

Poverty, gender, children, and tuberculosis

Tuberculosis is a classic example of a social disease, characterized by its close correlation to socioeconomic conditions.

Poverty fosters tuberculosis

Airborne mycobacteria spread easily in overcrowded places and where other illnesses and poor nutrition reduce the immune defenses. This puts impoverished people at high risk of acquiring infection and developing active disease. Two centuries ago, the urbanization of many societies during the Industrial Revolution created the conditions for an explosive growth in TB incidence. This association between TB and the living conditions of the working poor and the destitute is still found today throughout the developing world.

The global and national distribution of TB correlates closely and inversely with national average per capita income. Low-income countries have a high incidence of TB and high-income countries have a low incidence (figure 3.1).

Resolving the global crises of acute poverty and inequality is clearly beyond the scope of any single disease control program. But the commitment to achieve the full range of the Millennium Development Goals presents an unprecedented opportunity for international cooperation and integrated action across sectors and interest groups. The TB community, for example, has a special interest in the Goal of eradicating extreme poverty and hunger—conditions that foster TB and that TB then fosters.

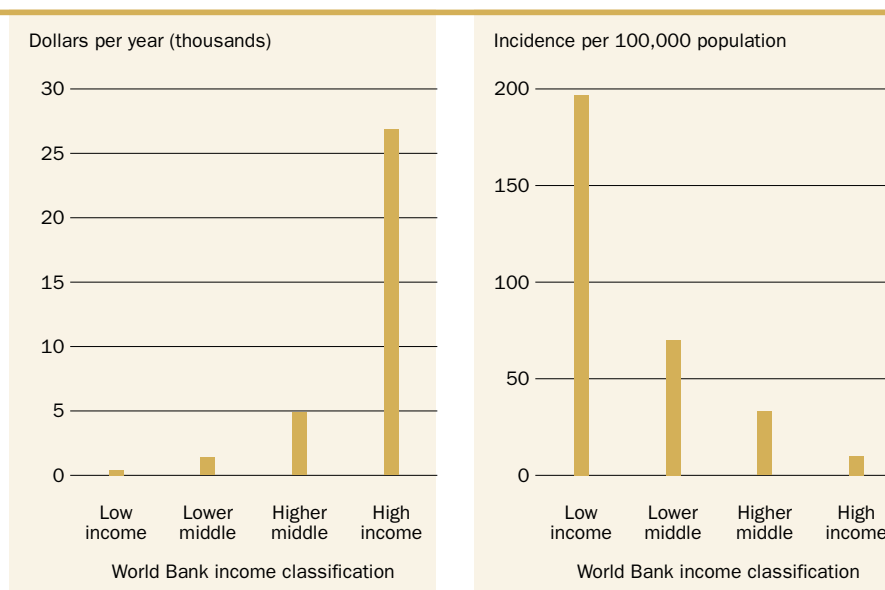
“Stop TB, Fight Poverty,” the theme of the 2002 World TB Day two years ago, reflected the central importance of tackling poverty as a route to tackling TB. Since then, increasing prominence has been given to the need to target poor people in efforts to expand DOTS, and reaching out—within the health sector and beyond—to other public health practitioners, governments, and institutions working on poverty reduction strategies. Importantly, leaders in

Figure 3.1
The correlation
between tuberculosis
and poverty

Average GNI per capita and average incidence of tuberculosis, 2000

Note: Countries are grouped by World Bank income/WHO tuberculosis incidence estimates for 2000.

Source: PIH 2004.



TB control and public health in some of the highest TB burden countries are committing to pay explicit attention to the needs of the poor in their operational strategies.

National TB programs rely on the full range of primary healthcare providers in public health clinics, hospitals, NGOs, private practice, community clinics, and the like to refer patients with symptoms that suggest TB for standardized diagnosis and treatment. But poor people—and other groups, including people in isolated rural communities, prisoners, refugees, the marginalized, the nomadic—often face serious financial, logistical, or political barriers to using health services. Thus there is a greater risk that their TB will not be diagnosed correctly or that they will start treatment late. Delayed treatment increases both the likelihood of death or permanent disability and the risk of transmitting the disease to others.

Within TB control, as across the spectrum of disease and illness, special efforts need to be focused on the most impoverished, vulnerable, and underserved populations. Programs must provide them with access to information, prevention interventions, diagnosis, and treatment. There is now growing evidence of significant socioeconomic differences within seemingly homogenous poor populations (Gwatkin 2003), so DOTS implementation must be designed to ensure that the poorest groups benefit fully. This is an area where further research is needed to monitor, evaluate, and recommend TB control approaches and tools aimed at enhancing equity.

