

Behavioral barriers in tuberculosis control: A literature review

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Introduction

Tuberculosis (TB) continues to cause a large burden of disease in the world, killing an approximately 2 million people a year. It is estimated that 95 % of all TB cases and 98% percent of all TB death occur in the South. Fueled by poverty, poor public health systems, and increasing HIV/AIDS prevalence, TB continues to be a persistent challenge for global health and development.

TB control programs currently emphasize the Direct Observed Therapy Short-Course (DOTS) strategy, promoted by the World Health Organization and the International UNION Against Tuberculosis and Lung Disease. The current goals are to achieve 85% treatment success and 70% case detection. Among others, TB global control currently confronts two challenges to meet those goals: diagnosis delay and non-completion of treatment.

The TB control community has recognized and addressed system components in which behavior is a key issue. Both diagnosis delay and non-completion of treatment are two central behavioral challenges. Patients are expected to seek care and complete treatment. Health care providers are expected to perform successfully a number of actions, including offering sputum smear examination to patients, conducting tests adequately, and monitoring medicine intake. Success in TB detection and treatment requires specific behaviors from patients and health care providers within contexts that facilitate those practices.

It is important to recognize that components of the DOTS strategy are, in fact, responses to behavioral challenges in TB control. Direct observation and supervision of patients is assumed to be more effective than self-administration to ensure that patients successfully complete the recommended six-to-nine month chemotherapy. Weekly distribution of medicines is intended to be a more effective method than monthly distribution to induce adherence. The provision of free diagnosis and medicines aims to eliminate costs that deter patients from seeking care and completing treatment. Packaging medicines in blisters and storing them in individualized boxes aims to facilitate correct intake and adherence. Recent studies seem to support the rationale behind those decisions. For example, treatment completion rates are higher among patients with direct supervision rather than among those with no supervision.

Several ongoing national and global initiatives that are part of TB control programs also aim to address behavioral challenges. Programs that offer enablers such as transportation and food subsidies for patients assume that by minimizing costs the numbers of patients seeking diagnosis and care would increase. Similarly, incentive programs also assume that modifying the behaviors of health providers is necessary to increase treatment rates, for example, through offering monetary retributions for each patient who completes treatment. Initiatives to expand the outreach of health systems through partnerships between public and private providers also

address behavioral barriers (e.g. distance from health services, trust of health providers) that affect care-seeking and adherence.

Goal

Given the importance of behavioral issue for TB control, this review summarizes what is currently known about behavioral barriers to cure in TB control programs. This assessment informs the Pathway of Ideal Behaviors, a tool to determine barriers that account for delays in diagnosis and completion of treatment.

Methodology

A comprehensive search in MEDLINE was conducted using the following keywords: tuberculosis, behavior, care-seeking, treatment, adherence, and completion. The search included publications between 1985 and 2005 in English, Spanish, and French.

Findings

Although it is difficult to draw generalizations applicable to different settings, available studies offer common findings that allow us to identify a set of factors that promote and deter ideal behaviors in TB control. Without exceptions, all studies analyze data from individual countries. No attempts to replicate findings from previous analyses or conduct cross-country studies to examine variations across health systems and cultures were found.

Research findings are presented in barriers for TB diagnosis and treatment.

Diagnosis

Studies have identified several factors that account for patient delay and healthcare service delay. There is no conclusive evidence to settle the debate about whether the quality or under-utilization of services accounts for a larger proportion of delay in case-finding. Instead, studies identify key factors that account separately for patient delay and healthcare service delay.

Numerous studies have found association between *patient delay* and knowledge, awareness, stigma, external constraints, and gender differences. When healthcare services fail to detect TB cases, case finding depends on voluntary presentation motivated by symptom recognition, as well as cultural and social influences.

The propensity to seek care depends on knowledge about and perceived risk of TB within reference groups (families, neighborhood) and communities at large. A number of studies have found a correlation between *knowledge* and delayed diagnosis. Knowledge includes the ability to recognize symptoms, identify causes and transmission routes, and familiarity with the availability of cure. Although the evidence doesn't conclusively suggest that knowledge independently determines care-seeking behavior, the correlation about knowledge and timing of diagnosis is well documented.

As demonstrated in studies in Ethiopia, India, Mexico, Nigeria, Pakistan and Thailand, patients with low knowledge about symptoms are more likely to postpone care-seeking and get tested. Poor knowledge has been found among older and less educated people in Nepal, and marginalized groups with limited media access in Vietnam. Conversely, patients with higher educational levels are more likely to know symptoms and seek care earlier. A study in India, however, suggested that knowledge was not sufficient to prompt people to seek care, and that motivation was necessary, too.

