost her job. Friends and family drifted away and the medication she was given kept her bed-ridden for three months.

Only her mother stood by her, nursing her back to health for 18 months and caring for her two young daughters. "I felt very alone, marginalised even by my family. The illness is hard enough, but the social stigma makes it so much worse. There were many times when I was ready to give up," says Cubas.

Each morning, a staff member from the local health clinic would drop by Cubas' home with the 11 pills and three injections she received daily to beat the disease. Sometimes the health worker would stay but mainly it was her mother who made certain Cubas took the medication. Apart from the TB medication, she also took pills to mitigate effects on her liver and kidneys and to control nausea. The entire treatment process, which is free under the Peruvian government's TB programme, took 18 months.

What changed Cubas' life was her decision to take part in the Victoria Castillo de Canales Association of Tuberculosis Patients in Comas, a sprawling, poor district in Lima, Peru. The association started 26 years ago and brings together people from government-sponsored TB programmes in 12 health clinics in Comas. It is the largest group of its kind in Peru with roughly 80 people participating in weekly meetings. The association's participants represent nearly 12,000 people in Comas who have TB or, like Cubas, are recovering from the disease and want to give something back.

Cubas joined the group in 1999, while still suffering from TB but when no longer contagious. Cubas began participating in activities and took part in a leadership-training course offered by the association. Several years ago she was elected president

of the association. "We are the strongest group and our members are helping others with the illness to realise that they are not alone, that they can beat the disease and the marginalisation. We are an example others can follow," she says.

Enrique Matta, who recently finished a six-month TB treatment programme, began the discussion at a recent meeting, telling the other participants how important it was for him to have been supported throughout the process.

"The solidarity of other patients helped me recover because I was able to see that they could do it and that they could overcome obstacles. We have to be here for others. I will continue participating in the group because I want to repeat the experience I had with others," said Matta.

An integral part of the association's work is collaborating with the health centres that form the backbone of the Peruvian government's tuberculosis programme, lauded by the World Health Organization (WHO) as one of the best in the world.

Health Minister Fernando Carbone says the DOTS program, started in 1990, is successful for one reason - its personnel. "The key to success is our personnel. Peru's health care workers have completely bought into the programme, actively looking for every case of tuberculosis. They follow each case closely which is why our strategy is seen as a model around the world," says Carbone.

Cubas attests to this, saying that the health worker on her case visited daily as soon as she was diagnosed. "She was always there making sure I took the medicine and following up on family, friends and contacts to ensure that it does not spread," she says.

Health promoters are an integral part of the Peruvian government's anti-TB programme. They are chosen from the community and, according to Dr Alfredo Villanueva, who coordinates their work at

a clinic in Comas, this allows them to reach out to their neighbours and break down initial fears and the rejection that comes with a positive diagnosis.

Villanueva works with four promoters, all of whom are trained in the DOTS methodology. The promoters have identified 36 new cases in the area covered by his clinic in the past few months, including four multi-drug resistant cases.

While Cubas says the government programme is good, she complains that the view is too narrow, focusing mainly on the medical side. Cubas would like to see the government expand the nutritional side of the programme, offering patients food and dietary supplements that help mitigate the side-effects of the medication. Under the current program, patients receive dairy products through a special programme for school children and receive some food products.

She wants the Health Ministry to carry out public awareness campaigns, to let the general public know that TB patients do not need to be isolated.

"We have to defeat ignorance. When people hear you have TB, they think you have some sort of plague. Changing the preconceptions is the only way to help us beat marginalisation," she says.

Carbone agrees, but says addressing the problem goes well beyond the scope of his sector. "Tuberculosis can't be treated only with medicine. We have to address the issues of poverty, of chronic malnutrition, which create ideal terrain for infectious diseases. We have to eliminate the causes of infection, but this means a concerted effort on the part of the government and society in general," he says.

Lucien Chauvin
HDN Key Correspondent
Peru
Email: correspondents@hdnet.org



Unsung Heroes: TB health workers on the front lines in South Africa

Lewis Ndlovu

“Dedicated front-line health workers are making a difference, reaching out to the most vulnerable” – Dr Mario Raviglione

“Dedicated front-line health workers are making a difference, reaching out to the most vulnerable,” said Dr. Mario Raviglione, Director of WHO's Stop TB Department. The story of a community front-line health worker (e.g. a lay health advisor, outreach worker etc), of reaching and improving the health of individuals seems ordinary, yet it is these extraordinary people who are crucial to public health and social services.

Community health workers are able to weave together an agenda to help change individual circumstances while ensuring access to appropriate health care services.

Too many individuals don't receive assistance and are unable to find their way to appropriate and effective health care as the walls around the systems appear to be too high for them to scale.

South Africa is a huge country at the foot of the African continent. It covers 1.2 million square kilometres (463,322 square miles), with a population of more than 45 million, mostly city-based. Public health care is free to pregnant women and children under six; others pay on a means-tested, fee-for-service basis.

We spoke to Dr. Mtshiyen Ka-Ndhlovu who is a tuberculosis (TB) front-line health worker within the Department of Health in Cape Town. These are his views based on a one-to-one interview. Dr. Ka-Ndhlovu has been in the forefront of fighting TB especially in the local communities of the city where many people live in make-shift dwellings. He regularly visits Khayelitsha, Langa and other places

to educate people and to see those affected by TB.

Q: Do patients and front-line health workers cooperate?

A: So many patients are lost to follow up, and efforts need to be made to promote better adherence and to achieve better treatment outcomes. Some patients and health workers do cooperate accordingly.

Q: What resources or educational methods do you use to reach out to people?

A: There has been a slight lack of capacity but a few resources have been developed for medical practitioners and training workshops are being held in most areas. Training manuals developed by the World Health Organization have also been introduced to trainers of facility health-care workers.

Q: Are these educational materials only for trainers? What about ordinary community folks who need to be educated about TB? How are they reached?

A: Community awareness programmes about TB, through sustained and highly visible campaigns, have been implemented. These campaigns have been used to advocate the need for more resources for TB control at all levels of the government and to bring together all partners involved in TB control.

Q: How is the DOTS [directly observed treatment short course] strategy implemented?

A: A few public and private hospitals, as well as prison health services implement DOTS. Several large private

corporations, in particular the mining sector, provide DOTS through their corporate health facilities.

Q: What are the responsibilities of the Department of Health?

A: The Department of Health provides general guidelines, but implementation and delivery of services is the responsibility of the provincial authorities.

Q: How are health worker's services managed?

A: The management structure and the implementation of TB control services vary considerably among provinces. There are developments of administrative districts, with health management structures in each province.

Q: How are tests or samples done? Do you do them yourself or are they taken to a central facility?

A: The National Health Laboratory Services (NHLS) is the main provider of TB laboratory services in eight provinces in South Africa and is divided into central, coastal and northern regions. Health workers only do minor tests and refer the patients to the clinics or hospitals.

Q: Is the local government doing enough especially in funding TB-associated projects in your community or the country?

A: The government should allocate more funds to TB and make more commitment to TB and the health care workers who deliver the DOTS strategy and health care. More stakeholders and NGOs can also help in the fight against TB because this is now everyone's responsibility and not that



of government alone. We all have to face this crisis and fight the epidemic. There is a serious discrepancy in health spending between the nine provinces; with some rural ones actually cutting health budgets in favour of education.

Q: What is the most effective treatment of TB?

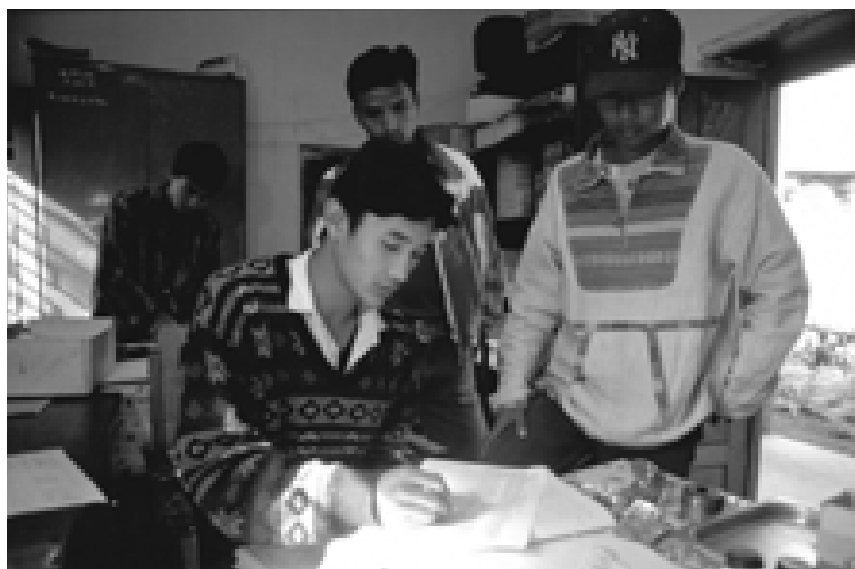
A: TB drugs must be taken regularly, and for a sufficient period of time, usually six months, in order to destroy the TB bacterium. Effective treatment depends upon the initial phase in which drugs are used in combination to kill rapidly multiplying populations of the TB bacterium, prevent the emergence of drug resistance, followed by a phase in which drugs sterilise and kill the remaining bacterium.

Q: Has there been a great change or shift in your profession or that of health workers as a whole?

A: Prevention was a hallmark of health providers' work many years ago. Community health workers used to conduct outreach, back when physicians made house-calls, and public health nurses delivered services and conducted prevention activities. Now we are armed with more information and education. Ever since apartheid ended in 1994, there has been a massive shift from racially biased, hospital-based curative care to easily accessible primary healthcare.

Q: So many people think it is dangerous for front-line health workers to go into neighbourhoods, or that greater quality could be assured if everyone came to a central facility. Some think it's not modern for medical personnel to go out where people live. How true is that?

A: Not everyone can afford to come to a central facility. Being a health worker is a dedication. Not everyone can do it. Like most professions, there are risks involved and one has to be alert at all times. You do get one or two people who don't want help and won't allow you into their homes, but again this all boils down to educating the



A social worker registers new TB patients, Bhaktapur, Nepal

WHO/TBP/Davenport

people about the greater dangers they might face themselves. Knowledge is powerful.

Q: What other attributes do front-line health workers need to possess in order to conduct their jobs in a more satisfying manner?

A: The gift of communicating, reaching, and touching individuals effectively in order to heal is perhaps the most promising hope that we have of eliminating health disparities while we mend a broken health care system. Using front-line health workers works well in bringing people into care. TB health workers need to be way ahead and knowledgeable about the latest trends and practices, medical information and any other information pertaining to TB. It is very crucial to know and understand your field very well.

Q: What do you base your profession on?

A: Reaching out into homes and communities to promote healing, educating people and promoting wellness especially to those affected and infected with TB is an integral part of my practice.

Q: Is there one way you can prevent

yourself from catching TB as a health worker? What are the chances of catching TB infection?

A: There is no one way of protecting yourself against the spread of tuberculosis, but there are a combination of steps you can take. It's important to remember that TB is spread by germs in the air.

Q: What steps do you take as a health worker in ensuring that you are not at risk of being infected with TB especially working with a lot of people who have TB?

A: In order to prevent tuberculosis as a health worker or in any health care facility, it is important to follow a strict regimen of health practices just as you would with any other disease. In health facilities, the air must be filtered. This may not entirely eliminate the risk, but it has been shown to lower it. Even after following these measures, they must still undergo testing to ensure that they are not infected with TB. It is vital to us as health workers to be on the precautionary side at all times.

*Lewis Ndlovu
HDN Key Correspondent
South Africa
Email: correspondents@hdnet.org*



Unsung Heroes: TB carers in Kenya

Edwin Limo

“Most of the patients that have been to big towns are likely to be HIV positive. Although we can fully test their status here, our hands are tied, as consent must be sought from the patient” – Dr Samuel Pilipili

In a remote centre in Kenya called Loitoktok live the Maasai, a nomadic pastoralist group. The Loitoktok sub-district covers an area of over 6000 square kilometres and has a population of about 100,000 people. The majority of the population live in small, dark, humid huts with poor ventilation.

Dr Samuel Solonka Pilipili, together with two nurses, runs a donor-funded project also supported by the Kenya government. He has adopted the World Health Organization's directly observed treatment short course (DOTS) regime in this mission. This clinic, called Manyatta, was set up in 1996 and consists of 15 huts, supposed to host five people each. At the moment, however, the huts are overstretched with 106 patients. They are 260 km from Nairobi, an eight hour trip by a dirt road that is impassable in the wet season.

A heart-rending story from Manyatta is that of a family of five. Ngina and her three children owe their lives to a good samaritan who was alerted by neighbours of the sick family. Ngina had a 9 month old baby who succumbed to tuberculosis a few days after arriving at the Manyatta Clinic.

She tells her story; "It started with a flu-like illness, with a cough from one of my sons who was treated for pneumonia in a nearby clinic. Nothing improved and soon all of us were coughing. My husband started coughing too but was not keen on having us seek treatment elsewhere since he had not appreciated the gravity of the matter," says Ngina.

Ngina continues: "When our neighbours noticed we were not coming out they asked a businessman who had come around to buy skins to bring us here (Manyatta, 80 kilometres away). When we tested positive for

TB, we were asked to remain here for treatment. My baby died after a few days," she says sobbing. "Dr Pilipili sent for my husband who was also infected by TB. He went home today to bring maize flour so that we can make porridge for the children to subsidise the ration we get here," she adds.

According to Dr Pilipili, Ngina's story illustrates the difficulties almost all his patients go through to reach the clinic. "A woman might complain of sickness, but the man will just postpone or send for paracetamol from the shop. It's only when things get worse, like a patient coughing blood, that a man agrees to take his wife to hospital," says the doctor.

Next door to this family's hut is another couple with their two-year-old daughter. The man, James, used to work at a tourist hotel in Kenya's coastal town of Malindi. When he became sick, he was told at a dispensary there that he was suffering from the effects of the ocean breeze since he was a night watchman. This was in November 2001. He was later diagnosed with TB and was put on treatment (not in Manyatta), which he says he completed. When he came home, the sickness seemed to recur, and meanwhile his wife became infected, along with their daughter. They have now been at Manyatta for three weeks and he says; "I am feeling much better now. I had started dreaming about death." According to Dr Pilipili "Once a member of the family becomes infected, it is almost natural that all the others will too," adding that he tests all family members once he detects one among them has contracted TB.

Sadly for James his story may not end there. Dr Pilipili says his diagnosis may not just be TB. "Most of the patients that have been to big towns are likely to be HIV positive. Although we can fully test their status here, our hands are tied,

as consent must be sought from the patient."

So far James has declined to be tested although he has gone through mandatory counselling which all TB patients are put through to prepare them for post-HIV-test eventualities. Dr Pilipili says there is a strong link between TB and HIV/AIDS.

According to Dr Pilipili, the stigma attached to TB, unlike in the days gone by, is no longer a problem. "Previously, this disease has been associated with witchcraft and therefore nobody sought medication or even admitted they had it. It was just like the stigma currently faced by those who are HIV positive. I am happy however that the community is now a bit enlightened and actually acts as a watchdog," says Dr Pilipili.

He is quick to add, however, that illiteracy is still the biggest hindrance to achieving 100 per cent success in dealing with TB. He says DOTS helps a lot since patients are monitored closely and interact with one another. "After four months here, they realise their case is not unique. When we release them and explain in their mother tongue (Maasai) how they are to continue with their medication for the remaining three months, they faithfully adhere," he says.

Since the project is funded by foreign agencies through the government, cases of the facility going without medicine are very rare. "We normally have a six-month buffer stock and apart from some little logistical problems to do with transport once in a while, the mission is running well," says Dr Pilipili.

Edwin Limo
HDN Key Correspondent
Kenya
Email: correspondents@hdnet.org

Community engagement

Front-line: Care about the community?

Nipaporn Intong

Due to inadequate public awareness, people still don't know enough about the 'hidden killer'

Community approaches to the control and treatment of HIV/AIDS are well accepted. Will the Thailand employ them to treat TB too?

Perhaps it was her own commitment to healthcare that inspired Dares Chusri to work so hard to find a new way to curb the tuberculosis (TB) epidemic in Thailand. Thinking back to 25 years ago, when she was a nurse in a TB ward, she remembers well the discrimination her patients suffered. Nobody was happy to have close contact with them, because the disease could be contracted through inhalation.

But even now, explained Dares, people still have the misconception that TB cannot be cured. Due to inadequate public awareness, people still don't know enough about the 'hidden killer' – 'hidden', because it lies dormant inside the body and only attacks when the host is weak. Dares now devotes her experience and commitment to people's health to the control of the 'hidden killer' in her native Thailand.

Dares's concern about TB control grew when she became conscious that unlike HIV/AIDS, TB was becoming a neglected disease in Thailand. Though the country had secured nationwide DOTS coverage since 2002 and achieved the global target for new

sputum smear positive tuberculosis case detection in 2003, the treatment success rate continues to be far below the expected target and too many patients die, fail to complete their treatment or are lost to follow up.

The name of Thailand continues to figure in 'infamous' list of 22 high TB burden countries. Even in the WHO Report Global Tuberculosis Control 2005, the country is ranked 17th by estimated number of cases. Dares speculates that something has gone wrong with the TB control programme in her country. In her opinion, the government has to reconsider its usual reliance on a 'service provider approach to healthcare' and reposition to a 'community-based approach'. The lessons learnt from active community participation in HIV/AIDS prevention and control can be replicated for the TB control too, she believes.

This strong belief in a community approach lead Dares to work as a community group manager with the Duang Prateep Foundation, where she has been since 2002. She is now implementing a pilot TB control project in Slum Klong Teoy, Bangkok. With 137,444 residents, Slum Klong Teoy is the biggest of 50 slums in the city, and is a big hub for migrant workers, both domestic and foreign. Poverty, crowded housing, poor sanitation and population mobility all

contribute to the transmission of TB in and around the slum. Many slum residents also carry TB back to their original homes, or on to new areas.

One reason for her devotion to this project is that TB is the number one killer of those with HIV/AIDS. Controlling TB, she says, can greatly prolong the lives of people with HIV/AIDS. A further reason is that a prime problem is relatively easy to solve; people in general lack awareness of TB, yet with education comes early diagnosis and treatment, greatly retarding the spread of the disease.

Dares' experience in Slum Klong Teoy provides a valuable lesson for others. Her first act in her new role was to identify and recruit a number of slum residents to join a 'community volunteer taskforce'. She trained her team about TB so that they were fully aware of the symptoms at the onset of the disease, and of how it can be prevented, diagnosed and treated. Volunteers also attend workshops and make visits to learn more about TB prevention in other places. Given these capacity-building activities, Dares feels confident that her volunteers can reach out and recommend patients for treatment, refer suspected TB cases to local health centres, and provide follow-up and home visits.

She is convinced that the volunteers



know the community situation better than outsiders, and can therefore also help plan project strategy. Indeed, Phase 1 of the project was completed last year thanks to the assistance of her volunteers in completing a needs assessment and community action plans.

"It is a tiring task and time consuming too when we try to involve the community for any development project," Dares admits, adding that flexibility and patience are key to success. Yet despite challenges associated with mobilising a community response to TB control, there are plenty of rewards. For one, she has a large body of volunteers to help identifying needs and problems, develop action plans and educate others about TB. Some volunteers are so effective they were referring suspected TB patients to the local health centre within a few training workshops, she says.

Speaking with TB patients themselves, Dares learnt most of them sought diagnosis and treatment only when they were too sick to work. This drives her to try and provide TB education and information as early as possible, before people get ill or can spread the disease. If things go as well as expected, the volunteers will indeed encourage slum residents to come forward for early TB diagnosis and treatment. The aim, of course, is that the whole

community will gradually have fewer TB cases until TB transmission has been fully interrupted. Lessons from this project will be shared with other TB programmes in the near future, confirmed Dares.

Phase 1 of the project received much deserved funding from the Office for Health Promotion, but in general Dares has encountered a lack of financial resources. Dares attributes this to the fact that the concerned sectors in government have not prioritised TB as highly as HIV/AIDS. And no governmental health agency seriously thinks of involving communities in TB control and prevention, she says. Health centres are doing well at treating the patients who visit them; but not everyone can afford or wants to go, and for them the centres offer nothing. Dares fears that community involvement in TB control will go nowhere if government policy remains inflexible and funds are not made available.

Dares needs more money to run her activities and subsidise the community volunteers. Her volunteer team are all poor, she points out, so even a small financial compensation for any loss of income is adequate. If possible, she would also like to request health allowances for the TB patients who are family heads. Treatment can take at least six months, during which period the major breadwinner in the

household is unable to work.

These are just a few examples of the obstacles to long-term TB control in Slum Klong Teoy. Dares particularly highlights the need for sustainable mechanisms to ensure a continuum of TB control activities, which she sees as only possible through partnership between the community and government health agencies; neither section can do it alone.

Dares's last word is on decentralisation of government health budgets to empower community organisations so that they can play an effective role in TB control and prevention. Unequivocal support in this area is urgently needed, with a simplified funding process and criteria to maximise access.

In the meantime, Dares will continue with her inspiring work, although funding is a perpetual worry; she currently has no support for Phase 2 of the project. Yet she remains confident that the government will soon realise the important role of affected communities themselves in helping to stop TB, as is already happening in the field HIV/AIDS prevention and management.

Nipaporn Intong
HDN Key Correspondent
Thailand
Email: correspondents@hdnet.org



WHO/TBP/Gary Hampton

Ugandan children outside a community health centre

Unsung Heroes: Education and social mobilisation: The keys against TB in a Kenyan slum

Rebecca Wanjiku

“...We want everyone who has signs of TB to get tested without fear, regardless of what they think or fear their HIV status might be” – Dr Nyamato

For the last two years, Dr. Nyamato has worked at one of the few tuberculosis (TB) and human immunodeficiency virus (HIV) clinics in Nairobi's Mathare slums. The Blue House clinic is run by Medecins Sans Frontieres (MSF). He has learnt two things: that TB is a treatable disease yet it continues to kill many Kenyans and that there are many innovative ways to educate the public and get them tested and treated. He shares his story with HDN:

HDN: Do all your patients come from Mathare slums?

Dr Nyamato: No, being one of the small number of TB-HIV specialist clinics in Kenya, we get referrals from other hospitals such as Mbagathi hospital. Others come to our clinic first and are then transferred to other centres but 60% of our patients come from Mathare.

HDN: What challenges do you face working with patients?

Dr Nyamato: The main challenge I face is convincing TB patients to get tested for HIV, it is a fact that 50% of the TB patients attending our clinic are HIV positive but one risks jeopardising the whole programme if one insists on testing. I would like a situation where the patients get themselves tested and if they turn out to be positive, they can access care and treatment early, but they are likely to share their experiences about testing with others and new patients may hesitate to come. The majority of our clientele is from the slums which are a closely knit society and word travels fast.

There is also the challenge of divorcing TB from HIV. Yes, TB is the number one cause of death among HIV patients but we want everyone who has signs of TB to get tested without fear, regardless of what they think or fear their HIV status might be. This is again a matter of information and education. Just like with malaria, if people in the villages notice signs of malaria, they are able to run and seek treatment. We want it to be known that TB, like Malaria, is preventable and treatable.

HDN: What motivates you?

Dr Nyamato: My relatives have died or suffered from TB and I want to play a social mobilisation role in my society. I want everyone to be in a position to seek medical attention.

HDN: How do you involve people with TB?

Dr Nyamato: Granted that 60% of our patients come from Mathare slums, we have close follow-up with the network of Community Health Workers (CHW). We ensure that each patient is attached to a CHW and he or she is closely followed up.

At the MSF clinic, we like to trust the patient with their own medication, we ensure they follow the direct observed treatment short course (DOTS) during the first two months but after that, we give weekly doses. Nevertheless we monitor the situation carefully. The patients are assigned counsellors who keep in touch with them and ensure that each week they pick up their dosages. They are expected to bring the empty foils at the time of their next visit. In case of default, the counsellors visit the patients in their homes to find out why they have not visited the clinic. This way, the patients have a say in their own health development because they are responsible for ensuring the medicine is taken on time every day.

Every morning, our counsellors and community health workers sit together to review the situation. Thus we are able to identify those patients who are defaulting and those adhering to medication. The community health workers also update on the education campaigns and identify people or areas in the slums that need to be targeted.

HDN: What is your vision?



TB patients sell crafts to support the local TB programme, La Libertad, Peru



Dr Nyamato: I would like to see a situation where in Kenya, treatment for tuberculosis is available at village level. Yes, the hospital infrastructure may not be so good, but if we maximise on what we have and continually train our medical and paramedical personnel, I believe this is possible. At the moment, many of the nurses in government hospitals may not be well versed with modes of testing for TB. They still test the sputum only, but TB (especially in late stages of HIV infection) can manifest itself in the liver, stomach or bones etc or can be sputum negative.

I would like an improvement in the medical staff's ability to perform tests and an enhancement in the quality of the laboratory services. Right now, the treatment centres in Mbagathi hospital, Kenyatta National hospital and other centres are doing their best to cope with the rush of patients. But there is need for more centres and facilities just in case the number of patients rises. You see, the HIV-AIDS pandemic caught us unprepared so we have to work backwards, trying to design mechanisms that we should have worked out much earlier.

In this regard, I would like to see a district or local hospital where all patients, whether they have TB, HIV and/or malaria are treated together. Specialist clinics are good but to minimise stigma. I believe we will have to all work together and design such coping mechanisms.