Even with greater success on this front, cure of TB is not enough without tackling the desperate poverty in which it breeds. Box 3.1 has a powerful personal statement from Winstone Zulu, the well-known HIV/AIDS and TB service provider and activist. For some, being cured of TB means anxiety, not relief, when they are deprived of the TB program's food ration, and testing

Box 3.1
Poverty: a fate worse than tuberculosis or AIDS

Source: Winstone Zulu, Kara Counselling and Training Trust.

Jennifer Phiri looked vibrant compared with a year ago when she had started taking her TB drugs. Nine months later, tests showed her TB was cured effectively. She now sat in my small office at our HIV testing and counseling center, looking miserable and depressed.

Joyce Besa was in tears. She was 24 and very beautiful. She said her day-to-day living was made worse by the results of an HIV test earlier that day. She was found to be HIV-negative.

Why would anyone who receives the great news that their TB is cured be depressed?

Why would anyone who is told that he or she is HIV-negative be sad?

The day I learned the answer to these questions was the day I felt like resigning as an AIDS/TB service provider and activist. You see, I live in a town called Kabwe. Fifteen years ago it was a rich and vibrant place for its 300,000 people. Today Kabwe is a ghost town. Thousands lost their jobs when the mine closed in 1995, and thousands more were laid off by the railway headquarters. A mass exodus of people has left in search of greener pastures.

So when AIDS hit Kabwe, it was dealing a death blow to an already dying town. Children who were “economic orphans” became real orphans as their parents died from AIDS. Thousands of farm workers, in the only remaining form of employment, are getting sick and dying from AIDS. The road to the once-thriving “Copperbelt” is lined with sex workers selling their bodies for as little as a dollar per session.

It is in this environment that I was given the task of setting up an HIV/AIDS program by the Kara Counselling and Training Trust, a well established NGO that offers integrated psychosocial services among poor people in two other towns. We quickly set up a counseling and testing center in July of 2003. This was followed up by a hospice for the terminally ill, and then a street children’s program. The voluntary counseling and testing program in Kara is not complete without solid support systems. These include a support group called Positive and Living Squads (PALS), which provides peer support and counseling for those who test positive. At a weekly group meeting, arts and crafts are designed and created, and members share their hopes and fears about the future. With money from the Stephen Lewis Foundation, 4,800 Kwacha is given as transport refund at the end of each meeting. This is roughly about 80 US cents per week per member.

The first meeting of the Kabwe PALS had 10 members. The following week we had 23 members and the third week an incredible 83. We were clearly heading for a budget overrun. So we decided to ask all the 83 members to test. Twenty-three were found positive. I was happy that only 23 were infected, as I feared for a worse figure.

The 60 people who were HIV-negative were not happy. Joyce was one of them. They wished they were HIV-positive so they could get the transport refund. The money is not used for transport but to buy food at home. Members walk long distances to come and get the few cents to help them sustain their lives. To be denied this money was worse than having AIDS.

Jennifer, sitting there in front of me, was complaining that now that her TB was cured, she would be removed from the list of patients who receive food packages of soya powder, cooking oil, and beans. She felt it would better to die of TB than starve to death. She said the food she received while sick was the only source of livelihood for her three children. Their father died of AIDS in 1988.

And here I am stuck with Jennifer and Joyce in my little office as they wish they had the most serious and fatal disease to have hit the world so they can get 80 cents every week. There are times when this planet looks so beautiful. There are times when one feels like migrating to some place elsewhere in the universe.

In a vicious circle, TB itself is a cause of poverty

negative for HIV means losing 80 cents a week to attend an HIV-positive peer support group.

Tuberculosis fosters poverty

In a vicious circle, TB itself is a cause of poverty. It imposes a severe economic burden on individual patients, their households, their health care systems, and their societies, mainly through the costs of diagnosis and treatment and the loss of income due to illness.

First, there are the direct costs, both for care and for accessing care. DOTS is an effective approach but it is also labor-intensive and expensive in terms of system costs. The cost of drugs to treat TB have decreased dramatically in recent years, but in those settings where people must pay for treatment, even the reduced cost can represent an impossible barrier for people living on less than a dollar a day. Patients and their families also often face significant additional costs—for travel, accommodation, and special nutrition during treatment. The substantial nontreatment costs borne by TB patients and their families are often greater than the costs of treatment borne by the health sector. In Zambia, researchers estimated these direct nonmedical costs incurred by TB patients were more than twice their medical costs (Needham, Godfrey-Faussett, and Foster 1998).

Second, because of the length of TB treatment, there are substantial indirect costs from lost production and lost income. Active TB is a debilitating illness that frequently causes prolonged absence from work and can result in loss of employment. Studies suggest that, on average, TB patients in developing countries lose three to four months work, resulting in lost potential earnings of 20–30 percent of annual household income. If the patient dies, their families lose an average of about 15 years of income. In India, researchers found that TB patients lost an average of 83 work days, with 48 days before treatment and 35 during treatment. Indirect costs represented 65 percent of these Indian families' costs for TB disease (Rajeswari and others 1999).

