

Sorting fact from fiction: Improving media reporting on TB

Nearly 10 years after the launch of an international effort to tackle the global health emergency of tuberculosis, TB remains one of the world's major causes of death. Millions of people are undiagnosed because of fear, stigma, poverty and ailing health systems. The media's role in dispelling fear and providing clear, factual information is vital.



This woman in Chennai, India, talks to TB awareness campaigners.

ATUL LOKE | PANOS PICTURES

Imagine a natural disaster hitting 14 million people around the world and killing almost 2 million. It would be headline news.

But when TB threatens the lives of the same number of people every year, it goes largely unreported. In 2006 Médecins Sans Frontières described TB as the world's second-most under-reported humanitarian story.

Yet for millions of people whose lives are devastated by TB, the problem is as urgent as a major disaster. TB exacerbates social injustice – it hits people and countries already suffering from poverty, overcrowding and inadequate nutrition, and makes them even poorer.

Although HIV has caused TB and multidrug-resistant TB to increase, the vast majority of TB is still treatable with simple, affordable drugs.

A major international effort to tackle TB has resulted in progress, but people still die needlessly.

The public need information based on evidence from research and they need questions asked of government on their behalf. Good research has been done which needs to be publicly discussed so that the right decisions are made about how to tackle TB. By drawing attention to research, making it accessible and raising questions that policymakers and the public engage with, journalists can lead the way in the fight against TB.

Media toolkit on communicating research

This is the seventh in a series of briefing documents for the media from the RELAY programme. RELAY works with Southern print and broadcast journalists to communicate the findings of academic research in an accessible way. The briefings set out the main issues around a topic, prompting journalists to pursue ideas and do further story research themselves. If you wish to receive future media briefings by email, please contact media@panos.org.uk. To find out more about the Panos RELAY programme, go to www.panos.org.uk/relay

A TB campaign billboard in Lusaka, Zambia.
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What is TB?

About one third of the world's population is infected with TB, caused by *Mycobacterium tuberculosis*. Most people do not become ill. However, more than nine million people whose immune systems cannot fight off the disease develop active TB annually.

Active TB can affect any part of the body, but it usually attacks the lungs, and is referred to as pulmonary TB. Typical ways of passing on the disease are through sneezing, coughing or spitting.

Fact file

- About 14 million people have active TB
- About 9 million people develop active TB every year
- About 1.7 million people died of TB in 2006
- TB is most common in Asia and Africa
- TB is curable: about 85 per cent of cases are cured with affordable drugs

Source: World Health Organization, 2008

HIV infection, which suppresses people's immune systems, is a major risk factor for developing active TB. The HIV epidemic is thought to be responsible for multiplying TB in some African countries.

TB is often thought of as a highly infectious, deadly disease. However, effective, inexpensive treatment is widely available, including for people with HIV. Nearly 85 per cent of all diagnosed cases are successfully cured by six to eight months of treatment with four simple drugs that cost between US\$10–12 per person.

The problem is that one out of every three people with active TB is not diagnosed. Many people do not seek medical help, or health workers may fail to detect the disease. Without treatment, many people with active TB die.

Worryingly, TB that is resistant to common anti-TB drugs is increasing. Multidrug-resistant TB has been reported in more than 22 countries. Drug resistance can result from patients not completing their full course of treatment or from health workers' mismanagement. Second-line drugs for multidrug-resistant TB cost as much as US\$12,000 per patient. Even more alarming is the development of extensively drug-resistant TB in places with high HIV prevalence.

However, it is important to recognise that the vast majority of TB is still treatable with simple drugs. The main problem is detection and access to treatment.

Stigma

In many communities, people with TB hide their illness to avoid being isolated, judged and stigmatised. The stigma associated with TB can prevent patients seeking or completing treatment for fear of being exposed and ostracised.

In many countries, the link between TB and HIV leads to shame and accusations of immorality. TB's infectiousness is wrongly linked with being unclean – another cause of stigma.

Myths about TB

Several studies in South Asia (Ganapathy and colleagues, 2008; J A Khan and colleagues, 2006; Nair and colleagues, 1997) highlight concerns that TB can affect a woman's marriage prospects, owing to fear about spreading TB through sharing utensils and worries about the cost of the illness. Myths that it causes infertility or can be passed through breastmilk affect other communities.

Vulnerability to TB

Poverty

Poverty is a key factor in making people vulnerable to TB. People in low-income countries are most at risk of developing TB, with 80 per cent of cases found in Africa and Asia.

However, poor people are less likely to seek treatment because of inadequate health education, distance from health facilities, and lack of time and money. Untreated TB then increases the rate of infection in poor communities.

Poor people's living conditions mean they are more likely to be infected through overcrowding, poor ventilation, malnutrition and ill health. Within poor communities, displaced individuals and those living in remote or informal settlements are particularly vulnerable to TB because of overcrowding and difficulty in accessing health services.