Rebecca Wanjiku
HDN Key Correspondent
Kenya
Email: correspondents@hdnet.org

Community partnerships against TB – Uganda and Nigeria

Eric Lugada

Community partnerships may be the solution to effective TB control in high burden countries with less than optimal primary health care programmes

Tuberculosis (TB) - an infectious yet curable disease - still remains a leading cause of death and a major public health concern worldwide. According to recent figures released by the WHO, nearly 9 million new TB cases occurred in 2002. Two million adults died of TB in 2002, and a staggering 95% of TB cases, and 98% of deaths, occurred in the developing world.

The Stop TB partnership's priority is to identify sputum smear positive individuals and achieve high cure rates among these. The strategy adopted has been dubbed directly observed treatment short course (DOTS).

High TB burden countries (HBC) with extensive coverage, relatively good and functional public health care (PHC) systems can potentially achieve the WHO targets for TB control. Countries such as Vietnam and India have already demonstrated this. Vietnam surpassed all WHO-DOTS targets with complete 100% DOTS coverage in just over 4 years. According to the Indian Prime Minister, the

National TB Control Programme in India now covers 800 million of its people, from a former coverage of 130 million in 1997. He further estimated that by the year 2005 the entire country about 1 billion people would be covered by DOTS. This would result in 2.6 million TB infections being prevented and half a million lives saved.

On the other hand, in HBC with high prevalence of HIV and less than optimal and functional PHC systems, DOTS expansion has proven to be a formidable task. Such nations abound in Africa and alternatives have to be sought in order to alleviate the suffering and death resulting from TB infection.

Dr Leopold Blanc, Coordinator for TB Strategy and Operations at the WHO, proposed alternatives to implementing DOTS in communities where the PHC is non-functional. This includes the integration of other health service providers not yet involved in TB control activities - such as not-for-profit-organisations. Encouraging local

communities to face up to and own the challenge of managing and controlling TB in their midst as a public health concern may also be an option for expanding control efforts. A review of two case studies follows - from Uganda and Nigeria - in which the two options have been tried, and where they have been proven to work.

Uganda is one of the top HBCs with a TB incidence of 41,000 cases nationally (2002) and 138 new cases per 100,000. Uganda has a less than optimal and functional national PHC system. Achieving the objectives of the DOTS strategy has proven to be a very real challenge.

According to Dr Francis Adatu the National TB Programme (NTP) Manager in Uganda, a community-based TB care (CB-TB) approach may be part of the answer to this challenge.

"We have developed referral systems at district level for effective implementation of DOTS," said Dr Adatu. "Advantages of the CB-TB models include; improved access to TB



care, decreases in direct costs incurred by the TB patient and equitable provision of care to those who most need it."

The TB referral system in some Ugandan settings commences with identification of a sub-county health worker (health assistant, health educator, health visitor or leprosy supervisor). This person then serves as the entry point into the community. With the health worker identified, the local leadership at the parish committee level can then be mobilised and invited for meetings. They are educated about the impact of TB disease in their community. They are guided through a process of understanding and undertaking of the role of the community in TB control, rather than relegating this to the health centre only.

The health workers also identify community volunteers to be supervised by the sub-county health worker, who reports to them and to the community health centre. The community volunteers advocate for household 'TB watch and awareness'. All suspect household members are referred to the sub-county health worker or directly to the health centre. The sub-county health worker provides support supervision and drugs for identified patients to the community volunteers, who act as DOTS treatment partners.

The community health centre is equipped with a light microscope and TB drug supplies by the NTP.

All health workers here are trained in community TB management and continuing medical education seminars arranged. The community health centre reports to and is supervised by the district medical officer's office, which in turn reports to the NTP manager's office. The district medical officer provides support to all health centres and supervises drugs and supplies.

From this set up, the NTP in Uganda has established that it is feasible to implement community-based TB models. They are more likely to be sustainable and are cost effective in the face of poorly functioning PHC.

The case from Nigeria is just as innovative. It clearly demonstrates that bottom-up initiated community programs can be successful, and are the best way to motivate and sustain community ownership and implementation of public health programs. An NGO, The Society for the Prevention of Tuberculosis in Nigeria (SPETBN) was formed in one community and registered with the Corporate Affairs Commission, Abuja, Nigeria as a corporate community trustee. Its formation was motivated by the public health threat of rising TB cases, and the absence of serious efforts by the national health system to tackle the scourge. Mohamed Yahya Sanda the society Co-coordinator mobilised local civil society groups into a society task force to stop TB in their community. This initiative is supported by the local community, which also largely meets its financial

obligations. Other sources of funding and support come from the national health system and local corporate organisations.

The society is an efficient and effective independent NGO participating in TB control and advocacy at the community level. They procure TB drugs and provide them free of charge to the local health centres. They offer treatment support services, diagnostics and laboratory reagents. The society monitors and evaluates the DOTS programme in the health centres they support, which are directly accountable to the society. They supply patient enrolment, follow-up and default notification charts. Defaulters are notified to the society, which then appoints volunteers to follow up on community members who default, establish why and encourage them to restart treatment. The society also undertakes to take care of the continuation phase of therapy in those who want to. They run a drug-dispensing outlet at the society's premises. All volunteers are community members and are non-salaried.

Although Nigeria is currently rated among the poorly performing PHC providers, such innovative mechanisms initiated by civil society may be most valuable in controlling TB in Africa.

Eric Lugada
HDN Key Correspondent
Uganda
Email: correspondents@hdnet.org



WHO/TBP/Gary Hampton

Traditional healers in Mpumalanga, South Africa

Front-line: Women volunteers as DOTS care providers in Myanmar

Jamie Uhrig

"On my way home from the morning market I make a little detour to perform my duty" – Ma Su Nyunt, Lady Health Visitor

Mornings at seven o'clock the string-bell at her fourth floor apartment rings. Daw Than Kyi knows it's not the newspaper boy, but her health worker from the nearby Minglar Taung Nyunt health centre. It is time to take her tuberculosis medication.

Daw Than Kyi is 49 years of age and lives with her husband and two children. She has been suffering from tuberculosis since 1998. "The first time I had tuberculosis I took medicine from a general practitioner for a couple of years. It cost me a hundred dollars a year for the medicine alone. It's only my husband who works and we could not afford to spend so much money. I was compelled to sell my jewellery in order to receive treatment. Although I did feel some relief at the end of the course, I started coughing again this year and it got worse."

She relates how she came to know about the tuberculosis medication provided free of charge at public health clinics in Myanmar. "My husband came home from his office and told me about free tuberculosis medication. He had seen a poster in his office marking World TB Day and advised me to seek treatment from my local clinic which is about fifteen minutes walk from our house. Since April this year I have been taking regular treatment for my disease. At first I visited the clinic three times a week to receive an injection and take the medicine. But at the end of the first two months when the DOTS supervisor asked me if I'd like to have a health worker come to my home and observe me take my medicine, I said yes right away. I thought it would be less tiresome."

Ring the morning bell is Ma Su Nyunt, one of the five Lady Health Visitors at Minglar Taung Nyunt clinic, who has been walking up the stairs to visit Daw Than Kyi in her home for seven months, to watch her take her

tuberculosis medication. "On my way home from the morning market I make a little detour to perform my duty": she tells us. "Daw Than Kyi is one of the three tuberculosis patients I visit regularly to provide DOTS medicine. During my twenty-five years of service, first as a midwife and now in my present job, I have experienced great joy in seeing my patients being relieved of pain and suffering from various illnesses including TB. This sense of fulfilment has brought to me something money alone could never match," she tells us as she smiles.

The township medical officer at the Minglar Taung Nyunt health centre in downtown Yangon explains how most tuberculosis control teams use a DOTS approach to reach their communities using their limited human resources. "When we find a positive sputum result we ask the patient which method of treatment he or she would prefer. The patient has the choice of either visiting the clinic regularly or requesting a health worker to visit their home. If the patient decides to have someone visit them at home, I assign a health worker who lives closest to their home to visit them on days when their medicine should be taken".

In addition to the health care workers employed by the clinics, a dedicated cadre of trained volunteers are vital to take DOTS to patients' doorsteps. Minglar Taung Nyunt clinic carries out its DOTS programme with the support of thirty volunteer workers from the Myanmar Maternal and Child Welfare Association. "Most of the volunteers provide their service in addition to the regular jobs they do," says the township medical officer, adding that in some instances a relative of the TB patient joins the team of volunteers in appreciation of the service they perform.

Ma Thazin Oo is one of these volunteers. She visits her seven year old girl patient to observe her taking her medication

before she goes to school. "I am happy visiting this bright eyed girl to watch her take her medicine. It gives me great satisfaction to see her getting better and attending classes."

The volunteer workers have been chosen to minimise any potential problems. "It is essential that we are not burdened with too many patients as the effectiveness of the entire programme depends on the dedication of volunteers," explains one of them. Patients chosen are close to their homes as no money for transportation is paid to volunteer DOTS providers. Since almost all of the volunteers are women, more women patients than men patients finish their course of tuberculosis medication in this township. The medical officer notes that many male patients visit the clinic to receive their medicine while the majority of women patients prefer to have someone visit them at home. There is a widely accepted custom discouraging women from visiting men alone at home.

And volunteers do not wear their trademark yellow blouses on their visits to patients' homes so that confidentiality is assured. However, Daw Than Kyi says that her neighbours are aware of her disease and support the treatment she's undergoing. "They know that tuberculosis will not spread to them as I am taking the proper medicine as prescribed. So there is no need for me to keep the Lady Health Visitor a secret from them."

So when the string-bell rings in the morning, tuberculosis patients in Yangon can look forward to a brief visit from either a health care worker or a volunteer: one who cares about the well being of her neighbours with tuberculosis.

Jamie Uhrig
HDN Key Correspondent
Thailand
Email: correspondents@hdnet.org

Spotlight: TB control at the local level in Pakistan

Zofeen T Ebrahim

Asked to pin-point the number one obstacle to tackling tuberculosis (TB), six Pakistan-based TB outreach volunteers point their fingers at 'poverty, lack of personal hygiene and general cleanliness' and then 'illiteracy'.

The six women, working for a non-governmental organisation, HOPE, have been trained to conduct focus group discussions to gauge knowledge about TB in villages around the historical city of Thatta, about 98 kilometres east of Karachi, capital of Pakistan's Sindh province.

Another challenge these women face is busting the age-old myths and fallacies attached to the disease. "Many people associate the 'scourge' with black magic, God's punishment for their bad deeds etc," explains Karima Nisa and adds, "Most villagers say they would hide if they ever contracted the disease, as it is contagious and if people came to know they would break all ties with them." This, says Karima, is true of a lot of women they met during their course of their field work. "Women have been divorced and deserted on discovery that they have TB. Some even asked to go back to their parents till they are fully cured. There have (also) been cases of young girls whose engagements have been broken."

But have there been cases when women have deserted their husbands? "No, never, that's unthinkable. They will take care of the husband in health and in illness. We held a discussion around this issue in a few villages and most men and their mothers were of the opinion that: "it's the wife's paramount duty to take care of the home, her husband and his children. And if she can't perform her duties, due to her illness, the husband has every right to look for another wife."

And while these six women concede that "it is a horrible disease" they are no longer terrified of it, as they were



Hiranya Pratap, social worker, talks with TB patients, Bhaktapur, Nepal

WHO/TBP/Davenport

"We know the symptoms, we know the mode of transmission and we know where the treatment is available. We can always transmit our knowledge to others. Our work does not need to stop when the project ends. It will probably end when TB is finally eradicated" – Seema Zaman

when they first begun their work. "Now that we are armed with the information and the knowledge, it has acted as an immense confidence booster." In fact, Huma Karim, who has been working on TB for the last two years, is well-known for her work on TB in her neighbourhood. "People, especially women, who don't want the whole community to know that they suspect themselves of having TB, often come to me at home and I get their sputum tested in the TB clinic I work in. There have been cases where I've been getting their medicines for them, too, as they don't want to be seen going to the TB clinics."

Since they started work carrying out various field surveys, about three months ago, they have talked to about 7,000 people in various villages and shared knowledge about the disease

with them. In the process they have identified several people who could be potential TB patients and "of which eight actually tested sputum positive and their treatment is underway." One thing is clear; they intend to carry on with this work, even when the project comes to an end. "We know the symptoms, we know the mode of transmission and we know where the treatment is available. We can always transmit our knowledge to others. Our work does not need to stop when the project ends. It will probably end when TB is finally eradicated," says Seema Zaman.

Zofeen T Ebrahim
HDN Key Correspondent
Pakistan
Email: correspondents@hdnet.org



Community contribution to TB care: practice and policy

Dermot Maher

Policy recommendations

National TB Programmes (NTPs), health services, HIV/AIDS care and support NGOs, and communities should take steps towards increasing the community contribution to tuberculosis programme service delivery in their settings.

This is especially so for settings where tuberculosis case load is overwhelming currently available resources. Even in those settings not currently experiencing an overwhelming case load, increasing community contribution, including community directly observed treatment (DOT), may expand access to treatment for under-served patient groups, and may further improve treatment outcomes.

NTPs should decentralise tuberculosis programme service delivery to the community in settings where health services are providing the basic elements of the DOTS strategy. Extension to the community improves scope for increasing access to services that are currently of acceptable quality, but are under some strain (e.g. services are costly or tuberculosis wards are congested). Extension to the community also offers the potential to increase access to tuberculosis services under difficult circumstances (e.g. community poverty, long distances to health facilities, civil disruption and insecurity).

NTPs should take the following steps when planning to increase the community contribution to tuberculosis programme service delivery:

- Obtain political commitment from local leaders (endorsement of support for approach) and Ministry of Health (responsibility

for financing to provide start-up and recurrent costs, either directly or by brokering funding from partners).

- Conduct a situation analysis that includes all tuberculosis services and community contributions to tuberculosis care.
- Identify all relevant players that might play a role in enabling community contribution to tuberculosis care.
- Specify the roles and functions of each player.
- Establish the relationship between the players and functions in the context of the existing health delivery system, in order to build upon and develop current strengths before seeking to develop new systems.
- Develop a training plan to cater for all the relevant players and functions.
- Design and produce training tools (e.g. technical and operational manuals/guidelines, training manuals) tailored to the roles and tasks of the players.
- Prepare for training (identify funds, identify relevant facilitators, conduct “training the trainer” sessions, schedule training).
- Conduct the training.
- Monitor and evaluate to identify new needs for training and retraining.

Community contribution to tuberculosis programme service delivery should not be separate from, or replace, local NTP activity.

Community contribution to tuberculosis programme service delivery should complement and extend NTP capacity, rather than replace NTP activity. Effective community contribution to

tuberculosis programme service delivery, especially community DOT, requires a strong reporting system, access to laboratory facilities and a secure drug supply. The roles of community volunteers need clear and careful definition.

The community and the government should identify tuberculosis as a priority public health problem and agree to take shared responsibility. The NTP should be strong, with all the necessary components in place, particularly an effective recording and reporting system. Tasks of the community tuberculosis treatment supporter may vary but could include the following: support to tuberculosis patients to ensure adherence to treatment (including DOT); promotion of information and education about tuberculosis; referral of tuberculosis suspects for sputum examination; referral of tuberculosis patients on treatment for sputum checks; recording necessary information in DOT cards; referral of patients who have adverse drug reactions; feedback of information about treatment outcomes to the local NTP; and involvement in early planning about community contribution to tuberculosis programme service delivery care. They may also provide counselling, support and may help de-stigmatise the disease.

Existing community groups and organisations should be approached to determine how they might be able to support tuberculosis programme service delivery, rather than setting up new systems, groups and organisations. For example, HIV/AIDS community organisations and groups represent an opportunity for collaboration with NTPs.



Children reading an information leaflet on TB, Ethiopia

While community DOT is cheaper and more cost-effective than hospital-based DOT, resources are needed for training and supervising community tuberculosis treatment supporters.

While recognising that this is a cost-effective approach, Ministries of Health need to ensure adequate financing of community contribution to tuberculosis programme service delivery on account of the new costs involved.

Key financing issues include the following:

Community contribution to tuberculosis programme service delivery is associated with cost savings but also with new costs which require new investment.

The community contribution should not replace government commitment or funding, but should be regarded as complementary and supplementary. Budgets should not be cut because of perceived cost savings – on the contrary, there is a need to manage more patients and to finance new costs.

There are urban and rural differences in programmes, which may need different approaches to financing and budget levels.

New costs for community contribution

to tuberculosis programme service delivery include one-time start-up costs e.g. situational analysis, community mobilisation, and supervision. On-going recurrent costs include training, incentives, supervision and management at district, regional and central levels. Options for sourcing funds include government, NGOs, and donors. However, government has the primary responsibility for financing and it needs to identify the new costs, put them in a national budget and seek partners for help with financing. As a general principle, patients should not be asked to fund their own care.

The selection of community volunteers and the way in which they contribute to tuberculosis programme service delivery should involve collaboration between the NTP, tuberculosis patients, community representatives and community group leaders.

Identification of suitable community tuberculosis treatment supporters requires consultation with the community and consideration of the benefits for sustainability of using a well-established, rather than a recently established, community group. It is necessary to ensure the selection of volunteers who can be trained to develop good practices, who can

maintain confidentiality and who will fit into the relevant team structure specific to the local situation.

Training requirements may vary depending on the setting, ranging from short, repeated 'on the job instruction' by NTP staff to more formal short courses of instruction supported by regular updates.

Training of community tuberculosis treatment supporters requires clear definition of roles and core tasks to ensure an effective working relationship with health workers. Training of different categories of health workers at the various levels of the health system as well as training of community members as tuberculosis treatment supporters have been important components in each of the pilot projects. Requirements include definition of the tasks and roles of the community tuberculosis treatment supporters, identification of relevant groups and categories to perform the identified tasks, and steps to be taken in management. Booklets to support the community tuberculosis treatment supporter have been developed together with more comprehensive training materials.

Systematic training of community health workers (CHWs) usually takes place prior to delivery of the relevant community-based health care activity, e.g. provision of oral rehydration solution for childhood diarrhoea. However, in the case of tuberculosis, an alternative to training community members in advance is to train someone at the time of identification of the tuberculosis patient. This may help to build motivation since the community immediately perceives the problem and thus feels more ownership.

Community volunteers need regular support, motivation, instruction and supervision by NTP staff to ensure quality outcomes are maintained.

Health service support to community tuberculosis treatment supporters, including supervision, requires a system of regular contact between the



community tuberculosis treatment supporters and general health service and NTP staff. Regular review meetings and a link person between the peripheral health unit and the community tuberculosis treatment supporters help to foster effective communication.

NTPs should consider what incentives for community volunteers, if any, are needed or appropriate.

Preventing 'drop-out' of community tuberculosis treatment supporters requires ensuring that they continue to receive whatever is the perceived benefit in a specific setting. Some community tuberculosis supporters may require direct incentives, others act in a purely voluntary capacity, while others may receive incentives 'in kind'. Local communities and programmes will decide cooperatively what is most appropriate and effective.

Regular audit and reporting of results is important to monitor and evaluate the community contribution to tuberculosis programme service delivery.

NTPs should ensure an effective recording and reporting system is extended into the community, with registers active beyond the peripheral health units. Records need to indicate the treatment supporter responsible for DOT for each tuberculosis patient and for recording anti-tuberculosis drug administration on the patient treatment card. The patient needs to keep an identity card with information including type of treatment, type of supporter for DOT, sputum results and other details of disease.

NTPs should actively monitor community contribution to tuberculosis programme service delivery using the standard NTP performance indicators (case finding and treatment outcomes), information on the numbers of patients choosing different DOT options, and, as they are developed, quality of care indicators.

NTPs should ensure an effective, secure and safe system of supply

of anti-tuberculosis drugs to tuberculosis patients and their treatment supporters. The regimens used should be consistent with national guidelines. Drugs should be provided and packaged in ways to promote adherence e.g. as fixed-dose combinations and in calendar blister packs.

Drug regimens: NTPs should choose drug regimens which are consistent with national policy and which facilitate community DOT. For example, all the 'Community tuberculosis care in Africa' projects used oral regimens, with ethambutol instead of streptomycin in the initial phase. Intermittent regimens can also increase patient convenience and acceptability, without reducing effectiveness.

Drug formulation and packaging: Drugs should preferably be provided in fixed-dose combinations and in calendar blister packs. The use of rifampicin in the continuation phase as well as in the initial phase depends on the availability of financial resources and the ability to ensure DOT throughout the full length of treatment.

Drug stock-keeping: There should be an established system of recording drug stocks at all levels. When drugs are provided to health units or sub-health units a designated person should record the amounts received. Standardised forms may be needed for this purpose. Similarly DOT forms will be needed for community-based workers to record drugs given to patients.

Drug supplies: The central level should procure anti-tuberculosis drugs. Proper and secure storage needs to be assured for all anti-tuberculosis drugs. Security of drugs is important. All attempts must be made to ensure that drugs are not stolen from health units and do not appear in the 'black market'. Periodic drug resistance surveillance will be important to monitor drug security procedures.

Drug distribution: There must be

a regular drug supply. This should be quarterly from central level and regional level to the districts. It should be monthly from districts to health units, and possibly two weekly from health units to community health workers. However, there needs to be flexibility in this approach, and the system adapted to the local situation. The important principle is that the patient has an uninterrupted supply of drugs and that drugs do not leak out of the system.

NTPs need to consider the key issues of sustainability and expansion of the community contribution to tuberculosis programme service delivery, and collaboration with HIV/AIDS programmes (leading to integration where demonstrably beneficial).

It is generally not sustainable to load community members with successive additional responsibilities. It is necessary to provide additional support commensurate with additional responsibilities. Obtaining the commitment of Ministries of Health, NTPs, donors and NGOs to ensure the sustainability of the community approach requires advocacy and policy development based on results. NTPs should develop costed plans for expansion of the community approach. NTPs should develop clear criteria for choosing the districts targeted for expansion (e.g. NTP performance, problems of access). Ministries of Health should consider opportunities for collaboration between NTPs and HIV/AIDS programmes (leading to integration where demonstrably beneficial), e.g. community health worker provision of integrated HIV/AIDS and tuberculosis care (provided that the stigma commonly attached to HIV/AIDS does not deter tuberculosis patients from obtaining care from HIV/AIDS groups).

Dermot Maher

World Health Organization

Online at:

http://www.who.int/docstore/gtb/publications/communityTBcare/tb_2002_312/tb_2003_312.pdf



Comment: Community contribution to TB care: practice and policy

Dr Theresa Watts

With so much co-infection with HIV, we need to give patients hope...

Dermot Mayer has given an excellent review of how TB can be managed in the community.

I would like to add a few comments:-

1. Volunteers (community health workers etc) need some return for their work.
Following/supporting TB patients may take a lot of time, and we found in central and southern Africa that this was just not feasible. The provision of bicycles was used as an incentive in some places, but repairs of bicycles proved difficult.
2. Patients and care providers need to understand about the disease and treatment and this does require some initial hospitalisation.

The difficulties in getting treatment for each patient also need to be explored.

I found 3 messages important:

- a. The TB drugs first of all send the 'bacteria' (word adjusted to listener) to sleep and only gradually kills them. If the drugs are stopped too soon the bacteria wakes up stronger than ever and often cannot be cured.

- b. The length of treatment illustrated by pictures of a 'good' and a 'bad' patient with a pregnant wife (to illustrate the length of time of treatment). At the end of the treatment period there is either a happy patient with a healthy baby and wife, or a dying patient with a thin wife and a crying baby!
- c. With so much co-infection with HIV we need to give patients hope so we had a series of pictures first of TB bacteria looking miserable contained by 'UN' security cells then HIV attacking the 'UN' cells releasing happy mycobacteria and finally TB drugs knocking out the mycobacteria despite the continued activity of HIV.

I cannot send the illustrations by email!

*Dr Theresa Watts
United Kingdom
Email: tw@twwales.freemove.co.uk*



2 TB patients and treatment



Front-line: In one corner of Romania

Claudia Catana

“The main fight is not with the bacillus, but with the mentality of the patient”

Alina was looking at me with suspicion, trying to get away from me. “She suffered a lot when her mother left them,” whispered the director of the orphanage where Alina has been living for two years.

Watching us with her big brown eyes, Alina tries to understand why a perfect stranger wants to find out so many things about her and her disease. Although she has been living in the orphanage since she was 5 years old, she still remembers that her family did not talk about her disease.

She could not understand at that time why it was such a shame to cough so often. She could not understand why, in Deva, a small town in Transylvania, people were avoiding her father.

One of the few memories from the time when Alina used to live with her parents is related to a scream, and the way a woman grabbed her son with whom Alina was playing in the park. She remembers the tears running down her mother’s cheeks, which made her sad. Actually, her mother used to weep quite often. Alina shared the same dank room with her parents, and at night could hear her mother’s cry, muffled by the pillow.

Now, Alina misses the weeping of her mother. She thinks that her mother left three years ago because they were poor and sick. Maybe her mother did not take her when she left because she was afraid she also might become ill, just like Alina and her father.

“Being a single parent who had to raise the child by himself, Alina’s father preferred to entrust Alina to an institution for child

care,” says the director of the orphanage. “He has TB and he is now pensioned because of his disease but he does not admit even to the doctors who take care of him that Alina got the disease from him four years ago, when she was only four. He is afraid and ashamed to speak about his disease. But when he remembers that his wife left him, he blames the disease.”

Things changed for Alina at the orphanage. People spoke aloud about her disease. Nobody was afraid to talk to her and the children invited her to play with them.

“We have several children here living with TB,” added the director. “As far as I know, there are more than ten children with advanced TB in institutions across the county. I can not tell you how many cases we have in the county. Even if the disease is symptomatic, analyses are not always performed due to lack of funds and consequently, the intermediary stages of TB are registered in the medical files and treated as severe cold.”