Although the aggregate real costs are higher for nonpoor patients, the relative costs for the poor are much higher. They have little disposable income because of the nature of their livelihood activities, such as daily wage labor and petty trading (Nhlema and others 2002). Periods of inability to work through ill health have a profoundly negative impact on employment and economic security, particularly for the self-employed and those working in the informal sector. In the absence of formalized laws that protect employment during serious and prolonged illness, even those with private sector jobs can find themselves out of work because of their illness.

Some coping strategies that households adopt to meet the costs of illness and death can have damaging long-term effects. In particular, selling family assets can reduce a household's economic prospects and incurring debt increases financial pressures. Reducing children's food intake or removing

TB is a top infectious killer of both men and women in their most productive years

them from school—to save fees or provide labor—can undermine their health, education, and future prospects.

Not all the costs are financial. TB patients and their families also pay the cost of TB in suffering, pain, and grief. TB has an impoverishing social impact. In certain societies, TB patients are seen as damaged for life or unmarriageable, and some may even be rejected by their families. This kind of stigma can result in anxiety, depression, and a general degradation of the quality of life.

Recommendations

- TB partners at all levels should strive to include TB in all antipoverty discussions and mechanisms. Most of the high-burden, least developed, and low-income countries do not include the impact of TB, nor do they target specific actions to control TB, in their poverty reduction strategies.
- In particular, national TB programs should be encouraged to address the links between TB and poverty in national guidelines and set the agenda politically, for example by advocating for the inclusion of TB control in official poverty reduction strategies. They should also welcome partners, such as NGOs, who can assist in providing the poor with services.
- DOTS programs must be flexible enough to meet the needs of patients who have special requirements or who live in particular conditions or geographical areas, especially the poor and vulnerable. TB partners should continue to find new ways to reach out to these patients such as community-based care, social support systems, and public-private models of service delivery.
- DOTS expansion should include equity initiatives in order to ensure that, even among the poor, the less well-off benefit as much as the better-off. DOTS strategy outcome measures should include appropriate indicators.
- Further research is needed to monitor, evaluate, and recommend refined TB control approaches designed to enhance equity and ensure equal access to services.
- Investment in novel R&D efforts to secure new, shorter, and affordable TB diagnosis and treatment is urgently needed in order to reduce the economic and personal costs to patients, their families, and society as a whole.

Tuberculosis and gender

TB is a top infectious killer of both men and women in their most productive adult years. Globally, males account for 60 percent of TB deaths and females for 40 percent. The burden of death among girls and women is great, at approximately 700,000 per year, and is of a similar magnitude to deaths due to maternal causes. According to TB case notifications reported to WHO, about twice as many men as women were notified that they had TB (WHO 2004j).

Studies suggest TB progresses from infection to active disease more rapidly in women of reproductive age

Prevalence surveys show that both the prevalence of infection with the bacillus that causes TB (*Mycobacterium tuberculosis*) as well as active TB disease is comparable between males and females until around age 15. However, a gender disparity with a rising rate among males emerges in late childhood and early adulthood and increases throughout most adult years, until it declines in old age.

Studies suggest that, given infection, TB progresses from infection to active disease more rapidly in women of reproductive age than in similarly aged men. Evidence of the impact of pregnancy on TB is inconclusive. However, it is clear that TB in pregnancy increases the risk of a poor pregnancy outcome. Case-control studies from Mexico and India report that pulmonary TB in a mother increases the risk of prematurity and low birthweight in neonates twofold, and the risk of perinatal deaths between three- and sixfold (WHO 2004l). Pregnant women with a late diagnosis of pulmonary TB also face higher risks of obstetric morbidity, miscarriage, eclampsia, and intrapartum complications (WHO 2004l).

A sociocultural factor affecting exposure may be the difference in social mixing patterns in many societies. Postadolescent women are often more restricted in their range of social contact, whereas men, with a wider range of employment and social activity, may increase their risk of infection through greater exposure (Dolin 1998).

Gender differences in behavior may influence disease progression. For example, poor nutrition, smoking, and alcohol abuse may result in decreased immunity. A 15-year study of 280,000 subjects across all age groups in southern India found that the risk of progression from infection to disease for pulmonary TB was 8.6 percent among men and 3.1 percent among women. Virtually all the alcoholics and smokers in the study population were men. After excluding smokers and alcoholics, the male-female ratio fell from 2.7:1 to 1.2:1 (WHO 2004l).