TB also makes poor people poorer, through loss of income during sickness or the high cost of getting healthcare (for example, the need to pay for transport or childcare, even if the health service is free).

TB treatment costs in Malawi

A study in Malawi by Kemp and colleagues (2007) found that the cost of TB diagnosis was too high for poor people (248 per cent of monthly income) even when free health services were within six kilometres.

A review of studies by I Bates and colleagues (2004, Part 2) indicates that TB started to decline as extreme poverty decreased in richer countries, even before effective drug treatment was widespread. With better nutrition, less overcrowding and improved ventilation, TB stopped spreading so quickly. The review concludes that reducing poverty in developing countries is also likely to be crucial to tackling TB.

HIV status

The HIV epidemic is a major contributor to the current rise in TB. Frothingham and colleagues (2005) showed that untreated HIV infection increases the risk of latent TB becoming active by a hundred times or more. HIV-positive people being treated with antiretrovirals still face five times the risk of developing TB compared with HIV-negative individuals (Gandhi and colleagues, 2006).

Co-infection with TB and HIV makes it harder to diagnose TB (Corbett and colleagues, 2006). HIV-positive people are more likely to develop TB in several parts of the body, which is harder to cure.

HIV infection also significantly increases the risk of developing drug-resistant TB. A study in South Africa by Gandhi and colleagues (2006) found a high rate of multidrug-resistant TB, and 6 per cent of TB patients were extremely drug-resistant. All extremely drug-resistant patients were co-infected with HIV.

Environmental factors

Smoking and air pollution decrease the lungs' defences and make people more vulnerable to developing TB. Smoking is one of the most common risk factors for developing active TB. A review by M N Bates and colleagues (2007) found that smoking causes a 40–60 per cent increase in an individual's likelihood of developing active TB.

Burning wood, animal dung and other biomass fuels for indoor cooking or heating in India was found to be a significant risk factor for developing active TB in a study by Mishra and colleagues (1999).

Age and gender

Most people with TB are in the economically productive age group of 15–59 years. However, people over 60 with TB may be under-diagnosed owing to atypical symptoms. They also have a higher risk of death from TB.

Children under three with immature immune systems are at greater risk of developing active TB. However, they often have no sputum-producing cough and are harder to diagnose.

It is debated whether women are more vulnerable to TB than men. Until the age of 14, the rates of infection are similar between the sexes. However, in males over 15, the reported rates of active TB in most developing countries are significantly higher (I Bates and colleagues, 2004, Part 1). Whether this is because the incidence in males is higher, or women are less likely to be diagnosed, is questioned. Holmes and colleagues (1998) report that gender disparities could be caused by immune system differences or differences in lifestyles (for example, smoking or poor nutrition). Other studies (Chang and colleagues in Malaysia, 2007; Huong and colleagues in Vietnam, 2007; Karim and colleagues in Bangladesh, 2007) show that women are more likely to delay seeking medical help and diagnosis. Some studies (Balasubramanian and colleagues in south India, 2004; Daniel and colleagues in Nigeria, 2006) show that men are more likely to stop treatment because of loss of wages from attending health facilities, and not get cured.

Reaching the most vulnerable

A number of initiatives are being proposed to improve diagnosis and treatment of those most at risk from TB.

Improved case-finding

Health systems across the world currently rely on patients with TB reporting their symptoms at health facilities (*passive* case-finding). However, I Bates and colleagues' review of studies (2004, Part 2) says that passive case-finding is estimated to only detect about half of active TB cases. Some TB researchers are calling for active case-finding (looking for TB symptoms) among vulnerable groups (Golub and colleagues, 2005). The World Health Organization (WHO) recommends that health workers in HIV counselling and testing centres actively look for TB infection.

Other groups in which active case-finding has been effective are homeless people, prisoners, residents of nursing homes, the very poor and people in close contact with TB patients (Golub and colleagues, 2005). Corbett and colleagues (2006) called for screening all HIV-positive people for TB, and preventative TB treatment for individuals who have tested positive for HIV.

Enhanced case-finding through community education and outreach in vulnerable communities may also be important.