Just like Alina, all the children in the orphanage come from extremely poor families.

“Sometimes I wonder how they survive,” said the director compassionately. “These people hardly have a meal per day. They do not work and their pension is their only income. Quite often they try to get hospitalised just because of the free meals. They prefer to bring their children to institutions. At least here they have meals and receive treatment.”

The last words remind Alina to take her pills so she runs towards her room. She prefers to take the medication herself,

without any need to be supervised. The only thing she does not like, when going to the hospital, is that she has to wait a long time before talking to the doctor. The doctor told her that she needed to take the medication every day and to come to see him monthly in order to be healthy again. She feels much better now after one year of taking the treatment.

“The problem is not the treatment itself, which is provided free by the state, but the difficulties we have in detecting new cases. The mass vaccination, which was done every 7 years, and the mass campaigns for tracking new cases of TB are history now,” said Alina’s doctor. “Also, there is no money for prophylactic treatment. There is a national TB programme, coordinated by the Ministry of Health and Family, but the funds cover mostly the treatment. Sometimes financial blockages within the health system lead to interruptions of the treatment. The health system is not working efficiently, not alone in respect to TB, but also AIDS and diabetes.”

“The explosion of TB cases is a direct result of the negligence of people who either see a doctor only when the disease is in an advanced stage, or even stop the treatment. They do not trust the free services provided by the state but cannot afford the private ones. They forget that the price they often pay is their life. This is how TB cases increased from 10,000 to 40,000 during the past ten years. The main fight is not with the bacillus, but with the mentality of the patient,” concluded the doctor.

Claudia Catana

HDN Key Correspondent

Romania

Email: correspondents@hdnet.org



Front-line: One family's struggle with TB

Abigail Erikson and Bobby Ramakant

Juanito is 43 years old and a resident of Manila city where he is married with a wife and three children. He is the fourth child in a family of six. His father died of TB four years ago and his elder brother also died of TB in July 2002. "I do not want to die young and with TB" he says.

Juanito is unemployed and lives with his mother in a slum in the centre of Manila. The area in which he lives has no safe water supply, although it does have electricity. His wife and children are temporarily located outside Manila, where they are staying with a relative, also in a slum area. The children do not go to school and his wife takes in laundry and is the sole earner for the family. He is happy that she and the children are away from him so that they will not contract TB, "I do not want them to suffer the way that I am right now" he says. His sisters also do not live at home. They moved out of the family home to reduce the risk of contracting the disease.

Juanito was diagnosed with TB at a government health facility in February 2001. The doctor suggested a three day confinement, which was not available due to the lack of a bed in the facility. He was given a prescription for rifampicin, isoniazid and pyrazinamide. Since he does not get any support in obtaining these, he buys his own drugs whenever he has the money to purchase them, which means that the remainder of the time he can not take them.

Following several bouts of hemotysis, Juanito's father went to a government hospital where, after a chest X-ray, throat swab and collection of sputum, he was diagnosed with TB. He was confined for three days to monitor his condition and also given drugs in the hospital. On discharge he was given prescriptions for medicines so that

"he would not infect any more people: Both his father and mother were unemployed and since, in his fathers opinion, his case was already terminal, he decided to stop buying and taking the drugs.

His mother was then diagnosed with TB. She was lucky, in that drugs were made available to her through a limited allocation from an NGO. The allocation she received was originally assigned to another person but that person died so the drugs were transferred to her and she finished her course of medication. Juanito is concerned about his mother contracting the disease again as she does not go for monitoring anymore.

When his brother was diagnosed with TB, he took the drugs. Unfortunately he died too, due to a complication involving liver failure. Juanito believes this was as a result of the drugs being too strong and toxic, which had an adverse effect on his brother's liver.

Juanito believes that TB is easy to treat as long as one has the drugs to take for a given period of time but he feels that he and his family have been discriminated against because they are poor and have TB. Even the health provider from the clinic no longer visits them. According to Juanito, "For



WHO/TBP/Falise

A TB patient covers his mouth in an attempt to stop the spread of the disease, Thailand

me health has been taken for granted. They look at health as a commodity – if you are rich then you can have good health and if you are poor then you do not have the right to it because you do not have the buying power to get it." Juanito believes that the government should provide both drugs and regular health monitoring to all people diagnosed with TB, especially the sputum positive ones.

Abigail Erikson and Bobby Ramakant
HDN Key Correspondents
United States of America and India
Email: correspondents@hdnet.org

"They look at health as a commodity – if you are rich then you can have good health and if you are poor then you do not have the right to it because you do not have the buying power to get it."



Comment: Lessons from the lost opportunities in TB control

Omar Mohamed

In the 1980's there was relative stability in many African countries and there were very few cases of HIV/AIDS. Nonetheless, national commitment and international aid for TB control in developing countries were limited. Developed countries for the first time saw TB as less of a public health priority and sidelined it. Not only were funds for TB control scaled down, but also the public health infrastructure supporting them was reduced. That was an unprecedented situation both in terms of public health policy and strategic long term planning. Indeed, it was an ample opportunity we lost, and we are now paying a heavy price collectively.

During that period, the main drugs used to control TB in most developing countries, to my knowledge, were as follows: Streptomycin and a combined tablet of INH/thiacetazone (known commonly as TB1).

Effective treatment for TB was announced for the first time by Sir John Crofton of Edinburgh, in the UK in the early 1950's. Short course chemotherapy was developed by Dr. Wallace Fox and his team from the British Medical Research Council (BMRC) in the early 1970's. Since then, an ample opportunity has been wasted.

Effective medications like rifampicin, pyrazinamide and ethambutol were not available for National TB Programs in many developing countries for over 10-15 years, due to a lack of funds or guaranteed sustainability after donors departed. The WHO concept at that time, to my understanding, was based on sustainability and affordability of TB drugs in developing countries. So, in consequence, less effective drugs were used with minimum supervision in many developing countries for over a decade.

The WHO concept at that time was based on sustainability and affordability of TB drugs in developing countries. So less effective drugs were used with minimum supervision in many developing countries for over a decade... The question now is: If most TB patients are living in poor and rural areas, how are national and international bodies going to reach them?

The Finnish Anti TB Association, in conflict with standing dogma, decided to start Short Course Chemotherapy in Somalia in 1981. At that time, we called it 'supervised treatment'. Patients were given, where possible, breakfast and medication. Thousands of patients were cured. The project covered the most heavily populated 6 out of the 18 Regions in Somalia. Had it not been for the civil war, the TB situation could have been very different in Somalia than it is now.

After more than 20 years of reluctance, the WHO finally declared TB a global emergency in 1993. For the first time benchmarks were set for both detection rate and cure rate to change the current TB trend. The UN, World Bank and many foundations appear more involved and committed than they have ever been before.

The question now is: If most TB patients are living in poor and rural areas, how are national and international bodies going to reach them? Maybe it is plausible to establish tuberculosis NGOs for outreach activities in hard-to-reach areas, that could be supervised and trained by mobile medical teams. This could be started as a pilot project and its impact could be evaluated every five years. It

is true the model that may work in one country may not necessarily work in another country.

The fact of the matter is that we lost ample opportunities to effectively control tuberculosis before. Now with overall awareness at its epitome we can change the TB trend dramatically. At this point in time the International Union Against Tuberculosis and Lung Disease (IUATLD) the World Health Organization (WHO), the Centre for Disease Control (CDC), UN agencies and other national TB organisations should be credited for their overall activities in developing TB programmes. More needs to be done in order to come up with creative ideas that are adaptable and applicable to local conditions. It is imperative that we pull together all the resources available, so we can enhance TB programmes in developing countries.

With unity, collaborative effort, political commitment and goal oriented TB programmes we can drastically change the TB trend and defeat this old scourge.

Omar Mohamed
Email: onmohamed@dhr.state.ga.us



Campaign: The Patients' Charter of the Tuberculosis Community

Erika Blair

“Get Up - Speak Up! Write Your Rights!” proclaimed activists Rolake Nwagwu, Joseph Coulibaly and Bertrand Kampoer at the Pan-African Treatment Access Movement (PATAM) Conference in Douala, Cameroon on the 14th of July, launching a call that must be heard around the world.

‘Write Your Rights’ is a campaign of community empowerment, an invitation to participate in the ‘open-source’ drafting of an historic international public health document. The Charter has started...

The Patients' Charter of the Tuberculosis Community is a synthesis of values, principles, and aspirations that are widely shared by people infected or affected by TB, TB-HIV, and [multi-drug resistant] MDR-TB in all regions of the world.

It is the standard of the rights and responsibilities, for and by, those living with the diseases.

The Patients' Charter is a declaration of fundamental principles for building an equitable, sustainable, and effective system of ‘patient-centred’ care, from

the perspective of those in need, in tandem with the new International Standards of Tuberculosis Care.

These two documents serve to foster ‘partnerships’, bringing patients and professionals together to contribute to the global fight against tuberculosis through implementation of these best practices in local communities.

Over two million members of the TB Community die each year - avoidable deaths from a curable disease. Tuberculosis accounts for up to a third of global AIDS deaths. For over a hundred years, people with Tuberculosis have not had any voice in the provision of care that their lives, and the lives of those around them, have depended on.

The Patients' Charter seeks to inspire a new sense of participation and ‘stakeholding’, interdependence and shared responsibility for the well-being of the Tuberculosis Community. It is the dignified expression of common cause and amplifies the voices of those who have a life or death ‘stake’ in the standards of care.

Add your Voice to the Patients'

Charter, and spread the word.

The ‘Write Your Rights’ campaign aims to be an open and participatory consultation process, the first ever conducted in the development of an international public health document concerning the needs of people living with communicable diseases. A series of consultation meetings and forums will be held in diverse regions of the world, from Lima to Lusaka, Dacca to Dakar, encouraging the participation of individuals and organizations on the ground, and online. With the pioneering support of the American Thoracic Society, a six month input process will bring forth two drafts, and culminate with the joint launch of the Patients Charter of the Tuberculosis Community and the International Standards of Tuberculosis Care in March 2006.

Send your input, ideas or concerns in any language by email to: voices@tbvtv.org or by post to: TBTV, Studio 2, P.O. Box 10087, Yaounde, Cameroon

Erika Blair

TBTV.ORG

Patients Support Network for TB-HIV-MDR

Email: info@tbvtv.org, blair@tbvtv.org

The Patients’ Charter is a declaration of fundamental principles for building an equitable, sustainable, and effective system of ‘patient-centred’ care, from the perspective of those in need

Spotlight: Complications of TB infection

Bobby Ramakant

During the onset of winter two years ago, Raju, a 42 year old vegetable vendor from Lalpur village of Uttar Pradesh province in India, developed fever, cough, loss of appetite and lethargy, which affected his ability to work. He consulted a pharmacist without medical training near his dwelling. He told Raju that “congestion of lungs” with retention of a lot of sputum was making him sick. He gave Raju some pills but they did not work. Raju lives with his wife and two children, in a temporary mud-brick house made of soil and cow dung with a thatched roof. The ventilation is poor and the food is cooked inside on a wood/charcoal stove. This makes the environment damp and smoky.

His failing health forced him to go to a homeopath in a neighbouring village and get some homeopathic medicines. He was too sick to work and needed money to sustain his family, and also to pay for his treatment. His savings depleted fast but his condition didn't improve at all. He borrowed whatever money he could. Raju was underestimating risks because he had had such symptoms in the past and therefore did not consider them particularly serious until one morning when he started to cough blood. He rushed to see a doctor at the nearest government Hospital in Hardoi and was diagnosed with tuberculosis. He had to purchase drugs from the market because of the non-availability of drugs at the hospital.

Initially there was some response to the drugs but soon severe symptoms of high fever, chest pains, breathlessness, loss of appetite and weight, with bouts of blood in sputum returned. He had to sell his meagre belongings, including his handcart. Accompanied by his wife and two children, he moved to a nearby district to consult a local private practitioner and underwent a chest X-ray. He was diagnosed as having developed a large collection of pus in the pleural cavity (empyema thoraces), one of the



A TB patient takes their medicine, Managua, Nicaragua

WHO/TBP/Davenport

dreaded complications of TB. This was aspirated and a tube was passed inside the chest to drain the pus. It was difficult for him to continue treatment because he had become almost penniless. Eventually he was referred to King George's Medical College Hospital (KGMC) in the state capital of Lucknow. In KGMC, treatment is no longer free and a nominal 'user charge' is payable. Here he was admitted under a thoracic surgeon working in the general surgery department, who has developed a pioneering operative technique for tubercular empyema.

Raju's empyema was surgically treated and he was put on an anti-tubercular treatment. TB drugs were sponsored by Om Sewa Kendra (a local NGO), and not procured under the DOTS facility, even though a DOTS facility does exist in the KMCG Hospital. This highlights the critically low awareness among the medical fraternity of the existence of the DOTS facility.

Raju recovered fast and after two weeks was fit to get back to his work. His TB treatment continued and his wife took the responsibility for regular, proper intake of these drugs. But the nightmare had not come to an end. His wife and both of the children contracted tuberculosis. TB drugs for the children are now also being sponsored by an NGO, and Raju is paying for the treatment of his wife. Raju did not know that the DOTS programme could provide him with free TB drugs. For Raju and his family the ordeal is not over. The struggle continues.

Speaking to the resident doctors of other departments of general medicine, general surgery, gynaecology and obstetrics, urology, neuro surgery, gastro-enterology, radiation oncology and ENT, it was evident that they were not adequately informed about the availability of free TB drugs under the DOTS/Revised National Tuberculosis

Early detection and treatment of tubercular empyema thoraces, and improved access to drug treatment through the DOTS programme and NGO schemes, will lead to improved TB control and reduce the risk of further complications with the disease.



Control Programme (RNTCP). Patients and people in the general population are also hardly aware of the DOTS facility.

With tubercular empyema, basic problems arise due to economic factors. A private doctor, often not qualified to manage such cases, keeps treating the patient and delays presentation to the appropriate surgeon. By that time thickening of pleura occurs and the lungs can't expand without major chest surgery but at that stage the patient is unfit for general anaesthesia (because of poor nutritional status, poor lung function, and the presence of broncho-pleural fistula). Accordingly, the chest surgeon has to proceed with less physiological

operations to save life, like Kant's modified open drainage under local anaesthesia.

In addition many cardio-thoracic surgeons do not like to treat tubercular empyema thoraces since it commonly affects poor patients and compares unfavorably with the money, sense of achievement, thrill and prestige that other cardiac surgeries can provide. If general surgeons could be trained sufficiently to surgically manage empyema thoraces it would improve the treatment access, care and affordability tremendously. Private doctors who practice alternative medicine, (e.g. ayurveda, homeopathy, unani) and who treat TB patients with their self-made drug preparations,

must be acquainted with the DOTS programme and be convinced to send suspected cases of TB to the nearest TB centre.

Early detection and treatment of tubercular empyema thoraces, and improved access to drug treatment through the DOTS programme and NGO schemes, will lead to improved TB control and reduce the risk of further complications with the disease.

Bobby Ramakant
HDN Key Correspondent
India
Email: correspondents@hdnet.org

Spotlight: DOTS in all districts of India: What next?

Dinesh Kumar Sharma

Directly observed treatment short course (DOTS) TB services are going to be offered in all districts of India by mid-2005. The Revised National Tuberculosis Control Programme, or RNTCP (which delivers DOTS services), was first implemented in five pilot sites in Delhi, Gujarat, Kerala, Maharashtra and West Bengal in October 1993. The year 1998 witnessed a rapid scaling-up of the RNTCP and within a few years it secured the distinction of being the 'fastest expanding DOTS programme in world'. At the end of the third quarter of the year 2004, these services were already available to 906 million Indians living in 521 districts of 29 states and union territories of the country. The long awaited target of full national coverage now seems within reach. 'What next?' is now the obvious question.

Rita Teatota, Joint Secretary, of the Union Ministry of Health and Family Welfare which looks after RNTCP, is unable to hold back her enthusiasm. "DOTS has been so successful that the death rate (due to TB) has come

Extending DOTS to all the districts of the country has no doubt been an onerous task and the challenges ahead are no less daunting.

down by almost eight times from 28 per cent to four per cent," she asserts. Even the cure rates have gone up to 85 per cent, Rita adds. Jens Seeberg, Adviser to the DANIDA-Assisted Revised National Tuberculosis Control Programme (DANTB) in Orissa state is in agreement with her. In a presentation made at Global Forum 8, held in Mexico in November 2004, he said, "the implementation of DOTS is beginning to bear fruit in terms of decreased morbidity and mortality. From an estimated one TB death per minute in India in 1999, the death rate has decreased to an estimated two deaths every three minutes." An extraordinary feat indeed! However TB is still the leading cause of death among adults. It is a reality that even the most enthusiastic optimist would find difficult to refute. The final journey towards an ultimate

goal might have begun, but the road to accomplishment is definitely not without obstacles.

A formidable threat to TB control in the country is posed by the growing AIDS epidemic. According to the new Director of the National AIDS Control Organisation (NACO), Dr S.Y. Quraishi, earlier only six states of the country were designated as 'high HIV prevalence states' but in the recently-changed system NACO has reclassified 14 states as 'highly vulnerable' and a remaining 12 as 'vulnerable' to HIV. Quraishi talks of a paradigm shift in national AIDS control policy in its new adaptation. The new policy focuses on a multi-sectoral approach to the AIDS epidemic in place of earlier 'single disease control concept'. He says that coordination between AIDS and TB control programmes has been



established at national level and in six states in particular. This integration is due to be extended to eight more states soon. The priority is to sensitise the health care providers working in the two programmes and establish linkages between HIV voluntary counselling testing centres (VCTC) and the RNTCP. The quicker the barriers between the two programmes are pulled down, the better it will be for tuberculosis control in our country.

A national consultation on nutritional security and the prevention, treatment and mitigation of TB and HIV/AIDS in India, organised by the World Food Programme in December 2004 added yet another component to control of the twin epidemics in the country. According to Professor Amitabh Kundu from School of Social Sciences, Jawaharlal Nehru University New Delhi, per capita calorie consumption has been consistently declining in the country. What worries him most is that calorie intake is still going down, even in the economically lowest one-third segment of population. This is compounded by a deteriorating micro-environment of living characterised by a lack of sanitation and an increase in the number of people living in one room units. This simply results in higher vulnerability to TB and HIV. Dr Kundu believes that the next challenge is how to design and amalgamate nutrition supplementation programmes with TB and HIV control programmes without inviting social exclusion. A few models of food supplementation using economic status as a criterion already exist in the country and can be expanded and modified to include people infected and affected by TB and HIV.

Multi-drug resistant (MDR) TB has already made its presence felt in several states in the country. According to official estimates, MDR patients account for about 3.4 per cent of TB cases in the country. Recently a civil rights group, Social Jurists, petitioned the Lieutenant Governor of Delhi to order a judicial probe into the deaths of MDR TB patients admitted to a TB hospital run by the Municipal Corporation of Delhi. According to advocate Ashok Rau the hospital has been without essential drugs to treat these patients for the past year. RNTCP has drawn up plans to test a new tuberculosis strategy to treat people who are resistant to existing drugs. The DOTS-Plus project will begin at the L.R.S. Institute of Tuberculosis and Respiratory Diseases in Delhi during the coming months. The next frontier in TB control in India will be the fight against MDR-TB and DOTS-Plus is hoped to reach out to these patients beyond the confines of Delhi sooner rather than later.

DANTB which supports RNTCP in one of the poorest states of country, Orissa, has taken the lead in the country by integrating health systems research (HSR) within its work. From 1997-2003 it undertook a range of HSR projects such as health-seeking behaviour, information, education and communication (IEC) strategies, supervision of treatment and gender issues. The results of these studies helped to develop a comprehensive strategy for RNTCP in Orissa. In phase II of DANTB the list of HSR priorities has been enlarged to include subjects that are crucial to DOTS delivery in the whole country and incorporate topics like the impact

of IEC and acceptability of DOTS at the community level; urban DOTS; defaulter analysis; quality of DOTS; working conditions of DOTS providers; and reaching the un-reached. The performance of the RNTCP is inconsistent between states, between districts within a state, between blocks of a district and urban and rural areas. Kerala, which boasts of one hundred percent literacy, is grappling with low smear positive TB case detection rates, while poverty stricken states like Orissa have come up with impressive detection and treatment success rates. Now that RNTCP has completed the details of setting up a physical structure for DOTS delivery in the country, it needs to enlarge its scope to incorporate HSR in its day-to-day working. The experience in Orissa has established how research, when integrated into health programme planning and implementation, can play an important role in improving utilisation and coverage of health services.

Extending DOTS to all districts of the country has no doubt been an onerous task and the challenges ahead are no less daunting. But TB advocates spread all over the country remain confident of final victory over the 'white plague' in the years ahead.

Dinesh Kumar Sharma
HDN Key Correspondent
India
Email: correspondents@hdnet.org

Spotlight: Improved TB case detection in Delhi (India)

Greg Manning

Background:

TB has proven difficult to diagnose through the Indian government's Revised National Tuberculosis Control Programme (RNTCP) for the people of Yamuna Bazaar, Delhi, where HIV prevalence is around 30% among injecting drug users (IDUs).

However, private centres, which are actively seeking to identify TB, diagnose TB in the same people who have not been identified through the system of sputum microscopy for directly observed treatment (DOTS).

The detection of TB in Sharan's (a Delhi based NGO) DOTS sub-centre in Yamuna Bazaar (which is part of the RNTCP) improved following an increase in the input of information from people living with HIV. There was also an increase in the number of people volunteering for TB screening.

This change occurred following an increase in the number of HIV positive people in the community. Their inputs were substantially different from those of medical doctors. The contributions of people living with HIV (in both local and international forums) included information about prophylactic treatments, nutrition, opportunistic infections, illicit drug use and diagnostic complexities associated with HIV infection. After an extended period of community discussion about this information, local community workers subsequently engaged and retained people for far longer in diagnostic processes, which led to a noticeable improvement in the general respiratory health of the community.

TB in India:

India accounts for nearly one third of the global TB burden. Every day in India there are more than 20,000 new



A young TB patient and her mother at a DOTS clinic, New Delhi, India

WHO/TBP/Gary Hampton

The crucial change that occurred in Sharan's service was the heightened awareness that people living with HIV who have symptoms of TB should be engaged in a diagnostic and treatment 'loop'.

TB infections and more than 5,000 people develop TB. There are more than 1,000 people who die every day of TB, i.e. about one TB death every minute. TB kills 14 times more people than all tropical diseases combined, 21 times more than malaria, and 400 times more than leprosy. TB in India kills more women than all causes of maternal mortality combined.

The Revised National TB Control Programme (RNTCP):

The public sector (i.e. the RNTCP) is single-mindedly pursuing its target to 'successfully treat at least 85% of new sputum smear-positive patients'. It is making progress towards this goal. Neither the rationale, nor the definition of this target has acknowledged the challenges that HIV co-infection poses to the RNTCP, despite recent claims of collaboration between the RNTCP and the National AIDS Control Organisation (NACO). Conceptually, the RNTCP is conscious

of preventing new TB infections, and preventing the development of multi-drug resistant TB, but less specifically about treating personal illnesses.

Practically, people living with HIV have to deal with a greater risk of developing active TB in a given year. HIV infection also promotes progression of latent TB infection to active disease and relapse of disease in previously treated patients. It is also common for sputum microscopy to fail to detect their illness. The NACO training module on HIV and TB shows that a person living with HIV has between a 30% and 50% chance of having their TB illness detected by sputum microscopy.

The input of people who are living with HIV:

The initial input of people who are living with HIV in Yamuna Bazaar came in the form of demands for health care. People wanted medical treatment for persistent coughs and



chest pains. When Sharan began working in Yamuna Bazaar, deaths, amputations and crisis referrals to hospitals, due to abscesses from injecting drug use, dominated the attention of the outreach team. Once information and services were implemented that prevented and systematically treated injection-related abscesses, the next apparent health crisis involved coughing and chest pain. All the while, Sharan had been drawing on private and public services for TB, but receiving very few early diagnoses of TB before people were already in a critical condition and in need of hospitalisation.

Treatment literacy material from South Africa's Treatment Action Campaign (TAC) provided the practical information that Sharan was lacking about TB and HIV co-infection. This material highlighted the problem of diagnosing TB in a person who is living with HIV. It introduced the importance of simultaneously preventing other opportunistic infections besides TB, through the use of cotrimoxazole. It also explored adherence to treatment in a context of side-effects from the medication. This material provided a platform from which the details of TB and HIV co-infection could be more practically addressed.

The information was made accessible initially through a forum, which brought together people who are living with HIV to specifically discuss how to gain access to treatment. But the material wasn't easily accessible to Sharan's community workers or to people who were living with HIV because they spoke Hindi and the TAC material was written in English. The information about TB was translated through community discussion. The discussion excluded professional translators. It excluded dictionaries, and it largely excluded doctors. Groups which contained English and Hindi speakers, who could communicate with each other, produced their own Hindi rendition of what was available in English and, when they were ready, they took their findings to the doctors from whom they sought medical support.

The group discussions added two other local community inputs into the discussion - nutritional support and access to oral substitution therapy for drug users. Further inputs from the TAC treatment literacy material refined the general term 'nutritional support' down to two elements - sources of vitamins and proteins.

Consultations with the doctors who serve in a continuum of care used by the people of Yamuna Bazaar confirmed that the active involvement of people living with HIV was essential to improve the treatment of TB. It became clear that the doctors were not going to voluntarily disclose the information that the community brought to them. Doctors from the RNTCP were not willing to link HIV and TB, saying, "TB has more stigma than HIV." Doctors were unwilling to tell people about the side-effects of medicines in advance. They did not volunteer information about prophylactic treatment options.

