



Who is most vulnerable to TB and what can we do about it?

Every year nearly two million people die of TB, despite the fact that it is easily curable. TB generally affects the most vulnerable people – those who live in poverty, are marginalised or economically and socially excluded. The disease thrives in conditions of poverty and consequently, poor and vulnerable people suffer even more when they have TB. So what can be done to support vulnerable people to better protect themselves against TB, access proper TB care services and cope when the disease affects them or their families? EQUI-TB at the Liverpool School of Tropical Medicine has been working with colleagues in China, Malawi and Zambia to answer these questions focusing on specific groups of vulnerable people – migrants, women and prisoners.

This policy paper looks at the concept of vulnerability and how it relates to TB control. Social and economic determinants at individual, household and community level affect a person's vulnerability to TB. Vulnerability to TB also emerges in special situations such as massive population movement, and in particularly poor living or working conditions. By using evidence that identifies vulnerability to TB, TB control strategies can become more focused on reaching those who need TB services the most. This makes for a more effective response to TB.

“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.”

Nelson Mandela XV International AIDS Conference, Bangkok July 04

Vulnerable people and TB

Poor and vulnerable groups are at greater risk of infection with *Mycobacterium tuberculosis* compared with the general population because of overcrowded and substandard living or working conditions, poor nutrition, interaction with other diseases (such as HIV and AIDS), and migration from, or to, higher-risk communities or nations.

Groups especially vulnerable to TB vary according to the context. Massive population movements make people particularly vulnerable. These tend to be displaced people, refugees, asylum seekers and other groups such as illegal immigrants, migratory workers, cross-border populations, and orphaned and homeless children. Within wealthier environments, ethnic minorities and other

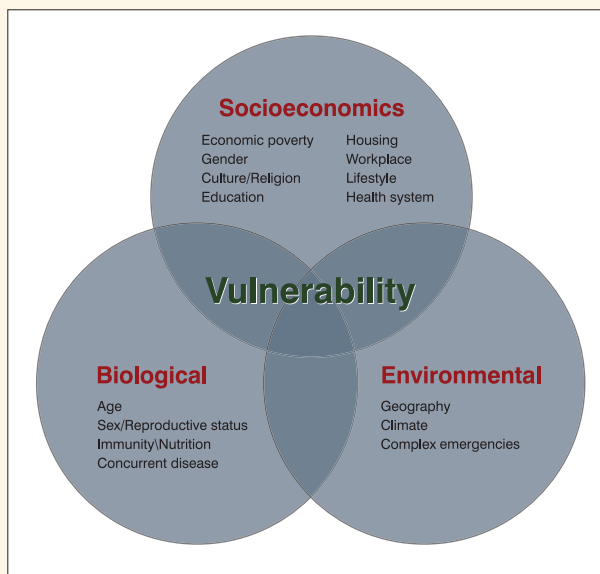
marginalised communities are at a greater risk of TB. For all of these groups, factors such as social isolation, reduced access to health services, lack of trust in the health system and lack of a voice in the community all have a negative impact on health.

In poor countries, the greatest ill health and death from TB is concentrated in the most economically productive age group of 15-59 and TB cases are mostly found in men. In reality, it is difficult to tell whether TB affects men or women more, as there are differences in access to treatment and varying degrees of stigmatisation. More than 10 million people are estimated to be co-infected with TB and HIV, and TB is the leading cause of death in HIV infected individuals in Africa. An estimated 70% of sub-Saharan Africans infected with TB are HIV positive.

The term “poor” refers throughout to a range of disadvantage (not just income poverty) including a lack of material well-being, of infrastructure, and of power and voice. In many African countries this constitutes 75% or more of the population and so raises issues of universal access and equity of systems.

What makes someone vulnerable?

Vulnerability to disease and ill health is a result of several overlapping factors ranging from biological factors, socio-economic factors affecting individuals, households and communities and broader environmental or social factors. Poverty makes people more vulnerable to shocks, reduces their capability to cope when these shocks occur and often means a lack of voice and representation. Exclusion, access to services and opportunities due to race, gender, ethnic or religious affiliation; residence in marginalised urban or rural communities; or because of lack of education to enable more secure employment, or improved health seeking behaviour, are all examples of ways in which vulnerability can emerge.



case study:

TB in prisons in Zambia

TB is spread through airborne droplets so overcrowding and lack of ventilation are key factors associated with infection and death. Institutions such as prisons are often sites for TB outbreaks. EQUI-TB Zambia and University College London carried out research in Lusaka to identify the extent of the problem of TB in prisons. In Lusaka there are three main prisons with a capacity of 650 but currently holding 2700 inmates. 95% are males aged between 16 and 45. There are 140 staff and health care facilities are minimal. There is a high prevalence of TB among prisoners and staff and a

close association between TB and HIV. It was found that out of 646 prisoners tested, 10% had TB and 56% were HIV positive. The Ministry of Home Affairs and the Ministry of Health are now taking action to look at multi-drug resistant TB among prisoners, to screen prisoners upon entry for all infections and to set up a separate clinic.

In another study, questionnaires and focus group discussions ascertained the knowledge, attitudes and perceptions of TB among prison staff. Around 60% of staff knew about TB, that it is transmittable and treatable. Most knew that it was airborne and that prison cells should be decongested but they lacked the opportunity to make the changes needed for improvement. The research suggested that there needs to be more education about TB, management needs to liaise with officers to clarify the perceived danger of TB and staff should be screened upon joining the service and offered prompt diagnosis and treatment if needed.

case study:

TB and Migration in China

In China, rapid and uneven economic development, the move away from rural collectives and a relaxation of controls on population movement have led to mass migration, particularly from rural to urban areas. Increasing numbers of people migrating from rural to urban areas are facing huge barriers in accessing TB and other health services. This is due to lack of knowledge about health services and limited financial capacity. China has the second highest TB burden in the world and an estimated 95% of cases are in rural areas. TB is also more prevalent in less economically developed provinces from which more people are likely to migrate. With such significant population movements, TB is becoming more common in urban areas.