Speeding up detection

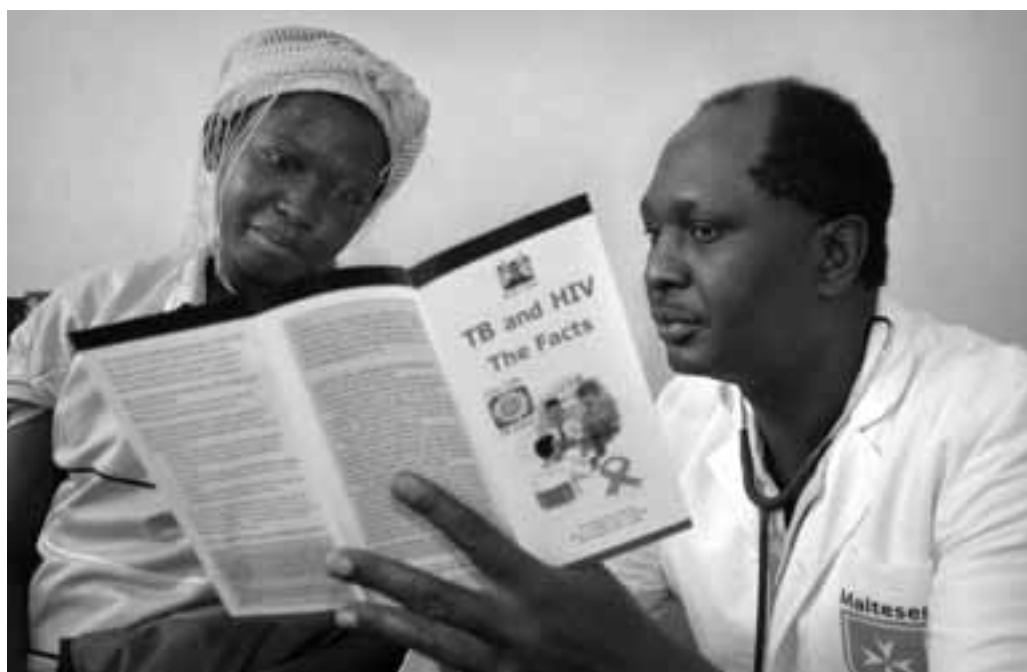
A trial of outreach services in rural Ethiopia by Shargie (2006) found that holding monthly diagnostic outreach clinics and educating people increased the speed of TB detection.

Better diagnosis

Even when people report with TB symptoms to health centres, a significant proportion are not correctly diagnosed. Bates and colleagues' review of research (2004, Part 2) shows that a number of problems at health facilities put people off seeking diagnosis or result in wrong diagnoses. These problems include: unhelpful staff, lack of confidentiality, broken equipment, dirty facilities, lack of trained staff, absenteeism, inconvenient opening hours and long waiting times. A number of initiatives are underway to improve health worker training and health facility functioning, though changes in government policy and legislative frameworks can influence the success rates of these programmes.

Another problem with diagnosis is that after a first visit to a health centre, many patients cannot return the next day to provide a standard follow-up sputum specimen. Researchers are now testing ways of diagnosing on the first visit. A small study in rural Ethiopia (Cambanis and colleagues, 2006) showed that two specimens taken on the same day were just as effective as two-day specimens in diagnosing TB.

A member of medical staff talks to a patient about TB and HIV at a clinic in Kayole, Kenya.
SVENNI TORFINN | PANOS PICTURES



Cultural barriers to diagnosis

A study by M S Khan and colleagues (2007) of a large urban health facility in Pakistan showed that women were under-diagnosed because they did not understand the importance of producing a deep sputum sample, an action which may be culturally embarrassing in public places. Getting a health worker to provide brief guidance resulted in a large (63 per cent) increase in case-finding in women.

Much work is being done to develop new tests that can diagnose TB more quickly and accurately. However, many are too expensive or inappropriate for laboratories in developing countries. There is a pressing need for a simple test that can diagnose multidrug-resistant TB quickly in laboratories with few resources.

Public-private partnerships

In many countries, the private sector plays a major role in healthcare. A report by the Indian NGO MAAS-CHRD (2006) found that 60 per cent of TB cases were managed by private practitioners. Many are not medically qualified or do not follow standard TB-control guidelines.

Where national TB programmes have made partnerships with private practitioners, there have been successes in controlling TB. This success shows that even in countries with limited health infrastructure, training community health workers can be effective.

Success by working together

A study by Kelkar-Khambete and colleagues (2008) found that training private practitioners in India resulted in more referrals of TB cases to free government facilities. Ardian and colleagues (2007) document how a private company in Indonesia has funded a TB clinic staffed by NGO health workers who follow national TB guidelines and receive government training. In Afghanistan, involving community health workers in detection, referrals and home-based treatment resulted in a 380 per cent increase in detecting TB (Ahmadzai and colleagues, 2008).

The role of the media

The media can play a significant role in addressing TB by raising awareness of the problem – and what can be done to tackle it. There is a need for accurate research-based information to lead people to seek diagnosis and treatment, to dispel myths, fight stigma and raise questions about what is being done to protect people from the disease.