Outcomes:

Shortly after the above process had taken place, Sharan's DOTS sub-centre was treating twice as many people as it had been before the information became available. In addition to this, the number of deaths and critical admissions to hospital was reduced, as had happened with injection-related abscesses.

- There was an increase in TB case detection.
- Chest infections besides TB were regularly treated
- People were volunteering for TB screening.
- People returned for a subsequent sputum test if cough persisted.
- The confidence of the DOTS sub-centre workers increased in achieving early TB diagnoses, good treatment outcomes and liaising with doctors.

The crucial change that occurred in Sharan's service was the heightened awareness that people living with HIV, who have symptoms of TB, should be engaged in a diagnostic and treatment 'loop'. The sputum test no longer

had the final say on whether or not people had TB. People were retained in treatment and diagnostic processes until their symptoms subsided, usually because of antibiotic treatment, or TB treatment, through persistent diagnostic efforts. People are now less willing to accept that they have to live with a cough.

Lessons Learned:

Among the lessons learned, it must be acknowledged that when people living with HIV in Yamuna Bazaar prioritised the importance of the new information, they made some surprising choices. They said that an egg and a glass of milk are a more appealing nutritional supplement than a meal, or fruit. Milk and eggs were considered more important than prophylactic treatments (e.g. oral substitution therapy or cotrimoxazole).

Conclusions:

Improving a single, urban DOTS sub-centre, is only useful for a small, local population. People from other parts of Delhi have been referred to Sharan's centre on the basis of reports of the comparatively higher quality of service. However, people who cannot access DOTS locally will be less likely to complete the full course of medical treatment. Access to TB treatment is the platform from which good adherence to treatment will be achieved.

Preventing people living with HIV from dying of TB requires a much more systematic response. It is of great importance that the RNTCP and NACO improve their collaboration. In order for this collaboration to be more effective, there needs to be more input from people living with HIV.

Greg Manning
HDN Key Correspondent
India
Email: correspondents@hdnet.org



Comment: The chase to meet DOTS targets – a few concerns

Dr Surya Kant

I have been following the discussions on the Stop-TB eForum and decided to pen my own experiences of the last decade in managing and treating TB in Uttar Pradesh, India.

One of the foremost comments I would like to make is on categorisation of DOTS treatment. As is evident, there are 4 categories of DOTS, and category IV treatment is not yet available under DOTS.

I have serious reservations about Category II DOTS treatment. This category includes those patients who have received treatment for TB for 5 months and are still sputum positive, or cases of relapsed TB, or treatment-after-interruption cases, with treatment for more than 1 month. The only difference in treatment for Category II patients is 24 injections of streptomycin during the first two months, the rest of the 4 drug regimen remains the same. So how can it be that those patients who have already taken the 4 drug regimen for 5 months (or more than one month at least) before they enrolled in Category II treatment (since they were still sputum positive), are expected to respond to the same regimen again with only one difference in treatment regimen?

The basic tenet of TB treatment (existing prior to DOTS or RNTCP) is that if the TB treatment regimen fails then we should replace 2 or more than 2 drugs. TB patients who have been on DOTS treatment for 5 months and are still sputum positive, are then roped into Category II. The DOTS plan for Category II is to put that patient (again) on a 5 drug regimen (where 4 drugs are same and the fifth additional drug is streptomycin). This is not an academically sound treatment regimen, and we don't adhere to this concept either.

Those patients who have taken the 5 drug regimen or 6 drug regimen, and

In our RNTCP, serious effort should be made to bring down the level of avoidable MDR TB, and if this lacuna in category II DOTS treatment is not dealt with properly and promptly, then the RNTCP shall be held responsible for this increased load of MDR TB

are still sputum positive, will again be treated under DOTS as Category II and the same drug regimen repeated. This will lead to avoidable cases of multi-drug resistant TB (MDRTB). This way sputum positive patients will infect more people for at least 8 months and according to studies done across India, they will infect approximately 15-20 people during that time. These people being treated under the Category II regimen of DOTS share the wishful thinking that they are receiving proper treatment. More shocking is the fact that the people these Category II patients infect will get MDR TB, which is harder and more expensive to treat and has a higher mortality rate. This is a completely avoidable burden of MDR TB we are adding to our already over-burdened health infrastructure.

In our Revised National TB Control Programme (RNTCP), serious effort should be made to bring down the level of avoidable MDR TB, and if this lacuna in Category II DOTS treatment is not dealt with properly and promptly, then the RNTCP shall be held responsible for this increased load of MDR TB.

Although this can't be proven with academic studies nevertheless I feel that this is another important issue to flag. Contracted-workers under the DOTS programme, who are pressurised to chase targets, are left with not much option but to complete records on paper.

There is enormous pressure to show completion of targets, and a good

success rate of DOTS/ RNTCP treatment, for these contracted workers in Uttar Pradesh. India was supposed to achieve DOTS coverage for its entire population by the end of 2005. The state of Uttar Pradesh is lagging behind with hardly 50% effective coverage. So pressure mounts up to show increased coverage and a higher treatment success rate. There are so many patients in this hospital who are a living testimony to this fact. One such patient was earlier sputum positive and treatment started under DOTS Category I or II, and then regardless of whether the patient improved or not, on record he or she was shown sputum negative upon completion of treatment. There are a number of patients in my ward who are sputum positive and completed DOTS at their local DOTS clinic, hardly 15 days or a month before they came to this tertiary hospital. How can these patients turn sputum positive again within 15-30 days of completing DOTS treatment?

Let me conclude with the remark that we don't need to pressurise DOTS workers unduly, either to meet targets or to have the desired, pre-conceived success rate. We also should address the issues raised regarding Category II treatment of DOTS.

Dr Surya Kant
Department of Pulmonary Medicine,
King George's Medical University
Lucknow, India
Email: kantsk@rediffmail.com



Front-line: Ground realities facing TB patients in China

Odilon Couzin

WHO/TBP/Davenport



A TB patient with Dr Moshtaque Ahmed Choudhury, Bangladesh

The road to Xiongzhuang village is a rutted dirt track. The houses are run down and stand behind crude mud-brick walls. There are hundreds of villages just like it in Henan, China's most densely populated province. The village's 3,000 residents eke out a living by farming tiny plots of land or, if they're lucky, find work in a nearby town.

But Ren is anything but lucky. He is 45 years old, with a wife and daughter who care for him as he spends much of his time in bed these days. He is infected with both tuberculosis (TB) and HIV.

Ren discovered that he had TB two years ago. When his cough wouldn't go away, he took some antibiotics, available without a prescription in any country market in China. The cough got worse so he consulted a doctor. Henan is an area with a high HIV rate caused by unsafe blood-selling during the 1990's. Government-run 'epidemic stations' are on the lookout for diseases

like TB and hepatitis, both rampant across China. But DOTS in China is only in place in certain provinces and only some of those provide free medicine. DOTS training for local doctors is often not enough to break them of long-standing habits.

"They said I had TB," Ren recalls, "and gave me a long list of medicines to take for a whole year."

End of story, right? Not exactly, Ren went to the dispensary, also government-run, to get the drugs but found that he couldn't possibly afford to buy them. Many fellow villagers in his position simply gave up but he was determined and went to a private clinic instead. The doctor there had a solution.

"He told me I could just take two drugs from the list," Ren said. "They were cheap drugs which I could afford."

Ren, who can no longer work, borrowed money from relatives

and bought the drugs isoniazid and rifampicin. After taking the first month's supply, he again ran out of money. He found another, even cheaper source for the drugs. He bought a full year's supply of the two drugs direct from a local pharmaceutical company. Again, Ren didn't need a prescription. In China, all but the strongest of drugs are available over the counter.

"I bought a year's worth," he said, "because the doctors said I mustn't stop before I was fully cured."

After a year taking the drugs, Ren still wasn't cured. As his HIV infection worsened, he caught a number of sometimes painful opportunistic infections.

"When the pain was too bad," he said, "I used to inject my own medicine, to avoid having to visit the doctor."

In fact, he didn't see a doctor for a whole year and didn't indulge in luxuries like clean needles. Visiting a clinic costs money and he says he was afraid the doctor would prescribe more expensive drugs, drugs he could not afford.

Ren's condition did not improve. The cheap drugs may have been fake, an extremely common occurrence in China, but it's also highly likely Ren was infected with multi-drug resistant TB. The WHO recently found that Henan province ranks second in the world for incidence of multi-drug resistant TB (MDR-TB).

The World Bank runs DOTS programmes in 16 Chinese provinces and boasts of a 90% 'cure rate'. But these numbers are deceptive. One

Ren's condition did not improve. The cheap drugs may have been fake, an extremely common occurrence in China, but it is also likely Ren was infected with multi-drug resistant TB.



WHO doctor in Beijing estimates that even in provinces with World Bank programs, only about a half of all cases are diagnosed, and fewer than half of those cases are treated at the TB dispensary.

In fact, Ren's case is probably better than average in China. Only half of China's provinces are covered by DOTS. In other provinces, such as Henan, China's Ministry of Health has what is called 'partial coverage' for TB. Local doctors are trained and TB diagnosis is free but patients pay for their own drugs. In reality, this system rarely works as hoped or needed.

"Of course, when you feel better, you stop taking drugs," Ren says, "If it's really bad, then you go to a doctor, but if you can stand it you don't."

The rapid economic transformation taking place in China means free public health care has disappeared. It has been replaced by for-profit hospitals, clinics, and doctors. Even when free treatment is available, smaller hospitals or clinics often refuse to send TB patients to the special TB dispensaries because that would mean losing a long-term and very profitable patient.

In the last few weeks, Ren has received some new hope. Because of the high rate of HIV infection in the county, the Ministry of Health has started providing a full course of four TB drugs free of charge to all TB patients. It's only one county out of many, but for Ren and his neighbours it will make all the difference.

Odilon Couzin
HDN Key Correspondent
China
Email: correspondents@hdnet.org

TB diagnosis and treatment compliance – a challenge

Dr Theresa Watts

I was in Africa at the time of the 'N studies' in the 1950s in Uganda, and have been concerned with TB in different countries in Africa since then, both academically and clinically. With nearly 70% of adults in East and Central Africa tuberculin positive, it is difficult to foresee much fall in the TB incidence during this HIV epidemic (WHO and personal surveys).

With increasing acid-fast bacilli (AFB) negative and extra-pulmonary TB, TB diagnosis presents a challenge. The elispot test seems to give some assistance in diagnosis, but I do not know the cost or the ease of application in rural facilities. We need a good reliable diagnostic test. We used to give a 2 week trial of treatment using ethambutol, INH and PZA but this was discouraged by the WHO. I found it very useful in difficult cases.

With the difficulty of transport and vast distances in many areas in Africa, TB medicines should never be

With increasing AFB negative and extra-pulmonary TB, TB diagnosis presents a challenge

separated from the patient. The recent emphasis of treating TB patients as outpatients from the outset prevents one from educating the patient and a relative/friend to assist the patient to take medicines consistently. At a brief interview patients are often too upset to take in health information. Also, one cannot monitor the reactions to the drugs. We need simple facilities to treat patients in a health centre for the first 2 weeks at least.

Health education should be simple and appropriate, and the story method often carries more weight. (I do not know how to adapt my health material appropriately, for example, the effect of HIV on TB and the need for comprehensive treatment or pictures

of the good and bad patient in taking medicines etc).

The most important thing is to have staff who are dedicated and care about the patients, and can help resolve problems before they adversely impact on the treatment and care of the patient. Work places, schools and other authorities in the area can help. TB clubs are useful in urban areas, and an Indian experiment had an initial payment deposit at the time of diagnosis and the money returned incrementally as treatment was taken. Not easy in many settings!

Dr Theresa Watts
United Kingdom
Email: tw@twwales.freemove.co.uk



Speak Your World: South Africa

Colleen Jackson

My name is David and this is my story.

I have had TB three times. I remember that it was very cold the first time that I got TB. It was the winter of 1992, yet I would wake up wet with sweat during the night. I felt very weak and tired, and my coughing disturbed everybody.

We live in the village of Nkambako which is situated in the far north-east of Limpopo Province, in a traditional Tsongo house. I live with my sister Doris and her family as I do not have a wife or children of my own. There are three rondawels, which are centred around a communal cooking area. I have my own room and Doris and her three children share the other two rooms. Her husband left a long time ago.

Doris took me to see a private doctor in town. It was very expensive and we didn't have money for food that night. The doctor didn't tell me what was wrong with me but just gave me an injection and some medicine. I took the medicine for a while but as I didn't improve I decided to go to see the traditional healer. I felt better for a while but unfortunately it didn't last and my condition soon worsened.

One morning Doris and I woke up very early and caught the bus to the hospital, which is about 50km from my village. Long queues of people were already waiting to be registered in spite of it being so early. I was sent for an X-ray after which the nurse put me to bed. Later the nurse told me that I had TB and that I would have to stay in the hospital for two months. I didn't mind staying. It was such a relief to just rest. I was so tired.

I was discharged after two months, with sufficient medicine for four

I have had TB three times – it's very difficult to deal with all these problems in my body.
I can't work anymore

months which the nurse said was very important for me to complete otherwise I would not get better. After two months I was feeling much better so I left the treatment and went back to work. I now wish that I had finished the medicine, and that the dangers of multi-drug resistant TB had been better explained to me.

In 1998 I became ill again. This time I recognised the signs and went to see the doctor at the health centre. They told me that I had TB and had to be hospitalised again for two months.

I had forty injections. It was very painful. After discharge I tried to take my treatment at the health centre but after three trips I gave up and went back to work. I was transferred to a town about 400 km away and didn't have time to go to the hospital. I felt better anyway so I didn't worry.

I forgot all about the TB again until 2002 when I started to have chest pains and was coughing up blood. I knew what was wrong and I returned home and went to the local health centre. The doctor was very good and spoke to me in Tsonga. This made me feel very comfortable and he took time to explain everything to me.

I was sent back to the hospital where they took X-rays and sputum. It was all negative. The doctor was still convinced that I had TB. He gave me information about HIV and arranged for counselling. I agreed to have blood

taken for HIV. The results came back HIV positive. It was hard at first but I accepted it.

I was admitted to the hospital again. John, the TB co-ordinator, took me to my village on discharge. This time we first stopped at Anna's, the caregiver's house. I was introduced to her and we arranged that she should visit me each day at 9 am to help me take my treatment. Then we went to my home where they explained my condition to my family. They were happy because now they understood. They supported me and they will stay with me. At least my sister and her children are healthy and have not contracted TB.

I also go to the support group in the village. That helps a lot. There are others like me and they understand how I feel.

I am very weak now. I have constant diarrhoea. This time I have taken the treatment regularly and yet I don't feel better. I can't work anymore. There is no money in the family as I was the breadwinner. Doris sells vegetables on the side of the road but that brings in very little. I have applied for a disability grant, but it is taking a long time. I don't know if I can hold on much longer.

Colleen Jackson
HDN Key Correspondent
South Africa
Email: correspondents@hdnet.org

Spotlight: Delay in seeking TB treatment in Pakistan

Zofeen T Ebrahim

“Despite the fact that the country now boasts near total coverage with DOTS, the case detection rate remains as low as 17% (2003) and the latter can only be improved by addressing the delay in case-finding”
– Dr Mubina Agboatwalla, chairperson of HOPE

Pakistan ranks sixth in the world by number of estimated tuberculosis (TB) patients. A whopping 2.5 million people develop TB every year here. To make matters worse, patients tend to reach the National Tuberculosis Control Programme (NTCP) health facilities at a late stage 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 developed to overcome stigma and gender disparities that get 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 the onset of symptoms and seeking treatment contributes to the spread of infection in the community. Despite the fact that the country now boasts near total coverage with DOTS, the 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 NTCP 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



Jahurui Islam, medical technician, examining sputum slides for TB, Bangladesh

WHO/TBP/Davenport



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 stigmatisation (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 the 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.

Zofeen T Ebrahim
HDN Key Correspondent
Pakistan
Email: correspondents@hdnet.org



3 The 'twin epidemic': TB and HIV co-infection

Unsung Heroes: Henminlun Gangte

Greg Manning

HDN Key Correspondent, Greg Manning interviewed 'Loon' Gangte, President of the Delhi Network of People Living with HIV (DNP+) and programme manager of Michael's Care Home, Delhi, a 35 bed residential care facility for people living with HIV/AIDS (PWHAs). He has been providing hands on care for PWHAs since 1998. He is energetically involved in local, national and international campaigns to secure better systems for the effective delivery of information and health care for PWHAs and drug users, and those who provide them with care. These campaigns vary from ensuring a minimum standard of care and cleanliness in public hospital wards to negotiating with pharmaceutical companies about the prices of drugs for PWHAs.

HDN: Can you tell us something of your personal experience with TB in India?

Gangte: A friend of mine, who also had been diagnosed with TB, recommended a private practitioner who diagnosed my TB nine years ago. Before meeting this doctor in Imphal, the capital of my state, I had seen four other doctors in my home town. None of them suspected that I might have been sick from TB. All they gave me was bottles of cough syrup. I was very sick - virtually a walking skeleton. I think my weight had gone down below 40kg. Everybody thought that I would die soon. The pain in my chest was unbearable, and even heroin would not give me a kick.

Even now, I notice that doctors do not inquire down the TB angle, even if the person asks specifically about it. I have come across people who are not [correctly] diagnosed with TB, [even] in a chest hospital or a general hospital. However, the specialist HIV doctors will diagnose TB in the same people. Diagnosing TB is a problem for people who are living with HIV. The Mantoux test may not provide clear evidence. The traditional means



The TASO drama group puts on plays about HIV/AIDS and TB, Uganda

WHO/TBP/Gary Hampton

of diagnosing TB - sputum smear examination and chest X-rays - are also not conclusive in people with HIV.

HDN: Who comes to Michael's Care Home?

Gangte: More than half of the people who stay in Michael's Care Home are not from Delhi but from the Northern States of India, such as Haryana, Punjab, Rajasthan, Bihar, etc. More than 50% of the people we treated in our residential care during the last four years were treated for TB.

HDN: Did they know they had TB before they came?

Gangte: No. Most are diagnosed with TB [only after] they come here. People don't suspect TB in their homes. Testing for TB is routine in Michael's Care Home.

HDN: What do you say about TB when you talk with others in DNP+?

Gangte: We don't talk about TB much. We know that it is treatable and curable. We know that it is important to complete your full course of medication. We also know that TB is an important opportunistic infection, and we see a lot of people cured of TB.

HDN: What makes you think about TB?

Gangte: Every time I feel a pain in my chest, I remember that I did not complete my TB treatment. I have had myself tested for TB another five or six times ever since I found that I was HIV positive. I feel very strongly that I am at risk of TB infection and that it is very dangerous that I did not complete my full course of medication.

"Firstly, I must say that DOTS is our first option in treating TB and it is a successful treatment programme. Every year, our DOTS centre reports a cure rate of over 85%. However, DOTS is not 'friendly' towards people who are living with HIV/AIDS" - Henminlun Gangte, President of the Delhi Network of People Living with HIV (DNP+)



HDN: In the past you said that DOTS is 'HIV unfriendly'. What do you mean by that?

Gangte: Firstly, I must say that DOTS is our first option in treating TB and it is a successful treatment programme. Every year, our DOTS centre reports a cure rate of over 85%. However, DOTS is not 'friendly' towards people who are living with HIV. There are three main reasons:

Firstly, the medicines are pre-packaged and so the doses are not flexible. People living with HIV need flexibility in their dosing if they have hepatitis, or are taking other drugs, which are toxic to their liver;

Secondly, access to DOTS depends upon a positive sputum test, and TB is less likely to show in the sputum of people who are living with HIV;

Thirdly, access to DOTS depends upon having a residential address local to the DOTS centre. Many people with HIV do not have a residential address close to the DOTS centre which might diagnose and treat them.

HDN: So how do you provide a full course of treatment to people who are diagnosed in Michael's Care Home but do not live in Delhi?

Gangte: We usually try to connect the families, or referring agencies of the people who need treatment, to DOTS centres close to them. Some people are not eligible for DOTS. They are usually people who don't have a residential address at all. In this situation we provide the medication, and support the person's carers to

provide the follow up to ensure that the full course of medication is taken.

HDN: Did you receive DOTS?

Gangte: No. I don't think DOTS was available in Churachandpur nine years ago. If it was, I was not aware of it. My mother bought my medication [from] the market. Once on medication, I recovered very quickly. Within four days I was feeling much better. My mother gave me a good diet. However, after four months she told me that we had to make a choice. She said that she could afford either the TB medication, or 'Number 4' [i.e. heroin], but she could not afford to buy both of them. I chose 'Number 4' and stopped my TB treatment.

HDN: Did you know your HIV status when you were diagnosed with TB?

Gangte: No. I was diagnosed with TB two or three years earlier than I was diagnosed with HIV.

HDN: How do you think you would have responded to your doctor if he had offered you an HIV test when you were informed you had TB?

Gangte: It is hard to say now, but I remember trusting this doctor, and probably would have happily followed his advice. When I met him, I knew that he would cure me. He gave me a very thorough physical check-up and told me that he was sure that I had pulmonary TB. The laboratory tests confirmed his suspicion. I found the doctor's confidence very therapeutic.

HDN: What do you remember about going for your HIV test?

Gangte: When I gave my blood for my first HIV test, I was sure that I would be HIV positive. I thought to myself; if what they write in the books about HIV is true, then I definitely have HIV. Despite my preparation for the result, I was very shocked to receive my positive result. I am still shocked. I was not offered post-test counselling at any of the centres where I have been tested.

HDN: What are your sources of information?

Gangte: I have a clinical manual from the Stop TB Partnership. It gives a very good description of the problems I have seen in diagnosing TB in people who are living with HIV. So I asked the doctor to explain it in a class for our staff. The doctor was able to explain some of it, but we are not satisfied with the answers to some of our questions.

Loon's own experience of living with HIV and TB, and helping others with both of these infections makes his perspective and response to an urgent situation very personal and practical. He highlights that international progress in diagnostics and treatment of TB is not keeping pace with the progress of HIV and TB epidemics, yet policy makers and health care providers are not maximising the potential of the technology and information currently available to them.

*Greg Manning
HDN Key Correspondent
India
Email: correspondents@hdnet.org*

Comment: Integrate TB and HIV treatment and care

Dr Adah O Stephen

In developing countries especially in sub-Saharan Africa, the scourge of the two most dreaded monsters – HIV/AIDS and TB – is really taking its toll on the most productive age group in the region. Something has to be done very fast to arrest the rate of destruction of these monsters. From personal experience, I have lost more than ten relations to these epidemics. Most of those dead were young people in their productive years leaving behind orphans without adequate social support and care. These epidemics kill both women and men in a short space of time. The waste is colossal, with its associated socioeconomic effect on the economy. Something must be done urgently to save these lives.

The scourges of HIV/AIDS and TB are interwoven, once a patient acquires HIV and develops AIDS, TB is often a companion. The costs of treating both diseases are enormous thereby creating a vicious cycle of disease and poverty.

One approach to tackling these scourges is to combine treatment in the same clinical setting, where fixed dose combinations of both TB and HIV drugs can be administered to patients (using the DOTS and HAART regimes) by trained health workers.

Non-adherence to HAART and DOTS poses a serious danger to the developing world, especially in sub-Saharan Africa, where poverty is a major problem. Non-adherence to HAART and DOTS can lead to resistance to the first line drugs used in the treatment of HIV/AIDS and TB. With the prevalent poverty in sub-Saharan Africa, shifting to the second line of drugs remains a Herculean task,

which might turn out to be a mirage. In Nigeria for instance, less than 5% of people living with HIV/AIDS are on the government ARV programme, while the majority source their own ARV drugs. With the coming of the President's Emergency Plan for AIDS Relief (PEPFAR), there is some hope for patients.

There are several factors responsible for non adherence to HAART and DOTS in sub-Saharan Africa. These factors could be classified into:

- 1 Patient related factors.
- 2 Community related factors.
- 3 Health facility related factors.
- 4 National/ International related factors.

Patient related factors form the core of the problem of non-adherence to drugs. The major problem is the cost and affordability of treatment. Most patients in sub-Saharan Africa cannot afford the cost of one month of therapy and this leads to patients purchasing drug in sachets that may last for only a few days, leading to non-adherence and resistance. For those patients who can afford the treatment, inadequate counselling, knowledge and treatment outcomes lead to fear and rejection of the treatment. At the same time, some patients develop pill fatigue and easily forget to take their medication at the right time, resulting in non-adherence. Many of the patients are security men and women and some are long distance drivers. In this group of patients, they are constantly on the move resulting in erratic intake of their drugs.

Community factors influence non-adherence mainly through stigmatisation of the patients. The

patients are afraid to take their pills in the presence of their relations. At the same time, poverty at the community level affects the contribution of the community, even if they are willing to help. This leads to reduced community support for the patients. Some patients share their drugs with their spouses and relations leading to non-adherence. The cultural beliefs of the community affect the patients in such a way that they forgo orthodox treatment for traditional treatments.

Health facility factors are really a problem, in that irrational diagnosis and prescriptions encourage non-adherence to treatment. The problem includes lack of trained staff, staff overload and inappropriate attitudes of health workers. Other problems include non-implementation of treatment protocols, inappropriate/ inadequate information on HAART and DOTS, non-availability of drugs and poor product presentation and labelling. At the international level the issue of branded and generic products is raising serious concern affecting the availability and affordability of drugs.

