



Barriers to accessing TB care: how can people overcome them?

Poor people with tuberculosis (TB) face huge barriers in accessing TB testing and treatment services. If TB control is to be effective, they need quicker diagnosis and treatment options as close as possible to their homes. The EQUI-TB Knowledge Programme has been working with TB programmes in China, Malawi and Ethiopia to ask the question, “Who is and who is not accessing TB care and why?” Findings show that people living in poor communities tend to have limited knowledge about TB and experience a variety of barriers preventing them from treating and curing their illness. This policy brief describes the inequitable situation in resource poor countries, where gender, age, socio-economic status and geographical location intertwine with poor and ineffective health systems to create serious challenges for TB control. There are a range of approaches that could be applied to make TB services more accessible to poor people, otherwise TB will remain uncontrolled among the very people who need TB control the most.

“We came back to wait for the results, we waited and waited but the results never came out.”

Mother in Lilongwe who suspects her daughter has TB

Barriers to accessing TB care in poor communities

Economic barriers – there is a complex pathway to care for poor people

Geographical barriers – distance from services providing TB diagnosis and treatment

Socio-cultural barriers – stigma and lack of knowledge of TB and available TB services

Health system barriers – lack of health system responsiveness

case study:

Malawi’s “lost” cases of TB

In Malawi, around 14% of patients with confirmed TB never start treatment and are so called “lost” cases. This is an important issue for TB control, not only because these people suffer ill-health and die, but they also continue to be infectious to the rest of the community. A study in Ntcheu District, rural Malawi located these lost cases and asked why they did not start treatment. Interviews with five lost patients and 14 carers of lost patients who had died, revealed that it had taken a long time to receive a positive diagnosis of TB. The major reasons for this were cited as health system structural barriers. The unifying feature of all the lost cases was poverty. Families were poorly educated, subsistence farmers living in basic housing. 14 of the 19 missing cases died within six weeks of their positive TB status being established.

Barriers to treatment

- Patients generally consulted formal medical services before traditional healers, but they encountered barriers with these services. Health centre staff were not considered responsive to patients needs even if they did recognise the symptoms of TB. Staff complained about handling what they perceived to be false cases.
- There were delays between being tested and receiving results. Some respondents claimed they received the result after the patient had died. Difficulties in transporting specimens and results are possible explanations.
- Patients did not have enough money to pay for care – costs include travel costs, guardian costs, food, daily necessities and extra medical expenses beyond those that are free of charge.
- There is stigma related to TB and HIV and AIDS which prevents people from seeking treatment. The reality is that 77% of TB patients in Malawi are HIV positive. Stigma is also gendered with women more reluctant to speak of TB as their illness.

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.

case study:



Man taking TB treatment

Challenges to TB control in China

In China, 5 million people have active TB, meaning China has the second highest burden of TB in the world. The TB case detection rate is currently at around 40%, far below the global target of 70% set by Stop TB. The main

problems facing TB

control in China are the low numbers of TB cases actually found, many TB patients fail to complete treatment, increased numbers of drug resistant TB cases and a lack of effective TB control among growing migrant populations. Many people with TB symptoms face difficulties in accessing health services, and those who do experience delays in getting an accurate TB diagnosis.

What are the barriers that exist to getting a quick TB diagnosis after first seeking care? Using qualitative and quantitative methods, this question was asked by researchers in a social assessment study in four provinces in China. Up to 60% of patients experienced a delay between first visiting a health centre and receiving a diagnosis. Most patients had to make more than one visit before receiving a diagnosis and between 17% and 30% made more than six visits.

Poverty and disadvantage

- Lack of money is the main reason for delaying seeking health care. Costs include transport, accommodation and time lost working. TB patients in low income brackets took four days longer to seek health care than wealthier patients. The social assessment found that perceived costs of TB diagnosis and treatment by communities were 2-5 times higher than the actual costs. This perception that TB care is very expensive prevents many people from seeking help. Even within a system where TB diagnosis and treatment is free, care is still found to be

expensive for poor people. Repeated visits to health centres before diagnosis (often up to six times) and over or unnecessary prescriptions of additional, non-TB treatments result in high costs.

- Gender, age and educational status may influence where individuals seek care. Gender shapes women's and men's access to resources as well as experiences of social stigma. Women take longer to seek care than men. Men are often prioritised for receiving health care as they are seen as the 'backbone' of the family. Women, young women especially, would find it difficult to get married if it was known they had TB. Older people are less mobile and would not want to burden families financially. Those with the lowest educational level are more likely to delay seeking health care.
- Lack of knowledge about TB is a serious problem in the general public in China. Health workers provide patients with very limited information during medical consultations and poor and vulnerable people are often missed by health promotion campaigns.

Disjointed health systems

- Village health care providers have low knowledge and awareness of TB symptoms, and poor communication and diagnostic skills. Few clinics have the expensive medical equipment or specially trained staff capable of identifying TB cases at an early stage. A nationwide survey found that 40% of the TB patients they studied had sought health care but had not been diagnosed with TB.
- Village doctors have become private practitioners in China. Financing mechanisms are such that local doctors or health providers 'lose out' on costs and fees paid by patients if they refer them elsewhere.
- TB control programmes do not have sufficient funds to offer attractive financial incentives for village and township level health workers to detect and refer TB cases. Neither do they have funds for effective health education and promotion of TB control services. There is a lack of cooperation between central and district or village level health facilities.