Issues to explore in more depth

- Government policies and legislative framework on TB. What proportion of the national budget does the government spend on health, and on TB?
- Cultural and religious factors affecting TB. For instance, what is the role of traditional healers?
- TB and its impact on children's lives
- The role of nutrition in preventing or exacerbating TB
- The role of health workers in managing TB treatment. For instance, what training do they receive?
- The role of international organisations such as UN agencies and WHO in tackling TB worldwide.
- Low profile of TB in the media compared with other diseases or disasters. For instance, HIV and AIDS or the tsunami of December 2004.

Story ideas

■ Research

Review your country's research. What are the key issues around TB in your country? Does local research reflect issues raised by research in other countries? Are there debates/ conflicting results in different studies? Ask questions about who is funding research: is it independent of vested interests? Interview a researcher. Highlight what research still needs to be done. What questions are not being asked? What is being done to implement research findings?

■ A profile of TB in your country (based on research)

What is the extent of TB? Who is most vulnerable? How do people get diagnosed and treated? Who provides that treatment? What proportion of cases are undiagnosed? What stops people getting treated? What problems need solving? Are there any success stories?

■ Knowledge and stigma around TB

Do a survey of ordinary people's knowledge about, and attitudes to, TB. What about politicians' or decision-makers' knowledge? Are there common myths or stigmas?

■ The human stories

Interview people with TB (while being sensitive to issues of confidentiality). Tell their stories: what is the human cost? What are the messages for the authorities? Are there any positive stories? Profile someone well-known who has overcome TB.

A technician in a TB laboratory in Nairobi, Kenya, studies sputum samples collected from patients in the Kibera slum. TB is a common disease among Kibera's inhabitants. SVEN TORFINN | PANOS PICTURES



Organisations conducting research on TB and vulnerability

International

FIND Diagnostics

The development of rapid, accurate and affordable diagnostic tests through public-private partnerships

www.finddiagnostics.org

email: info@finddiagnostics.org

Médecins Sans Frontières (MSF)

TB diagnosis and treatment, research and advocacy

www.msf.org

email: martine.usdin@paris.msf.org

The Special Programme for Research and Training in Tropical Diseases (TDR)

An independent global programme of scientific collaboration in research and health service strengthening

www.who.int/tdr

TARGETS partnership

www.lshtm.ac.uk/dfid/targets/partnersnew.htm

South and East Asia

India

MAAS – Centre for Health Research and Development (CHRD) (Pune)

email: maaschrd@vsnl.net

Member of TARGETS partnership

Pakistan

Association for Social Development (ASD) (Islamabad)

Research and implementation of TB diagnosis support tools

email: asd@isb.paknet.com.pk

Bangladesh

BRAC (Dhaka)

Indigenous NGO working toward poverty alleviation and community development

www.brac.net

Nepal

South Asian Association for Regional Cooperation (SAARC) (Kathmandu)

TB centre

www.saarctb.com.np

China

EQUI-TB, School of Public Health, Fudan University (Shanghai)

Part of EQUI-TB Knowledge Programme, promoting the implementation of pro-poor strategies that enhance care and support for TB among the poorest

email: qwjiang@shmu.edu.cn

Eastern Africa

Tanzania

Ifakara Health Research and Development Centre

(Dar es Salaam)

A not-for-profit, district-based health research and resource centre

www.ihrdc.or.tz

Member of TARGETS partnership

Uganda

Infectious Disease Institute (Kampala) Makerere Medical College

www.med.mak.ac.ug

email: office@idi.co.ug

Member of TARGETS partnership

Southern Africa

Malawi

Research for Equity and Community Health Trust (Lilongwe)

Part of EQUI-TB Knowledge Programme, promoting the implementation of pro-poor strategies that enhance care and support for TB among the poorest

email: bertha@equi-tb-malawi.org

Zambia

ZAMBART – Zambian AIDS-related Tuberculosis project (Lusaka)

University of Zambia, Department of Medicine

email: zambart@zamnet.zm

Member of TARGETS partnership

West Africa

Ghana

INDEPTH – Network of Demographic Surveillance Systems (Accra)

www.indepth-network.org

email: info@indepth-network.org

Websites

BMJ

Helping doctors make better decisions
www.bmj.com

Oxford Journals

Health Policy and Planning
www.heapol.oxfordjournals.org/

The Lancet

www.infection.thelancet.com

Ingenta

Access to International Journal of Tuberculosis and Lung Disease

www.ingentaconnect.com/content/1027-3719

Journal of American Medical Association

www.jama.ama-assn.org

Healthlink

www.healthlink.org.uk

StopTB

www.stoptb.org

World Health Organization

www.who.int/gtb



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2 From soldier to civilian: The challenge of reintegration

3 Ensuring a food secure future: Ingredients for change

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Topics for forthcoming radio and print features

Drug-resistant TB – How can hospitals protect their patients?

Deadly stigma – tackling the TB taboo

Double stigma – HIV and TB. What educators in Zambia are doing about it.

Injecting hope: former Assam drug users encourage addicts to get tested for HIV and TB

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