Challenges to TB control in China

- Health systems in urban China frequently fail to detect TB in migrants, often because migrants have difficulties in accessing services and are missed by health promotion activities.
- The majority of rural to urban migrants are farmers with low education, poor health awareness and knowledge of TB. Many undertake

hard manual work, have poor nutrition and have no stable income. This increases their vulnerability to TB. They then suffer increased stigma and discrimination.

- There are poor cure rates of TB among migrants. Health services lack capacity to support them to adhere to treatment due to language problems, discrimination by health professionals and the patient's lack of money to pay for additional associated costs.

Rural to urban migrants are among the poorest in urban populations. Unlikely to be covered by health insurance, migrants often have to pay full health care costs. Chinese government policy states that TB treatment is to be provided free to TB patients through designated dispensaries. Although drugs are provided free, patients have to pay other costs such as consultation, transportation, and bed fees. The Chinese Ministry of Health national TB prevalence survey found that over 45% of people diagnosed with TB cited financial problems as their reason for delaying treatment. A study in Shandong found that low-income patients took four days longer than average to seek care after the appearance of TB symptoms.

As rural migrants have less income to spend on increasingly expensive urban health services they only see a doctor when their symptoms are very severe. There is a low cure rate of TB among migrant populations. Many migrants move around constantly and so cannot finish the treatment course of six to eight months and get lost in follow up management. In Shenzhen, one survey found that the cure rate for TB in migrant populations was as low as 35% yet 93% for residents. Knowledge and perceptions (influenced by social factors like age, educational status and gender) about TB are also key. In a focus group discussion with patients, the main reasons for delay were clearly financial but included lack of knowledge about TB signs and symptoms and about how to access health facilities. The huge inequalities in access to prevention, treatment and information on TB must be addressed as a key element of TB control in urban areas.

Recommendations

- Gather robust evidence of inequalities between temporary and permanent residents in relation to TB prevention and control.
- Investigate and address barriers to TB control



People in rural China face huge barriers when accessing TB care

so that TB does not threaten the potential of economic development to improve the well being of the population.

- Find strategies to identify rural migrants with TB and support their information and financial needs.

case study:

TB in Malawi – gender differences in access to treatment

Poverty and disease are commonly linked. An association with TB and poverty is well established and widespread at national and regional levels. Poverty increases vulnerability to TB and TB treatment costs lead to further impoverishment. Many TB patients sell assets and take out loans to pay for treatment. For poor patients in Malawi, the total cost of TB treatment accounted for 248% of monthly expenditure compared with 124% of the monthly expenditure of wealthier patients.

In Malawi, gender differences affect access to treatment and care for TB in poor households. In 1999 in Malawi, 52% of notified cases of TB were found in men, compared to 48% in women. This was despite an expectation of more female cases as a result of a higher prevalence of HIV among women than men in Malawi. This difference could be explained by the lack of access to resources for seeking health care that women experience. One study in a poor urban community in Lilongwe assessed whether there are gender differences incurred in costs in the process of care seeking and care provision at the household level. Information was gathered using 18 focus



Women find it more difficult than men to access treatment and care for TB

group discussions, 30 individual interviews and 3 case studies. Key findings were:

- Women carry the greatest burden of care for TB within the household
- Women have fewer resources to access care
- Men have more decision-making power over resources
- High costs may pose greater barriers for women to access TB care
- The differences in time, costs and impact of TB care on men and women in Malawi may contribute to the observed differences in case notification for TB.

“Some people say that people should not chat with me because I have AIDS and when they breathe they may inhale the disease. So when I go in a group for example to chat, instead of people greeting me, they just stare at me. So to avoid that I don’t go anywhere.”

A woman from Lilongwe illustrates the strong link made by people between HIV and AIDS and TB which results in female patients experiencing stigma and discrimination.

Summary

TB control and poverty reduction cannot be achieved by concentrating on improving averages across the general population. TB control needs to address the specific needs of vulnerable communities. Directly Observed Treatment Strategy (DOTS) case detection and treatment success rates are well below targets in some regions, and it is the poorest and most vulnerable people who are unable to access care and treatment services. TB control efforts need to bring these services closer to those who need it most.

Recommendations from the EQUI-TB programme

show a need for:

- Sustainable strategies for addressing barriers to diagnosis and treatment completion for different vulnerable groups, especially addressing indirect costs.
- Practical tools and indicators for vulnerability factors to monitor how far TB control activities address vulnerability.
- Processes to include the voices of vulnerable people in planning and assessing the impact of DOTS TB control.

About EQUI-TB

The EQUI-TB Knowledge Programme at the Liverpool School of Tropical Medicine has been working since 2001 carrying out poverty focused research on tuberculosis. Partnering with key institutions in China (Fudan University, Shanghai; Chongqing University); Zambia (University Teaching Hospital, Lusaka); UK (UCL, London); and Malawi (REACH Trust, Lilongwe) research has focused on assuring quality of TB care for poor people in resource constrained settings. South-to-south exchanges of experiences and ideas, for example between China and Malawi have led to significant changes in policy and practice in each country. Healthlink Worldwide is working with the EQUI-TB Knowledge Programme to support the communication and dissemination component of the research programme. Policy paper written by Alison Dunn, design and production by Sam Richardson. EQUI-TB Knowledge Programme
Liverpool School of Tropical Medicine
Pembroke Place • Liverpool L3 5QA
Tel: +44 (0)151 705 3139