In Nigeria, treatment guidelines for HIV/AIDS exist but are not widely circulated. The national policy on HAART is yet to be streamlined in favour of the patients. The process of procurement and supply of drugs by the government is erratic and chaotic, though there have been some improvements. The problem of fake drugs in circulation is rampant and local capacity for manufacturing is still at the rudimentary stage.

We need to make sure that we have a strong programme in place to ensure drug adherence. There is also an urgent need to implement the WHO's '3 by 5' initiative and scale up provision of TB drugs to those who need them to remain alive.

Dr Adah O Stephen
Email: ogagbanos@yahoo.com

From personal experience, I have lost more than ten relations to these epidemics [HIV/AIDS and TB]. Most of those dead were young people in their productive years leaving behind orphans without adequate social support and care.

Spotlight: Preventive TB therapy – the obvious HIV link

Eric Lugada

Prior to the HIV epidemic, preventive TB therapy was less cost-effective than finding and treating active TB - particularly in low-income countries with a high prevalence of TB.

Today, in many such settings, however, a significant number of HIV-infected adults (estimated between 2.4 and 7.5%) will develop active TB each year. Among those with a positive TB skin test (purified protein derivative, or PPD), the rates of active TB are even higher (3.4 to 10% per year; Markowitz N et al 1997).

This prompted WHO and UNAIDS, in 1998, to recommend preventive TB therapy for PPD-positive, HIV-infected people who do not have active TB.

Despite this policy recommendation, TB preventive therapy programmes remain to be implemented in almost all countries with high HIV prevalence. Dr Paul Nunn, Coordinator of TB/HIV and Drug Resistance at the WHO in Geneva, attributes this lack of action to the failure by country health managers to grasp the critical connection between HIV and TB. He hastens to add though that in countries where DOTS coverage or effectiveness at finding and curing TB is not good, DOTS implementation remains the key priority.

DOTS is yet to succeed in countries where primary health care programs (PHC) are not functional. Such countries tend to be very low-income countries, many of which also have very high prevalence of HIV infection. Poor PHC systems present insurmountable difficulties for health care interventions such as DOTS.

Inevitably, HIV has worsened the TB picture. But the message that those infected with mycobacterium tuberculosis - without active disease - may be identified and given preventive therapy before their TB becomes active, has not received sufficient attention. Ultimately, offering a holistic

VCT centres are one of the few places at which large numbers of HIV-infected PPD-positive people may be identified efficiently

care package - to include but not be limited to TB preventive therapy - can probably only be achieved through the rapid integration of HIV and TB programmes at all levels.

Dr Adatu, National TB Programme Manager in Uganda, conceded that at the moment in Uganda TB preventive therapy cannot be incorporated in the programme. He has however, encouraged and permitted AIDS service organisations that are well organised and have the capacity to implement preventive therapy to do so. A case in point is the AIDS Information Centre, the largest and oldest voluntary counselling and testing (VCT) centre in the country. Since 2000, the centre has added TB preventive therapy and TB treatment services to existing VCT activities - in collaboration with the US Centers for Disease Control and Prevention Global AIDS Programme in Uganda.

Implementing TB preventive therapy programmes is challenging. It requires the identification of HIV-infected people early enough, before their immune systems are run down. VCT centres are one of the few places at which large numbers of HIV-infected PPD-positive people may be identified efficiently. But most VCT centres are not even thinking about TB, and are not equipped to eliminate possibly active TB infection. At best, this means that the only outcome under these circumstances is referral to another health centre or hospital that deals specifically with TB.

Before initiating preventive TB therapy, active TB must be excluded and those with a positive tuberculin skin

test (PPD) are most likely to benefit. HIV-infected people with advanced symptoms are often non-reactive to PPD tests and would not benefit from preventive therapy anyway. Furthermore, it is difficult to diagnose TB in HIV-infected individuals, since most are sputum smear negative (and hence non-infectious for TB), even though a significant number may have extrapulmonary (outside the lungs) TB. As with all drug-based prevention strategies, ensuring adequate adherence to preventive TB therapy is another potential challenge.

One way to manage dual HIV/TB infection - and deliver TB preventive therapy as well as DOTS for those presenting with active TB - would be to establish comprehensive HIV care clinics, in which VCT, DOTS, antiretroviral drugs (ARVs), prevention of mother-to-child HIV transmission services (PMTCT), and prevention and treatment of other opportunistic infections (OIs) is offered as a total package.

Better links between HIV care and TB control services would almost certainly increase access to TB preventive therapy for people living with HIV and would enhance performance of the TB strategy.

The 'observed' part of the DOTS strategy could also potentially be usefully employed to ensure adherence to preventive therapy, since defaulting from therapy is a legitimate concern.

Eric Lugada
HDN Key Correspondent
Uganda
Email: correspondents@hdnet.org



Comment: Preventive chemotherapy in TB-HIV and other co-infections

Jitendra Dwivedi

This is a very informative article and although I have been working on TB control for sometime now, I and the colleagues I work with, were so obsessed with the curative aspect of TB that we didn't think of preventive chemotherapy seriously until we read this article.

Isoniazid is like an antiretroviral (ARV) (which delays the progression of AIDS related conditions) it delays the progression of active TB.

The remark by Dr Thander Lwin that, "we are not treating the virus or

bacteria alone, rather human beings, so they need motivation and optimism to live and love their life.", is very truly said. It is not only true in Thailand but also here.

This is the biggest challenge, to motivate people enough to go and seek treatment for their own well being. They need to want to live on and live on as best as they possibly can. Mere provision of treatment at their doorsteps will not always work, and one analogy I will draw is with male condom promotion programmes: Despite of free distribution, people

don't use them. Despite knowing the benefits of using an HIV/STI prevention option, they don't use them, maybe because the desired behaviour change hasn't happened so far. I strongly feel that motivating people living with HIV-TB co-infection to continue to look after themselves, to comply with the treatment regimens, actively seek healthcare and live healthily is a massive challenge confronting public health systems.

Jitendra Dwivedi
Email: abf@post.com

I strongly feel that motivating people living with HIV-TB co-infection to continue to look after themselves, to comply to the treatment regimens, actively seek health care, and live healthily is a massive challenge confronting public health systems

Spotlight: TB and HIV inextricably Linked

Lee B Reichman

We know that HIV infection or acquired immune deficiency syndrome (AIDS) weakens the immune system and makes people at least 800 times more likely to have their latent tuberculosis (TB) infection activated. It wasn't realised until later that the reverse is also true: Active tuberculosis further suppresses the immune system of AIDS patients; curing tuberculosis actually improves the immune system.

The lethal combination of AIDS and TB is a worldwide problem. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), at the beginning of 2000, there were 34.6 million people in the world

I am constantly amazed that there is not more collegiality and cooperation among the legions of professionals involved with each disease, from social workers to doctors and nurses to researchers, donors, and government officials

who were infected with HIV. In the countries where most AIDS patients live, TB is the most prevalent serious infection they develop. One-third of the people who are reported as dying of AIDS actually die from TB. Worldwide, TB is the leading killer of people with HIV/AIDS. We who take care of AIDS patients know that essentially, nobody actually dies of

AIDS. AIDS weakens the immune system; people with AIDS die of diseases that are shrugged off by people with healthy immune systems.

In the early 1990's, in sub-Saharan Africa, Haiti, and Asia, the majority of adults already had latent tuberculosis infections. The TB bacteria were in their bodies, but their immune systems



were keeping the bacteria in check. When AIDS came on the scene and destroyed these people's immune systems, a waiting TB epidemic exploded. In several African countries, from 20 to 67 percent of patients with tuberculosis were also infected with AIDS. Autopsy studies in some West African countries showed that tuberculosis was the most frequent concurrent infection in patients who died of AIDS. They had AIDS, but they died of tuberculosis.

The situation is no better today. In some countries in Africa, 20 to 30 percent of pregnant women are infected with HIV, a sign of what HIV/AIDS is doing to the young, productive, economically active population. In South Africa, the most economically developed country south of the Sahara, 20 percent of the population is infected with HIV. Probably one-third to one-half of the people in these countries also have latent TB infection. In the countries with the largest number of people with HIV/AIDS, TB is still the most common cause of death in AIDS patients. This is particularly tragic because even in patients with AIDS, TB remains preventable and curable.

The co-existence and dreadful synergy between TB and HIV/AIDS is well known to international health care experts and to nurses and doctors working in affected communities. They see daily the tragic burden these dual epidemics place on young families, especially in Africa and Asia.

Therefore, I am constantly amazed that there is not more collegiality and cooperation among the legions of professionals involved with each disease, from social workers to doctors and nurses to researchers, donors, and government officials. For some reason, over the years, major AIDS meetings, such as the International Conference on AIDS, have only rarely included high-profile plenary sessions on TB. This may be a symptom, reflecting perhaps, an arrogant mindset among some AIDS professionals. These professionals seem to prefer to deal with AIDS while ignoring the companion epidemic of TB.

It isn't entirely clear why this is so. At the beginning of the HIV/AIDS epidemic in industrialised nations, the first patients – young, gay men – were unlikely to have latent TB infection and thus usually became sick with other organisms. Furthermore, they were often considered (without any scientific basis) to be likely to adhere to their treatment regimens. This group was considered very different from the other major transmission category, injection drug users, who usually had very high latent TB infection rates and, therefore, more active TB. Injecting drug users were often considered far less adherent and more difficult to deal with (again, without any scientific basis).

Perhaps the lack of cooperation and communication among these health professionals may have occurred because, historically, at least in industrialised nations, TB patients were usually cared for by pulmonary physicians or public health clinics, and AIDS patients were usually cared for by infectious disease physicians.

Because tuberculosis is spread through the air by breathing, rather than specific risk associated behaviours, it represents a much greater potential health threat to the world's population (more in developing than in industrialised countries) than HIV/AIDS. Yet, paradoxically tuberculosis still receives relatively little attention from UN agencies (aside from

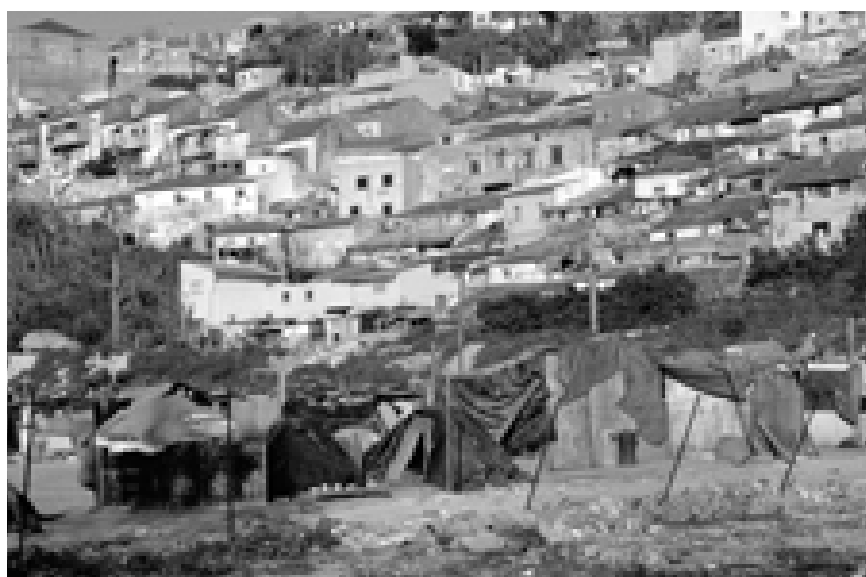
the WHO) and advocacy groups, compared to HIV/AIDS.

However, it is clear to me that health experts increasingly recognise the interaction between TB and HIV/AIDS. They see that curing or preventing TB increases or preserves immune function and that TB treatment methods such as directly observed therapy (DOTS) are now frequently being considered and studied for adaptation to complex AIDS treatment regimens.

Ultimately, the groups fighting each disease must cooperate more closely to prevent further loss of life. The recent global effort to make a 'Massive Effort to Fight Diseases of Poverty', which led to the Global Fund to fight AIDS, Tuberculosis and Malaria, which was endorsed by the WHO and some (but certainly not all) intergovernmental agencies (with varying degrees of enthusiasm or funding), is encouraging, suggesting that cooperation might come sooner rather than later.

*Lee B Reichman, MD, MPH
Executive Director,
New Jersey Medical School National
Tuberculosis Center
United States of America*

*Adapted from TIMEBOMB: The Global
Epidemic of Multidrug Resistant
Tuberculosis, McGraw Hill 2002 (used with
permission)*



6th of May slum, Lisbon, Portugal, where HIV/TB coinfection rates are high among injection drug users

WHO/TBP/Davenport



Looking back: Mandela – fight AIDS by fighting TB

Ian Hodgson

[Mod's note: This is the third in a short series of postings in recognition of Nelson Mandela's 87th birthday on July 18th 2005. This report is from the International AIDS Conference (IAC) in Bangkok, 2004, and describes Mr Mandela highlighting the importance of tackling tuberculosis (TB) as part of the overall strategy against HIV and AIDS.]

MANDELA: FIGHT AIDS BY FIGHTING TB

For the third International AIDS Conference in succession, former South African President Nelson Mandela has come to inspire and re-motivate us all. Yesterday his message was clear: HIV/AIDS cannot be tackled in isolation from other diseases like tuberculosis (TB).

"We are all here because of our commitment to fighting AIDS. But we cannot win the battle against AIDS if we do not also fight TB. TB is too often a death sentence for people with AIDS," Mr Mandela said on his arrival in Bangkok. "It does not have to be this way. We have known how to cure TB for more than fifty years. What we have

lacked is the will and the resources to quickly diagnose people with TB and get them the treatment they need," he added.

Speaking during a press conference to launch a new TB/HIV initiative supported by the Gates Foundation in three countries, Madiba (as Mr Mandela is also known) recounted his own experiences of TB while he was in jail on Robben Island.

"I was in jail when they took a specimen of my sputum and sent it to the hospital. I was diagnosed with TB. When the report came back they indicated that fortunately we sent the specimen before there were holes in the lungs," he recounted. "It would take only about four months to cure the TB if I treated it correctly. I went onto treatment and was completely cured in four months."

Mr Mandela shared the podium with Winstone Zulu, a Zambian activist who is himself a survivor of TB, and also living with HIV. "I am alive today because I took TB drugs when many people couldn't afford to get them," Mr Zulu said. "I have seen so many friends, and have lost my own

four brothers, who have died from tuberculosis simply because they did not get the drugs to have themselves treated."

"The world has made the defeat of AIDS its top priority. This is a blessing, but TB remains ignored," added Mr Mandela. "Today, we are calling on the world to recognise that we can't fight AIDS unless we do much more to fight TB as well."

On the penultimate night of the conference, Mr Mandela hosted a concert to mark his worldwide HIV/AIDS campaign named after his Robben Island prisoner number, 46664. The campaign was launched in November 2003 and aims to raise awareness. "46664 was my prison number. For over eighteen years I was imprisoned on Robben Island, I was known as just a number," he said. "Millions of people today infected with HIV are just that – a number."

*Ian Hodgson
HDN Key Correspondent
United Kingdom
Email: correspondents@hdnet.org*

Spotlight: HIV/TB co-infection and challenges

Rebecca Wanjiku

Whilst co-infection remains a major challenge, the government and other independent medical agencies have embarked on an HIV/AIDS education campaign and a TB treatment campaign as two separate exercises

In the past decade, there have been an increasing number of campaigns geared towards TB treatment and many Kenyans have been treated under the free medical scheme (for TB patients). But the rise in the number of TB patients has also coincided with the rise in HIV infection rates.

This has stretched the Ministry of Health's ability to cope with the twin epidemics and at the same time resulted in many deaths. Stigma has also been extended to TB patients and in some areas TB is equated with HIV infection. This means that some people do not seek medical attention for fear of knowing their HIV status and others prefer TB treatment and do not test for HIV.

Dr. Chakaya Muhwa, the head of Kenya's National Leprosy and TB Control Programme (NLTP) confirms that the increase in TB cases has coincided with the emergence of HIV/AIDS.

"In 2003 there were over 96,000 cases of TB and 80% were successfully treated. Five per cent died while receiving treatment while 15 per cent were not followed up or were transferred from their treatment centres," Dr Chakaya says.

Co-infection still a challenge

Whilst co-infection remains a major challenge, the government and other independent medical agencies have embarked on an HIV/AIDS education campaign and a TB treatment campaign as two separate exercises, according to Dr Ernest Nyamato.

Dr Nyamato, who works in Nairobi's Mathare slums, says that TB affects many people living with HIV and it is likely that 50 per cent of HIV patients will get TB at some point in their lives. In this respect, Nyamato says, there is a dire need to address the two epidemics together as they are affecting society in large numbers.

The Kenyan government's official policy is to use the directly observed therapy, short course (or DOTS) but, according to Dr Nyamato, superior regimens are available, especially for HIV patients, that guard against re-infection with TB. In his opinion, the insistence on DOTS is based on funding dictates. He argues that "many donors to the health ministry insist on DOTS even though the ministry has its misgivings".

"It is possible to limit re-infection through the use of superior treatment regimes that are only available in

private hospitals and at a higher cost," Nyamato says.

Asked about his misgivings about DOTS, Dr Nyamato says DOTS can limit access; it may overload the TB network if treatment is spread countrywide. This can happen especially if the TB clinics and other facilities such as modern laboratories are not put in place to ensure that people are well attended to.

"There is a scarcity of facilities to test TB that may result from [HIV] co-infection such as TB of the intestines, bones, and liver. Right now, under the DOTS programme testing is limited to sputum," Dr Nyamato adds.

Dr Nyamato says some hospitals in Kenya, which are reeling from the ever-increasing brain drain from the country, may not have enough personnel to supervise patients taking drugs since these hospitals insist



A TB patient with HIV/AIDS, Conakry, Guinea

WHO/TBP/Davenport



on direct observation. Moreover, some hospital laboratories are in a dilapidated state, often with obsolete equipment, and need upgraded laboratories to guarantee proper testing.

In his experience, there has been inadequate screening of patients to differentiate between TB and other ailments such as bronchitis. This, the doctor maintains, will not only need modern laboratories but also well trained/retrained medical personnel.

Given that DOTS is labour intensive, strict DOTS implementation could overstretch resources. In this respect, Dr Nyamato says concerted budgeting efforts will be needed from the government to ensure it can reach all those who need treatment.

“The government has to decentralise to the village level. Right now,

administration of TB drugs is centralised so you can only access it in hospitals like Kenyatta National Hospital or Mbagathi Hospital. If you are lucky, you can get treatment from international agencies like Medicines sans Frontieres (MSF),” Dr Nyamato argues.

On administration of drugs, Dr Nyamato recognises the need for harmony. He wonders why TB patients have to be supervised while taking drugs while we trust HIV patients to go home with a month’s dosage.

“ARVs do not need to be administered in DOTS. Right now, 90% of our HIV patients take their ARVs, so we can trust they will take their TB medication. It is a double standard to tell the patients to go home with ARVs then come to hospital every day for TB tablets” he adds.

Pursuant to this line of thought, Dr Nyamato is engaged in a pilot study on modifying DOTS in the Mathare slums. The project will also explore a change of regimen to give rifampicin for the entire eight-month period to establish how it can assist the patients.

Mathare is also engaged in a project testing how sputum can be tested better to give more accurate results. Under this pilot project, patients will also be educated on how to take charge of their lives and their medication.

The project will start by administering weekly dosages then move to monthly dosages. This will help to establish the rate of compliance.

Rebecca Wanjiku
HDN Key Correspondent
Kenya
Email: correspondents@hdnet.org

Speak Your World: HIV/AIDS opportunistic infections – a balancing act in clinical management

Nanao Haobam

Thirty-six year old Mr. X was previously an injection drug user (IDU) but has abstained from drugs for the past eleven years. He lives with his wife and son and is currently working as a counsellor in an NGO called SASO based at Imphal in Manipur state, India. SASO runs a drug and HIV/AIDS prevention project funded by the International HIV/AIDS Alliance. The following is a simple narration of his tribulations while fighting with HIV-associated opportunistic infections and the repeated events of his encounter with tuberculosis (TB).

It was in 1995 when he first developed symptoms of TB, he suffered from loss of appetite, loss of weight and chest pains. He consulted his physician and was advised to undergo some diagnostic tests for TB. The test reports were inconclusive, however his health continued to deteriorate. On the basis of his symptoms alone,

the physician prescribed him AKT-4 (a kit of drugs containing four first line anti-TB drugs, rifampicin-450mg, pyrazinamide-750mg, ethambutol-800mg, isoniazid-300mg). He took AKT-4 for 2 months and then shifted to R-cinex (a combination of two anti-TB drugs, rifampicin-250mg and isoniazid-150mg) and continued treatment for

Mr. X has probably been able to face the onslaught of TB and HIV-related infections because he was working in a health care setting... on the other hand, there are many patients who are not similarly advantaged or informed.



The baby ward, Brooklyn chest hospital, Cape Town, South Africa

another 10 months. During this period his health improved considerably and he regained appetite, weight and felt healthy enough to be able to attend to his duties.

He looked robust and was regularly attending to his office work as well as from his household chores. After a smooth ride with his health for a span of three years and he suddenly felt weak and suffered from similar symptoms as during the year 1999. On the advice of his physician he underwent a few tests for diagnosis of TB, such as chest X-ray and mirco-dot (a blood test) but yet again there were no findings (for TB). On a trial basis physician prescribed him AKT-4 as he suspected his symptoms were due to TB and there was a history of earlier infection. After a month of medication his health showed signs of improvement so he was advised to continue the treatment for a year. During this period he continued to work as a home based care worker under an OXFAM project implemented by SASO.

In 2002 he again developed his earlier symptoms: he felt ill and weak and the usual trend of disturbance followed. The doctors detected a tumour in his abdomen and performed a fine-needle biopsy (a type of biopsy in which a small needle is used to collect cells from a lump or mass) but there were no findings for TB. The test was repeated twice within a month but there were no signs of the disease. He was prescribed an anti-fungal drug (Candistat) but there was no improvement and his health continued to deteriorate. He

got tested for hepatitis C (HCV) & B (HBV). He was found reactive for HCV. His CD4 cell count (these cells are part of the body's defence against infection and their numbers decline throughout the course of HIV infection, as the immune system becomes overwhelmed) was just 117 (a normal CD4 level is about 1,000 cells in a microlitre of blood) at this time. His doctors advised him to start antiretroviral therapy (ART) with Triomune-30 (lamivudine, stavudine and nevirapine). His liver function became compromised within 25 days of ART initiation and he was advised to stop taking drugs immediately. This may have been linked to the hepatitis infection, which also can weaken the liver. He assumed that he had yet again suffered from relapse of TB and changed doctor. The doctor prescribed a fresh course of anti-TB medication but with a reduced dose. Surprisingly his health improved during the first 5 days and he consulted the doctor again. As he had responded to treatment, the doctor prescribed him the standard dose and he continued taking the medicine for a span of one year. Meanwhile he continued to work and life appeared to be a smooth ride.

Despite all the attention he paid to his health, he started to feel sick again in 2004. In view of his constantly deteriorating health he was advised to get a CD4 count and to his dismay the count had fallen to an alarming 5 cells per microlitre of blood. As a result of this finding he was once again advised ART. This time the combination was different and comprised of newer

drugs such as zidovudine, stavudine and Effavir. His health deteriorated further and he became terribly weak and was bed-ridden. Ultimately he was hospitalised and was fed intravenously for about a month, as there was no improvement in his appetite and general health.

His family members were very worried as his condition worsened with every passing day and they were running helter-skelter in search of money as well as physical assistance. Help arrived from different quarters and in different forms and the family was supported by friends and near ones. He was found to be suffering from cryptococcal meningitis (an opportunistic fungal infection found in people weakened by AIDS) and was administered Fungizone for 14 days. He did not follow the doctor's advice to stop ART during this period and kept on consuming it unnoticed. After a month his haemoglobin was tested and it had dropped very low to a count of only 4 units. The doctors transfused 8 units of blood and he was forced to stop ART intake for about 4 days during this period. A faint streak of promise and life appeared after 4 blood units had been transfused as he regained appetite and started to consume solid foods. He was advised consequently to change his ART regime and prescribed the combination of lamivudine, stavudine and Effavir. His haemoglobin shot up to a reading of 9.8 after the receiving 8 blood units.

With all the courage and the tireless zeal to strive for life he turned back to his office work. Now he works as a counsellor and serves people again. Mr. X has probably been able to face the onslaught of TB and HIV-related infections because he was working in a health care setting. He was aware of the signs and symptoms and had access to diagnosis, treatment and care but his journey has not been without stumbling blocks. On the other hand, there are many patients who are not similarly advantaged or informed. They have to run from pillar to post for information, knowledge and support. They continue to suffer in silence. One wonders when they will find their voice.

Nanao Haobam
HDN Key Correspondent
India
Email: correspondents@hdnet.org

Spotlight: An uphill struggle against TB and HIV in South Africa

Lewis Ndlovu

Despite the fact that the two diseases so often go hand in hand, South Africa is one of the few countries on the continent taking steps towards greater integration of HIV and TB treatments

Tuberculosis (TB) and HIV co-infection is a serious public health problem in South Africa and is being addressed through a national programme of collaborative TB and HIV activities.

A national TB/HIV coordinating body has been established to oversee collaborative activities, which have so far been implemented in 44 out of 174 sub-districts and are planned for expansion to cover the entire country by 2007. TB/HIV provincial coordinators and national staff have been recruited and national guidelines for care of HIV-infected TB patients, including access to antiretroviral (ARV) therapy, have been developed. Voluntary counselling and testing (VCT) for HIV infection is also offered routinely to TB patients in some places, although the acceptance rate remains low.

A number of NGOs are involved in providing TB services and are also mobilising community-based support, but more needs to be done to also encourage broader private sector participation.