There are notable geographical variations in notification rates between men and women. These probably relate to a varying array of biological, socioeconomic, and health service factors that affect exposure, infection, and illness onset as well as access to and use of services. A review of the current 20 high-burden countries that report notification by age and sex shows variations between countries. For example, Afghanistan reports higher notification rates in women of all ages. In Pakistan, rates between men and women remain essentially the same until around age 45, when men begin to outnumber women. Indonesia's notification rate remains equal until age 25. In other countries (Brazil, China, and Russia), from age 15 onward, case notification rates are much higher among men (WHO 2004j).

The current profiles of high-burden countries in Sub-Saharan Africa show consistently higher rates overall in men. However, with the exception of Tanzania, the gender ratio remains essentially the same (and in the cases of Nigeria

Women may delay longer in seeking care while men are less likely to complete treatment

and South Africa, women exceed men) at least until age 25 and in some cases until 35–40 (WHO 2004j).

Women ages 15–24 make up a higher proportion of TB cases in countries with higher rates of HIV infection (WHO 2004j). This fits with the observation that HIV prevalence tends to be higher in women than in men in this age range. As discussed earlier, HIV weakens the immune system and someone who is HIV positive as well as infected with TB is much more likely to develop active TB.

Gender differences in access to health care—and in preference for consulting private practitioners such as traditional healers, embarrassment, or fear of stigma—may be factors in differential case detection between men and women in some areas (Hudelson 1996). Studies have suggested that women may delay longer in seeking care for TB symptoms in a variety of settings, while men are less likely to complete treatment.

Both men and women suffering from TB can potentially experience devastating loss of income and social isolation. However, in many of the poorest, most heavily burdened countries, more women than men rely either on informal sector income or on the support of their partners. Many women may perceive social ostracism and the withdrawal of support by a partner and his family—where a diagnosis of TB in a woman is understood, among other features, as an indication of unsuitability for marriage—as a more immediately threatening prospect than TB itself.

Too little is understood about biological, socioeconomic, and health service factors affecting sex and gender differences in exposure, infection, illness onset, help-seeking, and utilization of services in TB control. This field of analysis is underdeveloped, but it has taken on more energy and importance as efforts expand and focus more on who is being missed and why.

Recommendations

- On current evidence, in most parts of the world, men face greater risks of TB than women, largely because of underlying biological factors and greater risk of exposure. Still, women fall ill and die due to TB in alarming numbers. If we aim to reduce gender differentials in development, then we need to address all important gender-related risk factors for disease or poor outcomes.
- As improvement in the welfare and development potential of women, especially in low-income settings, is a high priority, it will be important to examine underlying factors affecting either very large or very small gender-specific differences in case detection.
- In regions where TB-associated stigma for women is documented, it is urgent that health education and communication programs address this serious inhibitor to effective treatment and social well-being.
- As more information becomes available at the local and national levels documenting gender differences in TB disease and access to ser-

Children are particularly vulnerable to infection from household contacts

vices, prevention and control strategies should be adapted accordingly. New community-based and public-private service models that aim to increase access and effective treatment, especially for those most vulnerable, should seek to address known gender-related barriers to care.

Tuberculosis and children

Childhood TB has been described as “a sentinel event in the community,” as it usually indicates transmission from an (often undiagnosed or untreated) infectious adult (Shingadia and Novelli 2003). The risk for children in high-burden TB countries with large families and crowded living quarters is immense. Children are particularly vulnerable to infection from household contacts as they are often held close and breathed on. An estimated 20–50 percent of children who live in households with active TB become secondarily infected (Stop TB Partnership 2004) website.

The current worldwide annual estimate of pediatric deaths due to TB is 250,000. In infants younger than one year, TB often progresses very rapidly, resulting in severe and disseminated disease. Without accessible health care, the illness is frequently fatal before it can be definitively diagnosed. Indeed, diagnosis itself is difficult. Tuberculin skin testing is often an inaccurate indicator of *M. tuberculosis* infection in young infants and those infected with HIV. Since most young children cannot cough up sputum, smear microscopy is usually not a relevant test. Detection rates in children with pulmonary TB using smear microscopy are estimated at only 5 percent (MSF 2004).

TB in infants and children under age 16 has been a surprisingly under-developed area of research and attention. However, there has been recent movement toward better understanding and interventions in reporting and treatment of the disease in infancy and childhood (see, for example, Harries and others 2002). Under the auspices of the Global DOTS Expansion Working Group, a subgroup on childhood TB has now been formed.

Recommendations

- National TB programs should incorporate children with TB in all routine program operations.
- More work should be undertaken on diagnostic algorithms and the study of the epidemiology of childhood TB, especially in low-income settings where the burden is likely to be much higher.
- Operational approaches should be identified to enable health system workers to provide and maintain TB preventive treatment for children.
- BCG vaccine should continue to be promoted and made available for newborns, as part of the Expanded Program on Immunizations.

Investment is urgently needed to support the development of new, easy-to-use pediatric drug formulations and diagnostic tests that are effective in infants and children and appropriate for resource-poor settings.