Also, studies in Tanzania have found that, in some communities, patients with low knowledge are more likely to visit traditional healers and pharmacists rather than DOTS providers, thereby delaying diagnosis. Although the literature does not analyze the reasons, preference for non-DOTS providers cannot be assumed to be the result of low knowledge; rather, it seems to be a common care-seeking practice based on familiarity and trust with non-DOTS healthcare providers.

Studies have also reported that low *awareness* about the risk of TB symptoms is associated with delay in care-seeking. Patients with a higher perception about the severity of the disease are less likely to delay care-seeking and diagnosis. For example, a study in The Gambia found that patients with haemoptysis have shorter delays than patients with less severe symptoms.

Studies have also demonstrated a robust association between external constraints and patient delay. Distance from DOTS clinics (e.g. rural areas in The Gambia, Tanzania, Zambia) accounts for longer delay. Transportation costs (which are associated with distance between residence and DOTS clinics) also account for variations in timing of diagnosis in Zambia. Studies have found that other costs and financial difficulties more broadly also account for delay in China. Patients are more likely to delay diagnosis when they need to borrow money to get to healthcare services, lose daily income to attend DOTS clinics, and lack health insurance.

Also, studies demonstrate that stigma deters people from seeking care and diagnosis. TB stigma is not new. A well-documented literature has shown why and how TB has been highly stigmatized throughout history. Whilst the stigma of TB as “a disease of the poor” persists, more recently, HIV/AIDS stigma affects TB patients, particularly in communities where HIV/AIDS is prevalent as shown in studies in Ethiopia, Pakistan, and Thailand. TB patients suffer from double stigma.

TB stigma has been widely reported. Stigma is perpetrated and reinforced by health staff, family, neighbors, and other groups. Patients postpone seeking care due to fears of finding out their HIV status, and suffering stigmatization and social rejection as a consequence of their HIV and TB status becoming known. In some cases, even attending DOTS clinics to get diagnosed is stigmatized. If uncertainty about HIV status deters people from seeking diagnosis, knowledge of HIV status seems to be negatively associated with delay. A study in Thailand found that patients who are HIV positive have the shortest delay for TB diagnosis. The authors speculated that patients are more willing to seek care after they know their HIV status.

Studies have reported that women bear the highest burden of stigmatizing behaviors. In some communities, female TB patients and women who are suspected to have active TB are likely to

be forced to get divorced, send back to their parents' homes, and have fewer chances of getting married. In Bangladesh and Vietnam, studies show that fear of social isolation from family or community is a key factor contributing to delay among women. Stigma is suspected to be a contributing cause to why females are more likely to postpone diagnosis, are offered sputum tests less frequently, and feel more inhibited than men to discuss TB with their family.

The difference impact of stigma on men and women is only one dimension of significant gender differences in patient delay. Studies have documented that women have longer delays in Nepal and Sudan, and that women are offered sputum tests less frequently than men. The fact that, in some communities, women need to be accompanied to DOTS clinics also accounts for longer female delay.

Other studies have documented that gender differences in care-seeking behaviors explain delay differences between men and women. Men postpone care-seeking longer than women. Reasons for longer delay among males include fear of individual costs of diagnosis and treatment as documented in studies in India and Vietnam. Also, men are more likely to neglect symptoms longer until serious and then to public health services. Women, instead, are more likely than men to seek care immediately after symptoms. However, as studies in China and India have shown, women tend to self-medicate and/or choose private practitioners as the first point of contact after deciding to seek care.

Health provider delay is associated with several factors. Studies in South Africa and Vietnam have found that the inability of health services to screen patients in first contacts contributes to delayed diagnosis. Poor interpersonal communication and inadequate attitudes of health providers coupled with the lack of attention and support to patients account for delay in several countries.

Treatment

The literature identifies specific groups as likely treatment defaulters. A study in Ethiopia concluded that men have twice the risk of treatment default than females. Also, the most excluded sectors of society are more likely to interrupt treatment such as migrants, undocumented workers, the unemployed, the homeless, the mentally ill, and drug addicts in the United States and Western Europe. In developing countries, rural, older and less educated people are more likely to default.

One of main reasons for treatment default is knowledge. Studies in India, Swaziland, Thailand and Zambia indicate that poor knowledge about the length of treatment predicts default behavior. Most defaulting patients interrupt treatment soon after they feel better and/or around two months after initiating chemotherapy. For example, findings from India suggest that patients' misconception of well-being with cure leads to default. Also, patients who did not know about potential side effects of medicines were more likely to default.

A study in India showed that key differences among compliers and non-compliers included motivation, perceived severity of disease, and self efficacy. That is, those who are more motivated, have a higher perception of risk, and feel more confident about their ability to

complete treatment are less likely to default. Similar findings were found in a study in Thailand where compliance was more likely among patients with good knowledge, who perceive their illness to be more serious, and believe that treatment will alleviate the condition.