The two diseases form a deadly combination and many of the complications that bring TB patients to health clinics are associated with HIV. In 2002 up to 55% of TB patients in South Africa were reportedly HIV positive (Global TB Report, 2005).

Despite the fact that the two diseases so often go hand in hand, South Africa is one of the few countries on the continent taking steps towards greater integration of HIV and TB treatments. It is a national policy, for example, that all TB patients should be counselled to test for HIV, and conversely that all those who test HIV positive should be screened for TB.

Concerned by the close association of TB and HIV, the Centre for the AIDS Programme of Research in South Africa (Caprisa), is pioneering an innovative approach to see whether TB and AIDS care can be integrated. The idea is to recruit patients for antiretroviral (ARV) therapy before their immune system is so weak that their recovery is difficult.

HIV affects the immune system and increases the likelihood of people acquiring new TB infection. Immune suppression also promotes both the progression of latent TB infection to active disease and relapse of the disease in previously treated patients. People with HIV are up to 50 times more likely to develop active TB in a given year than HIV-negative people.

TB accounts for up to 40% of deaths due to AIDS in Africa as well as in Asia. It is one of the leading causes of death in HIV-infected people and, without proper treatment, approximately 90% of those living with HIV die within months of contracting TB.

Following reports by the World Health Organization (WHO), which declared South Africa as having one of the worst TB epidemics in the world, TB laboratory testing services, to ensure that infectious TB patients are diagnosed efficiently, have been improved and greater efforts are being made to offer tests and/or treatments promptly. Training 5000 health workers on the directly observed therapy (DOTS) strategy, has helped to ensure that all DOTS pilot districts have appropriately trained staff. The DOTS strategy is a health care management approach that seeks to ensure patient compliance/adherence by watching them swallow their TB drugs and ensuring that they complete their course of treatment. Other

components of DOTS include the appointment of TB managers, training of health staff and monitoring of the patients throughout the treatment process.

The South Africa Department of Health says although it's strengthening its TB management services, the TB burden continues to grow because of the escalating HIV/AIDS epidemic, high percentages of patients who do not complete their TB treatment and the rising number of drug resistant TB cases.

The DOTS system has been criticised for 'policing' patients, rather than educating them to take responsibility for their own health, as is the case with the AIDS patients about to begin ARV treatment. Making use of counsellors trained to educate AIDS patients about the importance of drug adherence is another plan yet to make it off the drawing board in South Africa.

NGOs, such as the South African National TB Association (SANTBA) and the Western Cape TB Alliance, are powerful partners in the effort to fight TB in the community. Cooperation between the government and NGOs is essential in linking health service staff to patients, families and communities, and thus curing more TB patients.

As former South Africa President, Nelson Mandela said during the International AIDS Conference in 2004: "We can't fight AIDS unless we do much more to fight TB." That may be more true in his own country than anywhere.

Lewis Ndlovu
HDN Key Correspondent
South Africa
Email: correspondents@hdnet.org



Spotlight: TB in HIV positive children – New opportunities and persistent challenges

Bobby Ramakant

Childhood tuberculosis (TB) has generally been seen as rarely infectious, and has been accorded a low priority in India – largely owing to a misplaced faith in the anti-TB (BCG) vaccination.

Following recent initiatives taken by TB programme managers and the national body of paediatricians in the country, however, management of TB in children has assumed its rightful place in the Revised National Tuberculosis Control Programme (RNTCP).

A few additional steps may still be needed to address the impact of TB in HIV positive children, who are at an increased risk of developing active TB and disseminated TB (outside the lungs) in particular.

During the First National Conference of the AIDS Society of India, held in New Delhi, in April 2005, Professor Soumya Swaminathan, Head of the HIV/AIDS Division at the Tuberculosis Research Centre in Chennai, spoke at length about challenges in treating TB in children with HIV.

She explained that globally there is insufficient information and understanding of TB epidemiology, diagnosis or clinical trials specific to children, and most of what is available are observational data from treatment centres.

Diagnosis and treatment of TB in HIV positive children

HIV-positive children are at risk of diagnostic errors as well as delayed diagnosis of TB. As with adults, pulmonary TB is the most common manifestation of TB in HIV positive children. However, its diagnosis in children presents special problems as sputum is often not available for examination. The tuberculin (Mantoux) skin test is less sensitive than sputum analysis, and chest radiography less specific for diagnosis of TB in HIV-infected patients. The poor outcome following anti-tuberculosis drug treatments, frequently reported in HIV-infected children, might be due, at least in part, to other HIV-related conditions being wrongly diagnosed as TB.

Various diagnostic techniques, such as improved culture techniques, serodiagnosis (using blood samples), and direct detection

As with adults, pulmonary TB is the most common manifestation of TB in HIV positive children. However, its diagnosis in children presents special problems ...

of TB bacteria through molecular techniques of DNA amplification, have been developed and evaluated to improve diagnosis of childhood tuberculosis. But again, a relative lack of baseline data on children, the need for high standards of technical expertise and high costs limit their use in children.

The India programme took a step towards improving case detection and treatment outcomes for paediatric TB patients in 2003. The RNTCP – responsible for providing directly-observed drug therapy (DOTS) services throughout the country – and the Indian Academy of Paediatrics (IAP) jointly introduced a simple algorithm for diagnosis of TB based on a combination of clinical presentation, sputum examination (wherever possible), chest x-ray, Mantoux test and history of contact. The guidelines advised that in the face of diagnostic difficulties, the child should be referred to a paediatrician for appropriate management. Careful adherence to these guidelines can help promote timely diagnosis of TB in HIV positive children, although difficulties with accurate detection of HIV infection are also known to compound diagnostic dilemmas.

Once a child is diagnosed as having TB, the next step is to classify the patient, determine the type of case and severity of illness in order to decide the optimum combination of drugs and duration of treatment. The standard six-month course of DOTS is adequate for treatment of TB in children, and generally shows a good response, with good clinical and radiographic improvement. But the new guidelines also make clear cut recommendations about specific treatment options.

Many studies show that HIV positive children have a higher rate of mortality during treatment of tuberculosis, compared to children without HIV, probably as a result of the underlying suppression of immune function and/or other complications and infections. So, dually infected children need close immunological monitoring, including CD4

counts, wherever possible. As in dually-infected adults, when CD4 reaches a critical limit, the child should be started on ARV therapy as a priority.

It is hoped that the algorithm and the diagnostic and treatment options it presents will go a long way to improving long term outcomes of TB in children living with HIV. Access to costly investigations and drugs, however, remains a mirage for many paediatric patients and health workers as is the case with adults.

Chemoprophylaxis – the prevention of active TB using drug treatments – is also an effective and safe option in children and has been accepted under the new guidelines.

One more positive step has been initiated by RNTCP. Innovative TB drug boxes are widely available and accessible for adults, but until recently it was a challenge for children to access anti-TB medicines. Recently, RNTCP and IAP met with TB programme managers and agreed to use the standard TB drug boxes available through RNTCP for children as well, and to use a weight band for dosage regulation.

These focused diagnostic and treatment issues may not, however, tell the whole story. Studies in different parts of India have shown that the vast majority of HIV-positive children are also malnourished when they are first presented to a TB clinic. Experience suggests that a combination of a good diet, personal hygiene and proper sanitary practices will reduce diarrhoea and other infections, boost immunity and preserve the health of a child with HIV. As the ramifications of the HIV pandemic and its impact on tuberculosis control in the country are more widely understood and acknowledged, the nation will have to adopt a more holistic approach towards management of dually-infected children in particular.

Bobby Ramakant
HDN Key Correspondent
India
Email: correspondents@hdnet.org





4 Policy, society and practice – other factors affecting TB control

TB and society

Spotlight: TB and poverty

Dinesh Kumar Sharma

“85% of the TB cases that my project has been providing DOTS services to live below the poverty line”
– Santa Raye, consultant with DAN-TB

“TB and poverty go hand-in-hand, sometimes we do not know which causes the other,” said Riyas Musa Ahmed from the National TB Programme of Afghanistan. Ahmed is in New Delhi to participate in the 2nd Stop TB Partners Forum.

He is not alone in voicing his concern about the suffering inflicted upon hapless victims by these two deadly killers. Now more and more people are talking about the linkages between TB and poverty. It has come to be identified as one of the core issues that remain to be addressed, leading to a consensus that TB control must find a central place in poverty reduction strategies.

It was the former Prime Minister of India, Mr. Atal Bihari Vajpayee who set the ball rolling during his inaugural address. He reminded participants that conditions associated with poverty – such as overcrowding and malnutrition – lead to increased vulnerability to TB. Pointing to the silent spread of the disease Vajpayee said that it wrecked lives and livelihood.

Over the past two years the relationship between TB and poverty has been explored in depth. It is clear that poor people face specific difficulties in accessing health services and experience long delays before diagnosis of TB can be made. These access delays are costly for the patients

and lead to further TB transmission. They are a major part of the impact of TB as an impoverishing disease.

Dr. Anhari Achadi, Advisor to the Indonesian Ministry of Health and Human Services says 17% of people in his country live in abject poverty. He laments that the awareness level of these poor people about TB (and other health conditions) is abysmally low. Even if they know that someone in their family has TB, they do not know that facilities exist for free treatment of the disease. Unfortunately these people are trapped in the vicious cycle of poverty, ignorance and suffering.

Santa Raye who works as a consultant with DAN-TB in Orissa State, India

says, “Eighty-five percent of the TB cases that my project has been providing DOTS services to live below the poverty line - with a daily income less than a dollar per day.” Her mantra for reaching the poor is simple: “Generate a demand for TB treatment from within the community.”

Dr. Karam Shah, National Manager of the TB Programme in Pakistan says that in his country TB control is part of the Poverty Reduction Strategic Plan (PRSP). The PRSP initiative targets rising population, illiteracy and infectious diseases together.

In Bangladesh one of the largest NGOs in the world, BRAC, which has devoted itself to work related to poverty



TB patients receive weekly rations of food to prevent malnourishment, Peru

WHO/TB/Davenport



alleviation and empowerment of the poor, joined hands with the national tuberculosis control programme over ten years ago. Dr. Faruque Ahmed, Director Health and Nutrition at BRAC explained that trained female community workers are playing a pivotal role in TB care.

"So as to increase the access of the poor to DOTS services, sputum collection has been decentralised and female workers, who earlier used to provide microcredit to poor women, are now also doubling up as DOTS providers," he said. "This has reflected in a gradual increase in detection rate and a high cure rate for TB."

In Peru, nearly half the population - or 6 million people, live in extreme poverty. The country has a high TB burden and cured TB patients have come forward and developed networks to support other TB patients.

Across the globe communities are clearly trying to develop pragmatic local responses and some of them are already showing signs of success.

The Coordinating Board of the Stop TB Partnership has approved the setting up of a Network for Action on TB and Poverty to become a platform for innovative implementation and sharing of experiences. The Network

aims to be the catalyst for expansion of best practices, as TB control activities extend and further adapt the DOTS strategy to better meet the needs of the poor.

The identification of poverty alleviation as a key element in TB control has helped to illuminate the human face of TB.

Dinesh Kumar Sharma
HDN Key Correspondent
India
Email: correspondents@hdnet.org

Comment: TB control in nomadic populations

Dr Adah O Stephen

Nomads form a significant portion of the West African population, but there are no reliable census figures to tell us the actual population. The Nomads are highly mobile populations that move with their animals depending on the seasons. They are herdsmen that are constantly on the move with their entire family. They are exposed to all forms of weather conditions all year round because they live in make-shift camps made of grasses, leaves and tree branches. They are exposed to all forms of hazards. In West Africa, there are two main seasons; the rainy season and the dry season. The Nomads were originally inhabitants of the northern part of the region on the fringes of the Sahara desert. This makes the availability of green vegetation all the year round difficult, due to the arid nature of the North. This informs the movements of the nomads in search of food for their animals.

During the rainy season, the nomads are found in the northern part of the region and as the dry season approaches, they prepare to move southwards to green pastures.

Provision of health services for nomads in the region is very difficult due to their high mobility. Tuberculosis is a common disease of nomads, probably due to their exposure to the elements, difficult lifestyle and malnutrition coupled with living amongst their animals.

Provision of health services for nomads in the region is very difficult due to their high mobility. Tuberculosis is a common disease of nomads probably due to their exposure to the elements, difficult life style and malnutrition coupled with living amongst their animals. Both bovine and pulmonary TB is common amongst nomads.

As they move, the male nomads interact with commercial sex workers in different localities on their route and this increases the risk of HIV/AIDS amongst them.

It has been observed that the nomads follow particular routes every season they migrate. Therefore health services can be organised at different points on these routes along with DOTS and VCT services. The nomads usually

settle in a particular camp for at least a month before moving on to the next camp. These DOTS centres should be fully equipped for full TB investigations using sputum smears and HIV screening kits. Those nomads diagnosed with TB can be directly observed to take their drugs for at least a month before they move camp. A special card should be designed for them to aid follow up of treatment in any of the DOTS centres, for record purposes, to reduce default rate and to reduce the chances of developing multi-drug resistance TB. The cornerstone for TB control amongst nomads using DOTS is to organise health services along their routes of migration in all seasons.

Dr Adah O Stephen
Email: ogagbanos@yahoo.com



Comment: TB control in nomadic populations (1)

John Grange

This is a very worrying situation, not just because of the difficulties in providing a full course of therapy, but because of the epidemiological considerations of HIV infection in populations at risk of acquiring both human and bovine tuberculosis. From work done in Scandinavia in the 1950s, there is good, though somewhat indirect, evidence that the risk of infection proceeding to overt tuberculosis (the disease ratio) is much lower for human tuberculosis when infected by *Mycobacterium bovis* than *M. tuberculosis*. This was attributed to the lower virulence of

M. bovis for humans. Also, human tuberculosis of bovine origin tends to affect non-pulmonary sites, such as lymph nodes, and therefore tends not to be infectious. In persons with compromised immune systems due to HIV, the epidemiological differences between the two types of tuberculosis would be wiped out and those infected with *M. bovis* would be at high risk of developing infectious pulmonary tuberculosis. Thus, human-to-human and human-to-cattle transmission of *M. bovis* leading to overt disease would occur, in a vicious circle with serious consequences for both the human and

cattle populations.

Accordingly, operations research to develop effective ways of controlling tuberculosis in this and other similar populations needs to be given very high priority.

*John M Grange
Visiting Professor
Centre for Infectious Diseases and
International Health
University College London, UK
Email: sophia@hagia.freemove.co.uk*

Speak your World: Beating the odds, Akha woman shares her story

Monruedee Laphimon

Nervously twisting a tissue around her fingers until it falls apart, she shares her tale. She laughs readily, though nervously, often on the edge of tears. Beautiful brown emotion-filled eyes hint too at the sorrows she has endured, darting constantly about the room in the way of someone who seldom feels safe. Ying is a 25 year-old refugee; an Akha (*) woman born in Burma, which is now known as the Union of Myanmar. Although she doesn't relate much of her life in Burma, the difficulties of that time led her to dream of a better life in neighbouring Thailand. Dissolving into tears she tells of being trafficked to a Thai brothel at the age of 17, by her own sister.

For the next 7 years Ying worked at several brothels in and around Chiang

Mai, Thailand. While life in Thailand had not quite turned out as she had hoped, she did meet a man and fall in love. Again, Ying was betrayed horribly. Promising to help her to find a new life, as she had begged him to do repeatedly, he instead sold her to yet another brothel.

About this time Ying began to feel sick. "I felt quite ill and coughed a lot. My body was very weak; I easily got tired and couldn't get out of bed. All I wanted to do at times was just to lie down," she says.

As sick as she was, Ying continued to work, until one day she was no longer able to entertain customers. She was taken to the hospital by her Thai boyfriend, who was able to communicate with the doctor. Ying

spoke very little Thai and had no idea what was happening as the doctor examined her. The diagnosis was tuberculosis (TB).

Back at the brothel, Ying was forced to continue working. She is able to recall very little from that time. "I got back home with lots of medicine. There were quite a few bags of them, filled with several kinds of tablets," she says. "I think it was about five to six pills at one time. Some were white and some were red and they were both huge in size." Not surprisingly, she became increasingly ill. The owner of the brothel returned with Ying to the hospital and helped to check her in. After a week's stay, Ying realised that she had been abandoned, and she would not see her employer again.



"I think that my TB contraction might have come from some of my sex worker peers living in the same brothel house," Ying admits. "There were ten sex-workers packed into that small house."

Fortunately, Ying's luck began to change while in hospital. "When I was at the hospital, I happened to meet a girl who was Shan(*)," she explains, "We chatted and she eagerly told me about EMPOWER."

EMPOWER is an NGO working towards the empowerment of sex workers in Thailand. Ying was provided with safe refuge by EMPOWER for one month, and was then referred to a safe house operated by the MAP Foundation for the Health and Knowledge of Ethnic Labour. MAP works hard on TB intervention among the marginalised population of migrant workers, communicating in several regional languages.

Happily for Ying the superintendent of the safe house, Sang Thong, is also an Akkha, allowing her to communicate once again in her mother tongue.

Ying has lived for almost 8 months at the safe house, sharing the 4 bedroom home with 5 others. Fellow residents are well informed of how to protect themselves from TB infection. Although Ying was originally provided with private dining utensils, she has never felt stigmatised or discriminated against by her peers.

Ying lost her appetite for four to five months while she was at the worst stage of her illness. Her new medication regimen is not quite as



WHO/TBP/Davenport

Street beggars, TB flourishes in poor neighbourhoods, Dhaka, Bangladesh

challenging as the first; she takes TB drugs twice daily, after breakfast and before bedtime.

Sang Thong has provided tremendous support to Ying, particularly in her early days at the home. She has assisted Ying in taking her drugs regularly and accompanies her on visits to the nearby hospital where Ying receives her TB care and treatment.

When asked what she hopes for her future, confusion is briefly reflected in Ying's shy, blushing face. She looks away and murmurs quietly, "It is not known to me at this stage."

While Ying's future is still uncertain - and as a refugee, with very limited options - she is doing well. She is now working three days a week as a paid housekeeper and continues to live in the safe house. She says she feels completely well again and will soon complete her treatment.

If a migrant worker is able to beat the odds, navigating successfully around all of these tremendous barriers and able to begin treatment, it is often short-lived. The sad reality of refugee people is that they have little stability in life, and often need to move on to a new location with little notice, leading to a premature end to their treatment course.

Ying is one of the lucky ones.

[* Footnote: the Akha and the Shan are an ethnic groups originating in the mountainous region bordering Burma, China and Northern Thailand]

Monrueedee Laphimon
HDN Key Correspondent
Thailand
Email: correspondents@hdnet.org

"I think that my TB contraction might have come from some of my sex-worker peers living in the same brothel house. There were ten sex-workers packed into that small house."



Front-line: Fighting TB in Senegal – a dead end for the marginalised

Gustave Gaye

These are true stories of two tuberculosis (TB) patients who were denied treatment during their lifetime. Whether it was the stigma attached to their illness, their social and economic circumstances or systemic failure that denied them this access is a matter of conjecture.

Camara was a 42-year-old man with just three years of schooling. Following the death of his father, while he was just a young adolescent, he became a street kid and travelled from one town to another with his peers. He was imprisoned at least three times. Camara was unmarried but had been frequenting female sex workers. He enjoyed the local alcoholic drink called 'soun-soun'. Later, he turned to drugs, including cannabis, and became addicted.

He was diagnosed with TB by a mobile health care programme. As he continued to move from one town to another he faced a number of difficulties in accessing treatment. He avoided talking to his friends and even health workers about his disease

because of the fear of the stigma attached to TB. Camara faced twin stigma, one of being a 'street kid' and other of being a TB patient. At the programme we tried to help him face his illness and social realities. Despite our best efforts he died in January 2005.

Cisse was just forty-five years old when he died. He came from a rural area. He was illiterate and at a very young age migrated to town in search of petty work. He also used cannabis and 'soun-soun'.

He developed a throat problem and sought treatment from various traditional healers, but to no avail. In November 2004 he came in contact with our organisation. We sent him to an ear-nose-and-throat (ENT) specialist who wrongly diagnosed his illness and prescribed surgery for removal of his voice-box. Our organisation could not bear the cost of such an expensive surgical procedure. Meanwhile his condition continued to deteriorate. Two months later a doctor from the same hospital diagnosed him

to be suffering from TB of the voice-box. Unfortunately it was too late. Within a few days of his admission to a TB ward, he died.

The stories of these two patients have a lot in common: poverty, illiteracy, drug addiction, itinerancy and failure to access treatment for their illnesses.

The first lesson from their tales is that resources are needed to diagnose and treat TB in hard-to-reach and/or marginalised populations in our countries. Pro-poor approaches need to be combined with TB control programmes to increase their access to people like Camara and Cisse. Yet another lesson for programme managers is that patients tend to deny their illnesses and avoid seeking treatment for fear of inviting stigma and isolation but end up paying a very heavy price: their own lives.

Gustave Gaye
HDN Key Correspondent
Senegal
Email: correspondents@hdnet.org

The stories of these two patients have a lot in common: poverty, illiteracy, drug addiction, itinerancy and failure to access treatment for their illnesses.

Stigma and TB

Spotlight: Stigma and TB in Tanzania

Tumaini Mbibo

Joseph Kambenga is a 35 year old who works with heavy trucks. He has contracted tuberculosis (TB) for the second time and is undergoing directly observed treatment (DOTS) at Kisarawe District Hospital in the coastal region of Tanzania.

“It is my second time to suffer from this deadly disease, the first time was in 1997” he says as he pauses to cough, “but this time I have experienced a very strange thing” he says in a low but welcoming voice.

He is not sure, but he thinks he may have contracted the disease initially through sharing a cup of water, although he readily admits that it could also be from sleeping in a crowd. This time however he believes the disease has reoccurred as a result of his failure to comply with the advice given to him by the doctors.

“I couldn’t stop working because I have a family to support, so I continued to carry heavy luggage contrary to what I was told by the physicians, and as a result the TB came back” he said.

Explaining his bitter experience, Kambenga says that on arrival at the hospital the medical personnel were clearing the TB ward in order to prepare for a special mission on malaria. The TB patients were temporarily being transferred to another non-TB ward. Kambenga describes the situation “It was a ridiculous scene, as if people were acting in a film; my friend it was unbelievable, not only were the fellow patients sneering at us but they also decided to boycott their beds as they were afraid of being infected”.

The doctor in charge of TB and leprosy explains that the fellow patients were very afraid of infection and were prepared to pack and go home rather than share a ward with TB patients. It took about three days for the hospital authorities to calm the situation.

This situation reflects the stigma and prejudice endured by TB sufferers. In fact, along with HIV/AIDS, most of the health-related stigma and discrimination cases in Tanzania can be attributed to tuberculosis and leprosy. In the old days, most people believed that only the very poorest people were prone to tuberculosis infections. But, since TB and HIV/AIDS have emerged as intertwined problems, the story has changed. According to the National Tuberculosis and Leprosy Programme in Tanzania, 60 per cent of the increase in the incidence of TB in the country can be attributed to HIV, while one-third of people who are HIV positive are co-infected with TB.

DOTS has proved its effectiveness in a number of ways in Tanzania. For instance, most TB patients are hospitalised and attended to effectively, and an attempt is made to follow up on those patients who are discharged. However this can be difficult and many disappear after being relieved of their most serious symptoms.

Experience from the field shows that among the factors that normally cause patients to fail to complete the prescribed course are:

- Long distance travel to collect drugs;
- Long duration of drug administration;
- Poverty and struggle for livelihood e.g. mobile workers often do not complete DOTS and invariably move on before the continuous phase is completed.

In addition, due to the huge stigma attached, many people will not admit to suffering from TB. As Kambenga explains “A number of cases have revealed that some of the patients do not report to the clinic at the onset of TB symptoms, believing that they might have been bewitched or inclined to the evil spirit”.

“You can assess the situation even from your bed-side at home. Once you are said to suffer from TB, you can see people coming and going just to see you” he said, “You also hear, even from the well wishers, a lot of speculation and rumours that you might have been caught by HIV (nicknamed ‘ngoma’ or ‘mtandao’ in Tanzania)”

“You can’t stop people from thinking the way they want. For instance, it has become a fashion that once you start frequent coughing and losing your body weight, you may hear people saying that you are already caught in the net of mtandao”.

In fact, although TB patients are often suspected of being HIV positive as well, the stigma may be specifically TB-related and it contributes to the rising occurrence of new TB cases in general, for people tend to hide their TB status, leading to further spread of the disease in the community at large.

Tumaini Mbibo

HDN Key Correspondent

Tanzania

Email: correspondents@hdnet.org

Due to the huge stigma that is attached, many people will not admit they are suffering from TB.

Unsung Heroes: Nun fights TB stigma with compassion

Elena Obieta

Maria van der Linde is a 61-year-old nun, German in origin, and naturalised as a Peruvian almost thirty years ago. Maria's vigour defies her age; she is full of energy and conviction. At present she works at the Cristoforo Colombo Health Institute (ISDEN) in Bangkok. I had an opportunity to meet her when I was in the Thai capital to participate in the International AIDS conference.

In 1976 Maria, both a nun and nurse, realised that people living with tuberculosis (TB) in Peru were suffering because of lack of diagnosis, proper treatment and, most importantly, denial of basic human rights such as food, employment, housing, health and education.

During the seventies, when Sister Maria started working with TB patients, the stigma attached to the disease was devastating. No one would accept that he or she suffered from TB, instead insisting: "I have some lung trouble". Patients had very low self-esteem; they tended to hide themselves and would not even speak out loud. The guilt of suffering from TB was awful. It stirred Sister Maria's conscience. She decided to fight for people who were suffering from poverty, discrimination and TB.