Ways to overcome barriers

Laboratory services

Getting tested for TB can be a complicated process, even after you have reached the health care system. Following WHO recommendations, patients must submit three samples of sputum at different times of the day, and on the following day. They must wait for results that sometimes take weeks to come as local level health care services do not have the equipment to carry out effective testing. Patients either have to travel long distances to submit sputum or village and district level centres have to transport sputum to central testing laboratories, a timely and expensive procedure. Many patients are lost in the system because they do not submit all the specimens, fail to collect results or are not registered for treatment.

Single smear methods Using a single smear instead of three smears is an innovative testing procedure that has shown promise. With only one specimen, there is a perceived risk that cases of TB will be missed. A study in Malawi however, showed that the difference in TB cases identified is not that great. An 'on-the-spot' diagnosis means that patients are brought closer to accessing TB care. The patient only has to visit the health care centre once and patients attending before midday are asked to wait for results. Because overall costs are lower and testing procedures easier, the chances of patients coming forward for testing are greater. With less time to wait and less effort required to return, patients are more likely to start treatment. In one study in Lilongwe, 63% of TB patients diagnosed by an 'on-the-spot' one smear test started treatment within a week of first attendance. None of the patients who had TB identified through a three-smear microscopy centre started treatment within a month of their first attendance.

Bleach smear in Ethiopia In Ethiopia a testing method in which household bleach is simply mixed with the sputum has shown promising results. Increased numbers of positive TB cases were found using this method. It is simple, cheap and kills the bacteria making testing procedures safer for laboratory staff. This can also be applied to single smear on-the-spot testing and increase the accuracy of the results and the study suggests that this might be an appropriate approach for screening TB suspects in resource poor countries.

Public bus services in Malawi In Malawi, transporting specimens from previously treated patients with new TB symptoms (recurrent cases) to central laboratories to test

for TB drug sensitivity patterns is complex and costly. An inefficient system of collecting specimens, was replaced in 1999 by an innovative approach using public bus services to transport sputum specimens. The development of a successful model for transporting specimens and reports might have a wider applicability and impact on TB control in other resource poor countries.

This resulted in:

- 73% of TB officers reported using the service and those that did had a better record of specimens arriving at the central TB laboratory.
- A problem was that the central laboratory did not receive specimens for 60% of patients with previously treated TB, possible caused by lack of adherence to guidelines by TB officers.
- Regular supervision and monitoring can improve good practices in the peripheral units. This combined with an assessment of the use of the bus service and considering other transport options could improve TB control.

Informal health providers and community structures

In Malawi, the cost of having a TB diagnosis is relatively high if you are poor. EQUI-TB worked with the National TB Programme (NTP) to understand the problems of inequity in TB care. NTP has responded by including equity issues in their new five year plan 2002-2006 to understand more fully the delays and barriers in accessing care in rural Malawi and identify different and multi-sectoral ways of addressing the problems. EQUI-TB has also implemented various community based approaches to complement TB control efforts.

Store keepers in an urban setting Chronic coughs and other common health complaints are already self-treated at a community level through grocery stores which act as a first point of call for many poor people seeking care. A pilot project where storekeepers are trained in TB symptoms and referral has been implemented in three districts in urban Lilongwe. It has gained strong support from the local community who feel better supported and informed about TB. This project grew from a study in Malawi exploring the potential role of shopkeepers and community groups in TB control in a poor urban community. Findings showed that:

- Storekeepers know about the symptoms of TB and want to refer their customers but are afraid they will be ignored without formal acknowledgement. Community awareness of the new health role of storekeepers is therefore essential.



- A broader health advisory role for TB and malaria might decrease the stigma surrounding TB and HIV/AIDS, allowing people to be more open in seeking advice.
- HIV and AIDS health education and home based care groups exist and want to support the storekeepers and community leaders in a health role.

“This advisory role is a new concept. Customers see storekeepers as businessmen so the communities need to be sensitised.”

Health workers during in-depth discussion.

Home-based care and civil society

An innovative project involving first time participation for a home-based care organisation in delivering TB care in Malawi, aims to increase the number of TB suspects being registered and receiving treatment. A local NGO in Lilongwe is working at community level with local leaders, village health volunteers and ex-TB patients to specifically target poor people likely to have TB but unable to access services. This reduces costly visits to health care centres, and ensures household assets are used for food and other welfare. The NGO has been active in the following areas:

- Educating people in the community about TB symptoms, diagnosis and treatment.
- Identifying people with TB symptoms and supporting them to go through all aspects of diagnosis and treatment, including providing bicycle transport of specimens to a local laboratory.
- Giving home based care and supervising Directly Observed Treatment (DOT) for all patients in the project.

Summary

Poverty affects people's ability to access services at all stages of care-seeking: from symptoms, to help seeking, health services, diagnosis, treatment adherence and a final positive outcome. Poor people need to have these barriers which prevent them from accessing services removed. Pro-poor approaches should include a range of measures to improve the geographical, economic and social access to TB services.

Recommendations from the EQUI-TB programme

show a need to:

- Bring TB services closer to homes including for remote and migrant populations or provide transport to services.
- Provide information, education and communication on TB that reaches poor people of different ages in remote rural areas. Tackle stigma and discrimination through effective health promotion activities.
- Introduce community based initiatives to help village and township level health workers to get more involved in TB control programmes.
- Address health systems barriers by increasing the capacity of local health services, and improving staff attitudes, motivation and communication skills.
- Promote free diagnosis and treatment of TB, advocate against user-fees and assure quality testing and treatment services, so that poor patients' perceptions of the quality of services improves.

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 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.

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