She started to bring TB patients together on one platform. Here they began to shed their fears and share their stories. Together, they learnt to overcome their misery. In 1987, they got together to meet the health



Mdme Oumou Bah-Sow, Director of the National TB Programme, Guinea

WHO/TBP/Davenport

minister to tell him that the X-ray machine at the local hospital was inoperable. When they were not allowed to see the minister, instead of raising slogans, they commenced coughing in unison. After that, meetings of TB patients organised by Maria were banned. However their unity survived as a local church allowed them to use its premises for meetings.

As the years went by people living with TB started to work as health promoters and initiated prevention activities within their own communities. Today there are twenty-six organisations of cured TB patients working at the grassroots level in Peru. The good work done by them has been recognised by international donors

and for the last three years they have been receiving grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Maria believes that silence is no option for the oppressed and sick, especially when it is a matter of life and death, humiliation and human dignity, and access to diagnosis and treatment of one's illness.

Elena Obieta
HDN Key Correspondent
Argentina
Email: correspondents@hdnet.org

As the years went by people living with TB started to work as health promoters and initiated prevention activities within their own communities...
the good work done by them has been recognised by international donors

Spotlight: Stigma – lurking on the edge of the TB response

Abigail Erikson, Bobby Ramakant and Dinesh Kumar Sharma

“They say what they say, but this is the reality of what is happening” – Mr Vijay Messaih, a social worker with Saahasee

There can be no denying the devastating impact of HIV related stigma. The social prejudice associated with HIV has helped sustain the epidemic, leading many of those infected and affected to retreat into a world of silence, denial and isolation.

Acknowledging the existence and impact of stigma is the first step towards addressing it and, in the case of HIV/AIDS, that first step has clearly been taken.

But, today, stigma is also fuelling another epidemic – tuberculosis (TB).

Historically, the most generalised basis for the stigma of TB is that it has been seen as a disease of poverty. In some settings and social contexts, TB infection is associated with poor hygiene, a lack of education and destitution.

While TB is still closely linked with poverty today, the high co-infection rate of TB and HIV in many regions – particularly sub-Saharan Africa – intensifies stigma and discrimination for those infected with TB. Nevertheless, and despite frequent patient testimonies describing the isolation and stigma they face at home and in the community, many TB programmes are failing to honestly take into account or address the issue.

During the opening remarks at the Second Stop-TB Partners' Forum in New Delhi, India (24-26 March 2004) Sushma Swaraj, then Indian Minister of Health and Family described stigma



Sharlas Khatoon, a newly diagnosed TB patient outside her home, Dhaka, Bangladesh

towards those infected with TB as a problem of the past.

"I remember the times when people refrained from admitting that a member of their family was suffering from TB. The word TB was tantamount to discrimination and the patient was treated as an outcast of society," she recalled. "I am glad this kind of thinking and treatment is now history and that the stigma of TB has disappeared."

People living with TB in India appear to disagree.

Just a few hours after the Minister's opening words, over fifty TB-infected patients from just outside Delhi arrived unannounced and walked into the conference room in quiet defiance. Within minutes, men and women were

lined up along the walls as standing testimony to the millions of people who develop TB every year.

With appreciation and conviction, a representative from the group addressed the meeting.

"My honourable brothers and sisters, each of the people that you see here has been infected with TB - some of them have been cured. We are poor people, working in small factories, rat picking and doing other petty jobs. A large part of our earnings are spent on treatment. About six years ago, the government started the DOTS programme in our region. Since then, a lot of TB-infected families have been cured. But we want the DOTS programme to reach out to all those places where it is currently not available.



If some families among us are cured from TB, but others are infected but do not get treated, then the whole community is at risk.

We are all here from 22 countries, and we know that TB does not stay in any one country. We are one world in the fight against TB.

I request once more, that is important to take the DOTS programme to all the unreached people. I have faith that in order to achieve this, and in order to save many innocent lives, we will all arrive at the right decision."

Following the statement, we talked with the patients and a local NGO worker, to find out if stigma was a reality for them, either at home, in the community or within the medical establishment.

Mr. Vijay Messaih, a social worker from the non-profit organisation Saahasee, has been working with TB patients for over seven years - he shared his experiences.

"Many TB patients do not want me to visit their homes. They are afraid that neighbours and community members will find out they are infected. If they find out, they will tell the person to put something over their face and tell them to stay home in isolation."

He mentioned that reluctance to get tested is also a problem and many become very sick before they will go to the doctor. Mr Vijay went on to say that stigma is also present within the health care system. He told us that just around the corner from the hotel where the Stop TB meeting was taking place, at Kingsway Camp Hospital in New Delhi, doctors often refuse to touch TB patients, even going so far as to force them to stand on the other side of the room during their examination.

When asked what he thought of the Minister of Health's claim that stigma has 'disappeared', he put his hands up, shook his head and said, "They say what they say, but this is the reality of what is happening."

The discordance between top health officials' and TB patients' views underscores the need for TB patients to have a voice and actively participate in the fight against TB - a message that is resonating loud and clear throughout the TB field and affected communities.

While India has emerged as a leader in the renewed commitment to fight TB, the failure to openly address the issue of TB-related stigma – and to involve those people most affected by the disease in discussions and decisions – threatens to seriously undermine the achievements and progress the country has made in recent years.

*Abigail Erikson, Bobby Ramakant and
Dinesh Kumar Sharma
HDN Key Correspondents
The United States of America and India
Email: correspondents@hdnet.org*

Practice and policy

Spotlight: Working towards a successful strategy in Pakistan: Interview with Dr Karam Ali Shah

Zofeen T Ebrahim

An unrelenting tuberculosis epidemic and steadily growing population are two major public health issues that confront Pakistan today. The country has been making an attempt to come to grips with these problems ever since its independence in 1947, says Dr Karam Ali Shah, Manager of the country's National Tuberculosis Control Programme (NTCP). However, a strong political commitment reflected in increased funding for the NTCP and imminent nationwide availability of directly observed treatment (DOTS) services has made Dr Shah confident about a definite victory over TB in the not-so-distant future.

He agrees that DOTS is still not a household term in Pakistan and explains: "The DOTS programme started in 1995 with a very patchy intervention and remained in the doldrums for the next five years till the disease gained frightening proportions."

It was in the year 2000 that the NTCP started to receive government attention with increased funding. The allocation for the NTCP rose from \$1.4 million in 2000 to \$17 million in



Immigrant children in the 6th of May slum, where TB rates are high, Lisbon, Portugal

WHO/TBP/Davenport

2002. This year the government has promised an additional \$18 million. The programme now enjoys the highest level of political support after polio, he claims.

According to Dr Shah, a further one billion Pakistani rupees will be funnelled into the programme. "Another measure of gauging the government's commitment is the fact that these funds have been provided from its own resources." There was

a steady swell of international and multilateral partners following government's initiative. A number of governments such as the United States, United Kingdom, Japan and Canada, as well as multilateral agencies such as the WHO are supporting the NTCP now.

While there may still be funding gaps, he claims the money has been well spent. The proof is evident by the figures that he has at his fingertips.

"Coverage does not mean that all TB patients now have access to DOTS or all TB patients seek DOTS.... coverage means the availability of the DOTS package in all government run health facilities"

– Dr Karam Ali Shah



"In 2000, the coverage of DOTS was a mere 3%, in 2004 it rose to 80% and by June this year, we will reach our target of 100% coverage."

"However, coverage does not mean that all TB patients now have access to DOTS or all TB patients seek DOTS" he explains. "Coverage means the availability of the DOTS package in all government run health facilities."

Of the four provinces of Pakistan, the North West Frontier Province (NWFP) and Sindh have 100% coverage; only two districts are left uncovered in Baluchistan, and in the Punjab, of the 34 districts, 29 have been covered. "Providing coverage to rest of the five districts would not be too difficult" says a confident Dr Shah

And yet achieving control over the TB epidemic is still a distant goal for Pakistan. In fact, if seen purely as a health problem, the country will perhaps never be successful in its battle. It is a disease that flourishes wherever there is poverty, neglect, exploitation and illiteracy. These factors, indeed, act as an obstacle to seeking treatment. "Our case detection rate of new sputum smear positive tuberculosis patients is as low as 30%. The major hurdle here is that most TB patients go to private general practitioners (GPs). Most of time these GPs are over-diagnosing, making incorrect diagnosis, or perhaps don't know what to diagnose." Although, according to the NTCP manager, once the patient reaches the NTCP clinics, then he/she gets a new lease of life as the cure rate is reportedly 85%.

While the vicious cycle of population growth, poverty, neglect and illiteracy are the main villains in perpetuating the disease, another factor that has led to an increase in the incidence of TB, is the high prevalence of TB among Afghan refugees. When the camps were running, Afghan refugees were getting plenty of international attention. Now that the refugees have ostensibly

returned, the various international health care organisations have also packed up and left. But there are many refugees who have now settled in the NWFP and Balochistan. "This is indeed a concern, and in fact, an alarming one, as the local population is getting infected," concedes Dr Shah.

"Our future plans for nationwide coverage can only succeed if we get into public private partnership by securing support from community based organisations (CBOs) and NGOs. The DOTS programme will also have to be well entrenched within the public health system," Dr Shah envisages.

However, he adds, "Awareness and community involvement can help us succeed in our endeavour." For that he feels that the government's devolution plan will come in handy in reaching the grassroots. "The success ultimately will depend on the motivation of the care providers in the public health system – led by the Executive District Officer (Health). DOTS does not demand a high level of clinical expertise, and is more of a management issue. If community based organisations (CBOs) are actively involved, as has been done in the NWFP, there is a definite improvement in access to DOTS services."

Utilising the services of the Lady Health Workers (LHWs) is yet another successful strategy adopted by the NTCP. "Of the 80,000 LHWs in the public health system, we've trained some 50,000 of them so far. That is part of the plan, to train everyone right from the EDO (Health), to the doctors at the rural health centres, the paramedics and lab technicians." While the number of LHWs might be just a drop in the ocean, they become significant in remote areas where the mobility of women is restricted and they cannot access TB treatment. "Since the LHWs go from house-to-house, and DOTS requires daily

supervision, this works out very well. However, we are seriously exploring the possibility of involving CBOs and NGOs to work with us," he says.

Dr Shah says one of the Millennium Development Goals (MDG) is reversal of the spread of HIV/AIDS, malaria and TB by 2015, so it is a priority for the Pakistan Poverty Reduction Strategy Plan (PRSP) too. "We are looking at ways of making DOTS more effective by exploring the possibilities of providing incentives (in the form of cash, credit or food) for both the patients and the care providers. For example, patients have time and again mentioned the amount they have to spend for transport to reach the NTCP clinics, or the debt they have incurred while getting treatment. For care providers we know sputum collection is not a very appealing proposition and they are not very comfortable with it. So we are thinking of ways to make participation in DOTS appealing for all groups."

The emergence of a strong local government has helped Pakistan mobilise financial support for TB control from the international community. This has helped the rapid spread of DOTS services across the nation since 2000. An innovative approach to increase access for women to these services through LHWs has won the programme accolades from across the globe. Conscious efforts to integrate TB control with the PRSP and seeking active support from CBOs and NGOs will definitely help extend the reach of the programme to under served sections. The NTCP now faces the challenge of building its own capacity to respond to increasing demand for DOTS in coming years and establishing a dialogue with the private health sector.

Zofeen T Ebrahim
HDN Key Correspondent
Pakistan
Email: correspondents@hdnet.org



Spotlight: Elusive targets and deteriorating public health service in Argentina

Elena Obieta

Living in the twenty-first century, we know enough about tuberculosis (TB), its epidemiology, bacteriology, modes of transmission and means of prevention and treatment. We also know a lot about its social and economic determinants. In directly observed therapy (DOTS), for example, we have a time-tested and proven strategy to control the TB epidemic. So why it is proving so difficult to reach the WHO treatment targets in Argentina?

Sometimes diagnosing a TB case can be difficult. In my country, Argentina, chest symptomatic patients (people who have had a cough for two to three weeks or more) often have to visit five or six different health care facilities before they are advised a sputum test. This cost-effective and easy-to-perform procedure, invented in 1882, is capable of detecting TB in 85% of patients. However sputum examination may have only a limited role in diagnosing TB in children, in people with extra pulmonary (outside the lungs) forms of the disease or those living with HIV.

Statistics released by the Argentinean national TB programme might give the impression that the country is doing a great job; however, health care providers delivering services know otherwise. Argentina is known to be poor at keeping statistics or case notification. It is common knowledge that private sector health facilities do not notify the public health system of TB cases they diagnose. Such patients do not avail of DOTS services and buy anti-TB medicines from the market. Most of these patients are from middle and upper income groups, and are hopefully educated enough to not to abandon their treatment mid-course.

Health care workers in the public health system are insufficiently trained and many a time are overstretched by other responsibilities. Yet another cause of concern is intra-country brain drain from public health services to the private sector. If unchecked, it has the potential of putting the entire gamut of public health services in jeopardy.

I work as an infectious diseases doctor in a public hospital in a very

debt of 728 billion dollars, a 63% increase since 1990. The external debt of Argentina equals nearly 400% of its exports. These harsh financial realities bite deep into national spending on basic needs like health and education.

In a country like Argentina where a large segment of the population lives below the poverty line, nutrition, education and health are low priorities. An Argentine child reads less than one

Statistics released by the Argentinean national TB programme might give the impression that the country is doing a great job; however, health care providers delivering services know otherwise.

poor suburban locality. We have an X-ray machine and also facilities to perform sputum tests on a daily basis. Unfortunately, the technician who is responsible for carrying out these tests (she is the only one we have at hand) gets a salary far lower than she would receive in the private sector. It will not be long before such a well trained microbiologist will be hired away by the private sector.

Public health care services are in crisis throughout South America. Primary health facilities both in rural areas and urban slums face a shortage of doctors and nurses, as these professionals are lured into the private sector by higher pay and state-of-the-art working conditions.

Poverty and external debt are two major concerns in South America. According to a World Bank report (2004) Latin America has an external

book per year on average. Only if s/he goes to school, gets an education, will s/he have the knowledge to know that if a family member has a cough for two or three weeks or longer, it could be TB.

Despite the multiple challenges, Argentine society is waging a valiant war against TB. Over the years more investments will be needed not only in health programmes but also in education, nutrition supplementation, housing and poverty alleviation. Tuberculosis control programmes cannot be run in isolation; they are a part of broad programmes to improve the quality of lives of people in developing countries like Argentina.

Elena Obieta
HDN Key Correspondent
Argentina
Email: correspondents@hdnet.org



Spotlight: United Kingdom – immigrants' experience of TB health care

Andrew Furber

London receives many accolades, but the title of 'TB capital of Europe' is probably one it would rather avoid. This is the term a senior member of the British parliament recently used to describe the situation in the city. The incidence of tuberculosis (TB) has risen significantly in London over the last decade to a point where notification rates are three times higher than anywhere else in the United Kingdom (UK).

Studies in London indicate that the key factors driving this increase are poverty, homelessness and deprivation. HIV infection and difficulty in accessing health services have also been identified as important issues. All of these are particular problems for immigrants to the UK from countries with a high prevalence of TB.

Most family doctors, known in the UK as general practitioners (GPs), will be aware of the rise in TB incidence associated with immigrants and all should know how to access treatment. However, few will have much experience in actually making the diagnosis, and it is a diagnosis that is easily forgotten. Few GPs will have had specific training on meeting the health needs of immigrants and communicating with those from other cultures must be part of that.

So how does it feel to come into the UK and find that you have TB? Eleven year old Obah came to London from Somalia with her family after persecution of her people forced them to leave. They arrived in May 2002 and were housed in a hostel in London. No health check was offered on arrival in the UK; only the advice to register with a local family doctor. In June, a couple of months after arriving, Obah developed abdominal pain. The family consulted their GP. Although a translator was provided, there were clearly communication problems. The family did not feel they were given a satisfactory explanation or diagnosis for the pain. No investigation was offered nor any treatment given. Obah's mother found the GP's attitude to be rude and dismissive and she chose not to go back.

As long as immigrants are stigmatised they will be reluctant to seek treatment and this will become the major barrier to controlling TB.

In October 2002 the family was relocated to Yorkshire in northern England. Obah's abdominal pain was getting worse; bad enough to require a visit to the emergency department of the local hospital. This time they found a more sympathetic reception. Treatment was given for a urinary tract infection which had no effect. But Obah's mother felt able to return to the hospital to explain this, and the result was admission to a ward. Tests confirmed the admitting doctor's suspicion of TB.

Obah's family has been very pleased with the treatment they have received in Yorkshire. Arabic speaking doctors took time to explain to the family what was going on. The family was required to appear in court in London as part of their asylum-seeking process only two days after Obah's admission. The hospital quickly arranged TB screening for the family and gave the all clear for the adults to travel for the hearing.

The future remains uncertain for Obah's family. Obah has made a good recovery, and the family hopes to return to London. The capital's schools were more familiar with the issues facing asylum seekers, and a small Somali community was able to provide social support. Obah remains on TB treatment and her family clearly understand the need to complete the course, even though she already feels well. The family's main concern has been that Obah might not make a full recovery, even though she almost certainly will. All of Obah's TB treatment has been completely free of charge.

Obah's older sister, Nemah, is a qualified nurse and has excellent English. However, delays at the British Home Office and the UK Nursing and Midwifery Council have meant that Nemah has been unable to apply for work. Nemah's advice made sure that

her mother persisted in getting treatment for Obah and Nemah would love to work to enable others to receive the health care they need. Meanwhile the Department of Health continues to recruit health workers from overseas.

Not all sections of UK society are sympathetic to people like Obah. A GP recently accused asylum seekers of putting British children at risk of TB by exhausting vaccine supplies, an accusation with no apparent basis in fact. In Wales, a group of asylum seekers were kept handcuffed whilst undergoing routine tests for TB in hospital. Whilst much of the increase in TB is associated with those recently arriving in the UK, it is clear that blaming these people for "bringing TB into the country", as the media often portrays the problem, ignores the bigger picture, including the re-emergence of tuberculosis in many urban areas regardless of inward migration. The accusation is unfair. As Nemah says, "The media doesn't have the right to blame; we didn't choose to bring this illness."

There have been many calls for action. Encouraging health workers to think of TB as a possible diagnosis will improve detection, as would the offer of screening to immigrants to the UK. Structural changes have already been made to the TB programme in London. However, the most important need is to change attitudes. As long as immigrants are stigmatised they will be reluctant to seek treatment and this will become the major barrier to controlling TB.

Andrew Furber
HDN Key Correspondent
The United Kingdom
Email: correspondents@hdnet.org

Speak Your World: Argentina

Elena Obieta

Simple, cheap but intelligent decisions have to be taken at a national and international level

My name is Elena. I graduated with an MD degree almost fifteen years ago in Buenos Aires, Argentina.

I can still remember my first TB patient's face. She was a beautiful young lady from a wealthy family who lived in a luxurious house in Buenos Aires. She had two little girls. While she was pregnant, her father died and this sad event, plus pregnancy-related immune deficiency, probably determined the reactivation of her primary tuberculosis infection. Prior to her medical consultation, she had been using approximately ten different over-the-counter cough syrups and had had at least four visits to the Emergency Room in an attempt to alleviate the symptoms. I was lucky enough to make the diagnosis and start treatment that very same day. The only things we needed were a chest X-ray, a sputum smear for acid-alcohol resistant bacilli and four drugs.

She was astonished and started crying, putting the blame on her Peruvian maid. How could this 18 year old girl from Peru, who had been living with her and the children for two years,

do this to her? In fact this girl did not suffer from TB. Unfortunately TB carries such a stigma that many people (colleagues too) believe that this is a disease of poor people and blame it on immigrants, ex-convicts, low social status, and now HIV infection and AIDS.

Years went by and I found myself working in infectious diseases in a public hospital in a suburban area in Buenos Aires, Argentina. I could see how poverty, unemployment, drug abuse and alcoholism, could influence TB incidence. With the advent of HIV everything was made much more difficult.

Tuberculosis is typical of infections that require a cellular immune response for control. In Buenos Aires we have a large proportion of the population living in poverty, in prison and in housing conditions that favour airborne transmission. In addition, factors such as under-nourishment, alcohol abuse, intravenous drug use, HIV infection and patients with end-stage renal disease, all cause low immune status. All of these factors, allied to a population exhibiting little

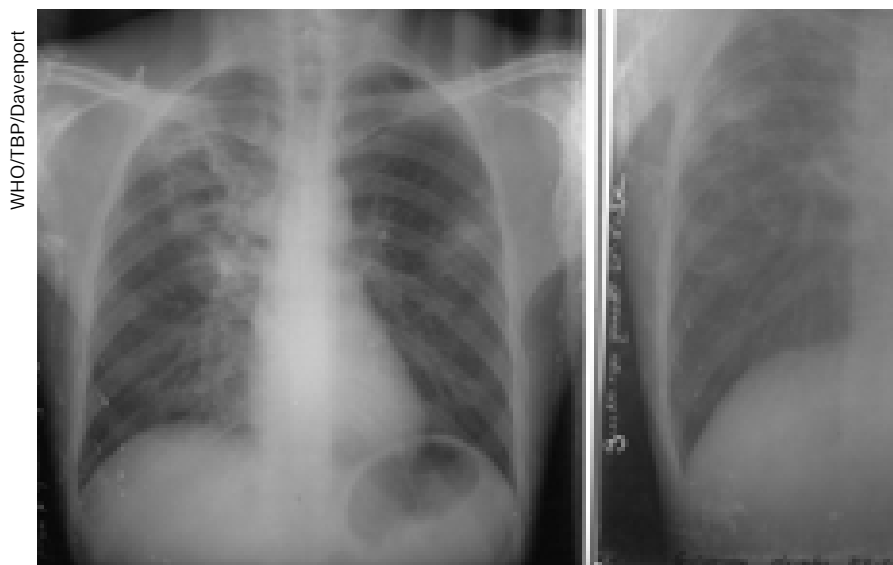
or no native or acquired resistance, make the risk of contracting this disease very significant.

The earliest descriptions of TB in HIV patients with advanced disease emphasised the risk of reactivation of remote infection, as a result of cellular immune compromise. People living with HIV were reluctant to come to the office. Julia, a patient under DOTS, told me: "I'd rather tell my next door neighbour, who is sitting in the waiting room, that I have hepatitis. I don't want anybody to know that I am HIV positive and have TB."

We have many difficulties in Argentina in our attempts to control and eradicate TB. The primary problem is that more than 60% of people live in poverty. Therefore, they are undernourished, have multiple household contacts (i.e. children and parents sleep together) plus there is a very common tradition in our country of drinking 'mate' (an infusion that is drunk by using a common straw called a 'bombilla') In fact, one of the TB outbreaks we had in Buenos Aires of MDR-TB (multi-drug resistant tuberculosis) was found to be caused by the same strain in patients who had shared 'mate' and cigarettes during hospitalisation.

Even if TB can be diagnosed and treated for free in public hospitals in Argentina, there is not enough TB awareness. Unfortunately, every day more and more people are falling to the bottom of a society whose health care system is stretched beyond its limits.

Approximately 60% of TB infected patients die before the onset of treatment. This happens mainly because of the lack of efficient diagnosis, quick illness progression and absence of appropriate drugs. Control measures for this special



WHO/TBP/Davenport

Lungs clouded with TB show up on X-ray, Leon, Nicaragua



situation have to be taken promptly, and these include a correct and fast diagnosis, patient isolation and last but not least effective drugs.

While highly sophisticated and expensive diagnostic tools and isolation systems exist today, the health network in Argentina is overloaded and we frequently run out of the basic requirements such as drugs, beds and X-ray films in many areas. Moreover, people can be so poor that they cannot reach a health post other than by walking very long distances, which in many cases is not possible.

Living with TB carries a stigma in our society. Fear of infection is high. Women may not seek medical assistance or come to the hospital for medication during DOTS because they have to stay at home and look after their children. If they are HIV positive they would rather save the money for a bus ticket in order to send their husband to the hospital (he is usually the wage earner) and/or take the children to the doctor before seeking help and care for themselves. In fact, in our experience, women present in more advanced stages of TB and AIDS than men.

How far can we get with science, special equipment and drugs, while throughout the world treatable and preventable diseases are still killing and burdening children, young people and health care professionals? Simple, cheap but intelligent decisions have to be taken at a national and international level in order to achieve a more just and fair society.

Elena Obieta
HDN Key Correspondent
Argentina
Email: correspondents@hdnet.org

Vertical TB programming is a challenge

Festus Ilako

I am an infectious disease specialist working in East Africa, I have found the discussion and opinions on Stop-TB interesting and useful.

I would like to add my voice to the discourse:

Firstly, TB is currently implemented as a vertical programme in most of the countries that I have worked in. The ministries of health do not want to let go despite the fact that the health systems are so weak that vertical programs cannot take root.

Decision-making, needs prioritisations, awareness campaigns are designed by urban-based programme managers for urban audiences, this is done without consultation and involvement of the target groups. The majority of TB cases originate from rural areas, especially the hard-to-reach areas, mainly due to poor access and lack of knowledge and information about TB and DOTS, with all the associated stigma and denial.

The ambulatory treatment policy and HIV/AIDS epidemic in Africa has complicated problems further.

TB is currently implemented as a vertical programme in most of the countries I have worked in

We know that it takes at least two weeks for a smear positive client to become non-infectious. Currently WHO and governments recommend ambulatory treatment of TB patients unless they are extremely ill (less than 5% of cases). This means sputum smear positive people travelling and living in our overcrowded transport services and shelters are continuously spreading the TB bacilli to friends, families and communities. Shouldn't we admit smear positive TB patients for two weeks?

The problems with clinical diagnosis of TB are well known: inadequate laboratory services in rural areas, lack of X-ray equipment, lack of trained personnel and supplies.

Suggested solutions: We need new policies to transfer decision making, provide TB information and services to the grassroots using the same old primary health care concepts. We need a balanced mix of both horizontal

and vertical programming. DOTS, as is implemented today, has failed to achieve the desired goals and objectives. Current TB programs need to be more creative and innovative to ensure DOTS reaches everybody who needs it. This should be done in tandem with awareness creation and TB education and access to information for rural and hard to reach populations.

We need to deal with the problem of double stigma of HIV and TB. TB by itself is very stigmatising, with HIV-TB co-infection at nearly 60%, this is a big problem which MUST be dealt with urgently. I have not seen behaviour-change communication (BCC) strategies dealing with this issue.

We all need to deal with this disaster in a more creative manner.

Dr Festus Ilako
AMREF
Email: festusI@amrefug.org

Drawing lessons from leprosy elimination campaigns

Dr Chandrakant Revankar

Does the future of TB control lie with front-line health workers? Yes.

I would like to contribute to this discussion forum based on the lessons learnt from a most successful leprosy elimination programme with Multi-Drug Therapy (MDT) as an intervention. A large number of paramedical workers in leprosy endemic countries reduced the global case load from 12 million to less than 0.5 million using MDT as an intervention tool. I look at TB/HIV from the perspective of leprosy treatment, with my experience since 1974 in India and other countries.

For the purpose of this discussion, I consider the following as front-line workers (salaried/volunteers) working in the public health system: NGOs or voluntary organisations, social service bodies (NSS, scouts, guards, youth associations), individuals (house wives, students, teachers, community leaders, patients), media, community/slum welfare groups, religious organisations etc. All these groups played/are playing an important role in leprosy elimination programmes.

A large number of such health workers/volunteers played very significant role during Leprosy Elimination Campaigns (LEC) in India by identifying more than 200,000 new cases hitherto unidentified in the community by increasing geographic coverage for a specific period. Maybe the Stop TB partnership and country governments could think of campaigns like LEC (or with modifications according to geographic situation/endemicity) to achieve rapid case detection, expansion of TB-DOTS, awareness about availability of DOTS, its efficacy and early signs and symptoms of pulmonary tuberculosis and energise the public health system including political circles.

To achieve rapid geographic and population coverage, to increase case detection (especially sputum positive) and to increase treatment success rate, I suggest the following to build up an army of front-line workers and sustain their commitment, morale and interest for a national cause.

Leprosy NGOs and other social organisations ... would be in a better position to organise TB-DOTS activities and also develop innovative methods to achieve the set targets in India

1. Simplified task oriented training/ orientation of all those who are interested in being friends of the Stop TB network and participating in the TB-DOTS programme in whatever way they can. Public/private/NGO workers doing full-time work should have on the job training either during supervisory visits or review meetings in addition to their basic training in TB-DOTS. Generally after the initial training, workers are left to their fate where even supervisory personnel may not visit, especially in difficult locations (hard to reach areas).

2. The public health system should be very flexible and should have flexible targets to achieve depending on the geographic situation/endemicity. Too rigid operational guidelines would only result in manipulating data, over or under reporting and lack of interest. Guidelines should be uniform without any controversies/confusions as happens in leprosy (views vary as per experts visiting the field). Health workers/volunteers should have flexibility to implement innovative approaches in their population as they are the masters of their field area.

3. Provision of transport (depending on the geographic areas) and other logistics/facilities increases work performance, geographic coverage and patient compliance (as happened in the leprosy MDT programme).

4. Recognising publicly the good work done by these heroes/heroines builds up confidence in them and in turn improves the quality of work. If they are salaried workers, the system/organisations should ensure adequate and regular flow of their salaries (otherwise, they divert their time in other activities for their survival or go to work elsewhere).

5. More than 250 NGOs are actively participating in the leprosy elimination programme in India. These NGOs workers/volunteers (who work in even the most difficult areas) have vast experience in organising field activities and providing treatment to all those who need it, irrespective of geographic locations. NGOs enjoy flexibility to develop innovative/alternate approaches to identify cases, treat and cure them within limited resources – unlike the public health system which is not flexible.

Like leprosy NGOs, there are many other social organisations, religious groups, youth groups, NSS/scouts groups who are committed to contribute to a social cause if approached. Such groups have been utilised for leprosy activities. It is left to the governments (national/state) to seek their cooperation with flexible approaches to increase geographic coverage.

In view of integration of leprosy within the general health system (GHS) and transfer of diagnostic and treatment functions to the GHS, front-line workers of NGOs/social organisations could also take up TB-DOTS treatment, care and support programmes (even HIV). As these unsung heroes/heroines have become masters of the community/slums/tribal/mountainous areas, they would be in a better position to organise TB-DOTS activities and also develop innovative methods to achieve the set targets (I am referring to India). As these workers are moulded to flex themselves, they are even capable to work with private practitioners in the evening time in their local areas. Leprosy NGOs are gradually taking up TB/HIV activities.

Dr CR Revankar MD, DPH
Email: revankarcr@gmail.com,
drrevankar50@vsnl.com

Comment: Debt forgiveness and TB

Dr Adah O Stephen

Dear members,

The recent declaration by the G8 of 100% debt forgiveness in eighteen developing countries is a great milestone in TB control in developing countries. As far as TB control is concerned, the G8 leaders are also in the same league as all health workers involved in the control of TB. To eradicate or reduce poverty in any form is tantamount to eradicating or reducing TB globally.

Debt forgiveness and the ability of countries to obtain loans to aid development is commendable, but that should not be an end in itself. We must lay emphasis on prudence and transparency in the use of these resources at all times. The leaders of these developing countries should make sure that TB/HIV/AIDS control is the cornerstone of their health development plans. These diseases are anti-development because they destroy the productive population of these countries. Focusing on TB/HIV/AIDS amounts to focusing on development. Reducing the prevalence of TB/HIV/AIDS will go a long way to preserving the life of the young and

productive population thereby aiding the development of these countries. Debt forgiveness in developing countries will reduce TB and HIV/AIDS drastically, as this will translate to improved socioeconomic status of the people thereby reducing poverty.

We look forward with great hope and anticipation to 100% forgiveness of the debts of the remaining developing countries by the G8 leaders. It is imperative that the leaders of the remaining developing countries heed the call of the G8 for good governance, transparency and accountability in their respective countries. Corruption must be stopped, likewise TB/HIV/AIDS.

Thank you.

Dr Adah O Stephen.

Email: ogagbanos@yahoo.com

Private-public partnerships: a challenge

Jitendra Dwivedi

Very often the most successful private TB expert is the same person who sits in government hospitals. how can we think of private-public partnership when conflict of interest is to this degree?

Dear Friends,

I have been following the discussion on the Stop-TB eForum and it is of great interest.

In this posting, I will like to draw your attention to those private practitioners who also sit in government institutions (hospitals, medical colleges, clinics) and run DOTS, and circumvent the 'ban on private practice' and do it unabatedly.

As a result of which services at government institutions, in terms of DOTS delivery, are compromised, and private institutions are flourishing indeed.

We may refer to this as conflict of interest too. In terms of improving DOTS delivery, I would like to draw your attention to the fact that very often the most successful private TB expert is the same person who sits in government hospitals. How can we think of private-public partnership when conflict of interest is to this degree?

My first hand experience is that we had tough time seeking

treatment for TB at a government run facility in Kanpur and even Lucknow and ultimately had to turn to the same person sitting in a private clinic environ. Of course he was extremely warm and accessible and on all three occasions, we got proper treatment - at a cost.

I believe that pharmaceutical companies also have a stake here, in boosting their sales and patronising the same people who sit in government institutions as well as have flourishing private clinics.

I look forward to a more intense debate on this issue.

Regards,

Jitendra Dwivedi

Abhinav Bharat Foundation

(Gonda-Bahraich-Kanpur)

India

Email: abf@post.com

Comment: Private-Public partnerships: a challenge (2)

Vineet Bhatia

Dear Members,

In continuation to the previous posting on this issue, I would like to add some ideas here.

It is not just the private-public mix that should be seen as a challenge. Involvement of all sectors whether private, public or corporate in DOTS strategy remains a challenge. This apparently is because:

1. Lack of trust amongst various sectors for each other. National TB Programmes (NTPs) often require a signed memorandum of understanding (MOU) for collaboration, which most private practitioners would be apprehensive about. An open dialogue explaining the rights and duties within the MOU needs to be initiated among the public and private sector. On the other hand NTPs should be open to criticism from private practitioners and put forth their point with facts and figures rather than evade criticism.

2. Conflict in goals: Through the public sector, NTPs try to address the issue of TB as a public health problem, where as private practitioners are dealing with individuals/ patients who are their source of bread and butter. Not that this gives private practitioners a right to indulge in wrong practices, but then a small apprehension could make the practitioner shaky and overcautious on what regimes to adopt. Again it is scientific data that would help convince practitioners. Similarly, the corporate sector is apprehensive of its workers being found positive for TB – and the effect on their sales and costs the management would have to incur on getting them treated. DOTS needs to be projected as a cost efficient

strategy that would create a healthy and more productive work force.

3. Let us also confess the fact that most human beings are resistant and sceptical about change. Doctors are only human. However things change with time.

4. On the issue of public sector doctors indulging in private practice and providing services at a cost, raised by Mr Jitender Dwivedi, This is more of a moral issue which needs to be addressed by professional bodies.

Overall I would say we need to 'market' DOTS. Just to take an example - how is it that a pharmaceutical company is able to launch a new drug and doctors start prescribing it? Primarily because the information, supported by facts and figures, spreads quickly and effectively through a well laid network.

We need to do the same thing for DOTS. We need to promote it as an appropriate strategy for treatment of TB and not make practitioners feel as though this is another government policy 'forced' upon them.

Thanks

Vineet Bhatia

Delhi, India

Email: vineetbhatia_2000@yahoo.com

Comment: Private-Public partnerships: a challenge (3)

Prashant Pastore

Certain efforts are taking place in this direction [public-private partnership to fight TB] like the World Economic Forum's Global Health Initiative, which has brought together seven top Indian business houses and the public sector to work together to stop tuberculosis in India. Specifically, this alliance of companies will implement the Revised National TB Control Programme (RNTCP) for their workers and families in collaboration with the Indian government.

The Alliance launched on World TB Day (WTBD) comprises the Global Health Initiative, RNTCP, the Confederation of Indian Industry, the WHO and the Global Partnership to Stop TB. The companies involved are Aditya Birla, Larsen Toubro, Lupin Ltd, Modicare Foundation,

Novartis India, Reliance Industries, Tata Steel and Triveni Sugar. These companies together cover a population of 3.5 million and have publicly committed to control TB in India.

The aim of the 'Indian Business Alliance to Stop TB' is to tackle tuberculosis in an area where it can cause the most harm – closed workplaces, and also eliminate the attached stigma and lack of awareness about TB.

Prashant Pastore

Programme Manager

MAMTA-Health Institute for Mother and Child

New Delhi, India

Email: prashantp@writeme.com

Comment: Private-Public partnerships: a challenge (6)

Dr Vikas Inamdar

Yes we agree that it's a big challenge to involve private medical practitioners in the National TB Programme for India (called Revised National TB Control Programme).

We would like to share our experience. I am the programme manager for Pimpri Chinchwad Municipal Corporation covering a population of one million people and implementing DOTS since October 1998.

To begin with we should focus more on primary care physicians with appropriate training for identifying TB suspects and referral; and help them to act as DOTS providers and encourage them to refer patients to a public health facility/ designated microscopy centre for sputum examination (because the majority of people on initial appearance symptoms visit a primary care physician).

Intervention at this level gives you positive results. We have tried such methodology since 1998 and from initially working with two private medical practitioners, now we work with 119.

However, to achieve this, the public health system should be strong enough to manage the patients referred by the private sector and its response should be quick and positive in terms of diagnosis and initiation of treatment.

Recently one of the NGOs did a research study to find out the quality of care under the RNTCP in our area and the results of the study substantiated our observations. Some highlights of this study were:

- * Close to a third of the patients consulting private practitioners had been advised sputum microscopy and about 30% of patients diagnosed as having TB by the private sector had undergone sputum examination.

- * Delays were significantly less for patients who had consulted private practitioners who were participating in 'public-private mix' approaches.

- * Once they entered the RNTCP, more than two-thirds



WHO/TBP/England

Elise Languez, NTBP staff doctor standing beside cartons of TB drugs, Togo

of patients had been diagnosed within 3 days (after 3 visits) about half of them put on treatment within two days of diagnosis, and a quarter of them on the same day of diagnosis. This quickness in response is a clear indication of the quality of the RNTCP.

- * DOTS centres were more accessible for patients, 91% travelling on foot. On average patients had travelled 2 km and spent 12 minutes to reach DOT centres.

So public-private mix can contribute positively.

Thanking You
Yours sincerely

Dr Vikas Inamdar
Senior Medical Officer
City TB Control Society
Pune, India

Email: ctcsasd@vsnl.com, dtomhpim@tbcindia.org



Comment: Private-Public partnerships: a challenge (8)

Vineet Bhatia

The recently posted responses to this discussion raise two important issues pertaining to this subject:

1. Whether private-public partnerships (PPPs) damage equity
2. The possibility of compromise on quality of care including usage of improper regimen by private doctors because of partnerships.

Here we must take into consideration the following points:

1. In developing countries with multi-tiered health care systems, a substantial percentage of patients visit the private sector as their first point of contact. Private-public approaches help ensure these cases get treatment under DOTS regardless of first point of contact. Costs here would not hold much relevance as the patient voluntarily opted to get treatment through the private sector, knowing that this would involve costs. However if PPPs adopt DOTS, this would promote equity in access to quality care. Adoption of DOTS by PPPs is more likely to reduce the costs to patients rather than increase it, with savings specifically on delays and unnecessary diagnostic procedures.

Further, there are financially well off patients who would not like to wait in a queue, often seen outside public health facilities, and would rather pay for prompt attention received at a private facility.

Private facilities also offer convenient timings for patients that are essential for DOTS.

2. In resource constrained countries, primary health care facilities may not have sufficient outreach. Lack of infrastructure as a constraint to TB control has been

In developing countries with multi-tiered health care systems, a substantial percentage of patients visit the private sector as their first point of contact

identified by the WHO in 12 of the 22 countries with the highest burden of TB (2005 report on Global TB Control). Even where physical infrastructure is available, qualified health professionals cannot be assured. The private sector has a role to play in plugging the gaps here.

3. The pitfalls of health care delivery in the private sector, specifically lack of adoption of standardised regimen, should in fact be addressed through building partnerships and taking them into confidence.

Finally, the private sector has, and will continue to play an important role in health care delivery by complementing and supplementing the public health system. We can neither deny nor do away with their existence. A positive approach would be to harness this potential to the maximum benefit of patients.

Regards

Vineet Bhatia

Delhi, India

Email: vineetbhatia_2000@yahoo.com



Further reading

Below is a list of selected websites where readers can access a wealth of materials on TB and HIV/AIDS.

EQUI-TB Knowledge Programme: The purpose of the programme is to promote the implementation of pro-poor strategies, which enhance care and support for TB among the poorest.

<http://www.equi-tb.org.uk/>

Global Alliance for TB Drug Development: seeks to develop and ensure equitable access to new tuberculosis drugs. Their website features organisation information, disease information, new drug developments, and news.

<http://www.tballiance.org/>

Global Health Reporting.Org : provides journalists and others with the latest information on HIV/AIDS, Tuberculosis and Malaria

<http://www.globalhealthreporting.org/>

International Union Against Tuberculosis and Lung Disease (IUATLD): The IUATLD has as its mission the prevention and control of tuberculosis and lung disease, as well as related health problems, on a world wide basis, with a particular emphasis on low income countries

<http://www.iuatld.org>

New Jersey Medical School National Tuberculosis Center: provides professional training and resources related to tuberculosis and its management

<http://www.umdnj.edu/ntbc/>

Stop TB: Stop TB is a global civil society led movement to accelerate social and political action to stop the unnecessary spread of tuberculosis around the world.

<http://www.stoptb.org>

Stop-TB eForum: An electronic forum dedicated to improving the quality of the discussion on issues around TB control linking thousands of people working on TB control - including front-line health workers, clinicians, researchers, civil society participants, policy makers, media

and others. This is managed and moderated by Health and Development Networks

<http://www.hdnet.org> <http://www.healthdev.org/eforums/stop-tb>

TB Alert: is the only British charity working solely on fighting TB in the UK and overseas.

<http://www.tbalert.org/>

TB Education & Training Resources: service of the U.S. Centers for Disease Control and Prevention featuring information on tuberculosis, funding resources, TB-related organizations, events, and more.

<http://www.findtbresources.org/>

The Francis J. Curry National Tuberculosis Center (CNTC): creates, enhances and disseminates state-of-the-art resources and models of excellence to control and eliminate tuberculosis.

<http://www.nationaltbcenter.edu>

The Global Fund to Fight AIDS, Tuberculosis and Malaria: The Global Fund was created to finance a dramatic turn-around in the fight against AIDS, tuberculosis and malaria. To date, the Global Fund has committed US\$ 4.4 billion in 128 countries to support aggressive interventions against all three.

<http://www.theglobalfund.org/en/about/tuberculosis/>

Tuberculosis Research Centre, Chennai, India: permanent research institute of the Indian Council of Medical Research (ICMR), an autonomous organisation under the Ministry of Health and Family Welfare, Government of India.

<http://www.trc-chennai.org/>

World Health Organization-Tuberculosis: The web site provides WHO fact sheets on tuberculosis and links to various WHO publications.

<http://www.who.int/health-topics/tb.htm>



Glossary of terms

Acid-fast bacilli (AFB) – a term used to refer to mycobacterium tuberculosis: during a smear test the cells do not lose a coloured stain when treated with acidic organic compounds

AIDS – Acquired Immune Deficiency Syndrome. The symptomatic manifestation of infection with the Human Immunodeficiency Virus (HIV). The Centers for Disease Control and Prevention (CDC) lists numerous opportunistic infections and cancers that, in the presence of HIV infection, constitute an AIDS diagnosis. In 1993, CDC expanded the criteria for an AIDS diagnosis in adults and adolescents to include CD4+ T-cell count at or below 200 cells per microliter in the presence of HIV infection. In persons (age 5 and older) with normally functioning immune systems, CD4+ T-cell counts usually range from 500 - 1,500 cells per microlitre. Persons living with AIDS often have infections of the lungs, brain, eyes, and other organs, and frequently suffer debilitating weight loss, diarrhea, and a type of cancer called Kaposi's Sarcoma.

BCG – a preventive vaccine for TB named after the French scientists Calmette and Guérin. BCG is often given to infants and small children in countries where TB is common.

Cavity – a hole in the lung where TB bacteria have eroded the surrounding tissue. If a cavity shows up on a chest x-ray, the patient is more likely to cough up bacteria and be infectious.

Chemoprophylaxis – the prevention of active TB using drug treatments, for example in HIV positive people, or those at high risk of infection or reactivation

Chest symptomatics – people who have serious symptoms related to their chest and lungs

Chest X-ray – a picture of the inside of the chest. A chest X-ray is made by exposing a film to X-rays that pass through the chest. A doctor can look at this film to see whether TB bacteria have damaged the lungs.

Contact – a person who has spent time with a person with infectious TB

Culture – a laboratory test to see whether there are TB bacteria in the phlegm or other body fluids

Directly observed treatment short course (DOTS) – The internationally-recommended TB control strategy. DOTS depends on a patient meeting with a health care worker or supporter every day or several times a week to ensure proper and regular intake of medication.

Elispot test – an immunological test for TB that produces fast, accurate results, not affected by BCG vaccination status or exposure to other mycobacteria

Empyema thoraces – the collection of pus in a lung cavity

Extrapulmonary TB – TB disease in any part of the body other than the lungs, for example, the brain, the kidneys or lymph nodes

HIV infection – infection with the human immunodeficiency virus, the virus that causes AIDS (acquired immune deficiency syndrome). A person with both latent TB infection and HIV infection is at very high risk for active TB disease.

Infectious TB – TB disease of the lungs or throat, which can be spread to other people



Infectious person – a person who can spread TB to others because he or she is coughing TB bacteria into the air

INH or isoniazid – a drug used to prevent TB disease in people who have latent TB infection. INH is also one of the five drugs commonly used to treat TB disease.

Latent TB infection – a condition in which TB bacteria are alive but inactive in the body. People with latent TB infection have no symptoms, don't feel sick, can't spread TB to others, and usually have a positive skin test reaction. But they may develop TB disease later in life if they do not receive treatment for latent TB infection.

Mantoux – A skin test for TB developed by Charles Mantoux and Felix Mendel in the early 20th century (see Skin Test)

Micro-dot – an immunological test for TB; older and less sophisticated than the Elispot test, this cannot distinguish BCG vaccination from active TB

Miliary TB – TB disease that has spread to the whole body through the bloodstream

Multi-drug resistant TB (MDR TB) – TB disease caused by bacteria resistant to more than one drug often used to treat TB

M. tuberculosis – bacteria that cause latent TB infection and TB disease

Negative – usually refers to a test result. A person with a negative TB skin test reaction probably does not have latent TB infection.

Positive – usually refers to a test result. A person with a positive TB skin test reaction probably has latent TB infection.

Pulmonary TB – TB disease that occurs in the lungs, usually producing a cough that lasts longer than 2 weeks. Most TB disease is pulmonary.

Resistant bacteria – bacteria that can no longer be killed by a certain drug

TB skin test – a test that is often used to detect latent TB infection. A protein called tuberculin is injected under the skin on the lower part of the arm. A positive reaction to this test indicates latent TB infection.

Treatment for latent TB infection – treatment for people with latent TB infection that prevents them from developing active TB disease. Also known as TB prophylaxis

Serodiagnosis – any diagnosis for TB made using blood samples

Smear – a test to see whether there are TB bacteria in the phlegm. To do this test, lab workers smear the phlegm on a glass slide, stain the slide with a special dye, and look for any TB bacteria under the microscope.

Sputum – phlegm coughed up from deep inside the lungs. Sputum is examined for TB bacteria using a smear; part of the sputum can also be used to do a culture.

Tuberculosis (TB) – an illness in which TB bacteria are multiplying and attacking different parts of the body. The symptoms of TB disease include weakness, weight loss, fever, no appetite, chills, and sweating at night. Other symptoms of TB disease depend on where in the body the bacteria are growing. If TB disease is in the lungs (pulmonary TB), the symptoms may include a bad cough, pain in the chest, and coughing up blood.

Tuberculin – a liquid that is injected under the skin on the lower part of the arm during a TB skin test

Sources: Adapted from the World Health Organization (www.who.int/en), Stop TB Partnership (www.stoptb.org), National Institutes of Health (<http://health.nih.gov>) and Massive Effort (www.massiveeffort.org) websites



What is the Stop-TB eForum?

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

The main goals of the Stop-TB eForum are to:

- Support and promote multi-stakeholder participation in the Stop-TB Partnership;
- Provide an essential and visible platform for debate, advocacy, continued fundraising, and inclusion of new partners, particularly those from civil society;
- Ensure that civil society stakeholders are openly and genuinely involved in the Stop-TB Partnership;
- Expand discussions and public awareness around TB;
- Foster new partnerships between forum members and promote a multidisciplinary approach to TB.

The Stop-TB eForum began in mid-2001, in the lead-up to the first Stop TB Partners' Forum, and has since focused on annual World TB Day events and the second Partners' Forum in 2004.

Stop-TB currently has over 3,500 members worldwide. Members of the forum are organisations and individuals from Asia and the Pacific, Africa, Latin America, Northern America and Europe and consist of:

- People living with HIV/AIDS
- TB/HIV/AIDS service organisations
- Those working in government ministries, non-governmental and community-based organisations, and other national and international organisations
- Representatives of the business sector
- Academics, researchers and teachers
- Documentation/information centres
- TB research institutes and centres
- Educational establishments
- Front-line health workers, including doctors, nurses and pharmacists
- Provincial and district level administration
- Community- and faith-based organisations
- Journalist/media groups

How can you join?

To join the ongoing Stop-TB eForum discussions simply send an email to: join-stop-tb@eforums.healthdev.org

You can also view and search the archives as well as join the Stop-TB eForum online at: www.healthdev.org/eforums/stop-tb

HEALTH & DEVELOPMENT NETWORKS

www.hdn.net.org

Email: publications@hdn.net.org

EC Email: correspondents@hdn.net.org

A global Movement for health and development-related issues requires a move of resources to civil participation, accountability and ownership of sustainable development. It needs to be more reflective, inclusive and participatory than the top-down approach it is.

Individuals, communities and organisations must be able to learn from the actions and experiences of others, and adopt and copy these lessons in their own contexts.

Current health- and development-related discourses are mostly exclusive, take place in different and separate levels, among isolated sectors, and only rarely encourage direct civil society participation in active dialogue or policy-setting.

HDN efforts provide a platform for thousands of people and civil society organisations at all levels to connect with each other and to share visions. They facilitate a bottom-up approach in information gathering and view any given topic from several different perspectives in order to validate its significance. The efforts also provide a unique learning opportunity for members.

The Correspondents' directory, which is a record of the exceptional contributions made to HDN efforts by effort members, Key Correspondents and specialists in the field of health and development. Drawing on their essential source of experience and perspectives, The Correspondents' directory offers an alternative platform to policy makers, politicians, civil society organisations and individuals aiming to respond to health and development practices.