Stigma does not seem to affect treatment adherence as strongly as diagnosis delay. Only a few studies report that stigma contributes to poor adherence, particularly in the early weeks/months of the treatment.

External constraints are also predictors of adherence. A study in Ethiopia found that default is higher among patients who need travel longer distances to health center and pay for consultation. In Thailand, findings suggest that patients who cannot cope with the economic costs associated with treatment adherence (e.g. paying for transportation to go to clinics) are more likely to default. Besides poor knowledge, poverty largely accounts for default in Zambia: patients lack means to travel to the hospital and pay for consultation coupled with lost income for clinic attendance.

Another important finding is that the quality of healthcare provider-patient interaction accounts for variations in treatment adherence. One study in South Africa has shown that the quality of the health practitioner-patient interaction coupled with correct causative belief were more strongly associated with compliance behavior whereas knowledge, onset of TB, socio-demographic variables, health care seeking, and health beliefs were not associated. Research in Ghana and South Africa concluded that regular visits by liaison staff and voluntary workers improved compliance.

Other studies report a variety of systemic problems as the main causes for low case-finding and treatment default in Nepal.

Conclusions

The literature review confirms what current rates for TB diagnosis and treatment completion demonstrate: TB control programs do a better job holding rather than finding cases. Although both are pressing tasks, bringing people in to get diagnosed seems a more formidable challenge than ensuring that patients get and complete treatment once they are in the health system. As long as monitoring and supervision are adequate, the majority of patients are likely to complete treatment. Certainly, both diagnosis and treatment effectiveness require that the infrastructure of TB control programs had a minimally acceptable functioning. That is, drug supply is reliable and sustainable, laboratory facilities are available and sufficiently equipped to perform tests, monitoring systems are in place, and human capacity for different tasks (e.g. supervision, laboratory work) is adequate.

Although poor TB knowledge is a good predictor of care-seeking behavior in general, other factors seem equally important to explain patient delay. Low awareness, low individual and social risk perception, high stigma, and external constraints (e.g. distance, transportation, economic limitations) account for delayed care-seeking and diagnosis. Also, conventional care-seeking behaviors (e.g. consulting traditional healers, pharmacists, and other private providers) also explain delay, particularly among women. Gender differences are crucial to understand

diagnostic delay. Females in poor communities in developing countries are more likely to be less educated, be stigmatized for seeking TB care, and suffer more from external constraints.

Because only a few studies have actually correlated those variables, it is impossible to reach conclusions with general validity. Many factors that predict delay seem to be mutually associated. It is impossible to single out one factor that, regardless of other conditions, explains diagnosis delay and treatment default. Moreover, even multivariate analyses that offer an explanation for TB detection and treatment adherence in one community, do not provide conclusive results that are applicable to different settings. Although the literature has plenty of case studies with individual findings that can be tested, the dearth of comparative studies does not allow us to draw general conclusions.

The inability of health systems to screen people before they develop active TB largely accounts for system delay. From the studies reviewed, a number of factors account for why health systems miss patients. The lack of diagnostic tools in health clinics, bad implementation, overall under-utilization of health care services, and oversight by healthcare providers (due to insufficient knowledge and neglect) are plausible explanations. Once people come in contact with health clinics, then, the poor quality of services explains why a large number of patients are not diagnosed. Problems with the quality of services range from poor interpersonal communication of healthcare providers to infrastructural deficits.

Treatment default is associated with incorrect knowledge about length of treatment among patients, external constraints (basically, monetary difficulties to afford costs required to attend clinics), and the quality of health services (mainly, weak monitoring and poor communication from health providers). Research on adherence to TB treatment largely confirms what the general literature on adherence to medical regimens already suggests: social support and low physical and social barriers are key conditions to increase the likelihood of completing treatment.

In summary, the literature suggests that a range of socio-cultural and communication-educational factors influence patient care-seeking adherence behavior such as gender, urban/rural residence, care-seeking practices, knowledge about TB care and cure, and socio-economic factors. Likewise, factors related to health care system (e.g. poor training and supervision of health community workers, lack of flexibility for treatment supervisors, inadequate supplies for treatment centers, centralized treatment delivery) also account for problems in case-finding and treatment default. All these factors must be taken into account in the design of interventions to improve case finding and patient adherence to treatment.

Lessons for behavior change and communication interventions

One of key lessons to be drawn is that behavioral assessments of factors that cause diagnosis delay and poor treatment adherence are needed to plan behavior change and communication (BCC) programs. Although we have solid evidence showing that a small number of variables affect behavior, studies demonstrate the different relative weight of many variables. Consequently, cookie-cutter approaches that ignore or underestimate how different factors

affect care-seeking and adherence seem inappropriate to address multi-causal behavioral challenges.

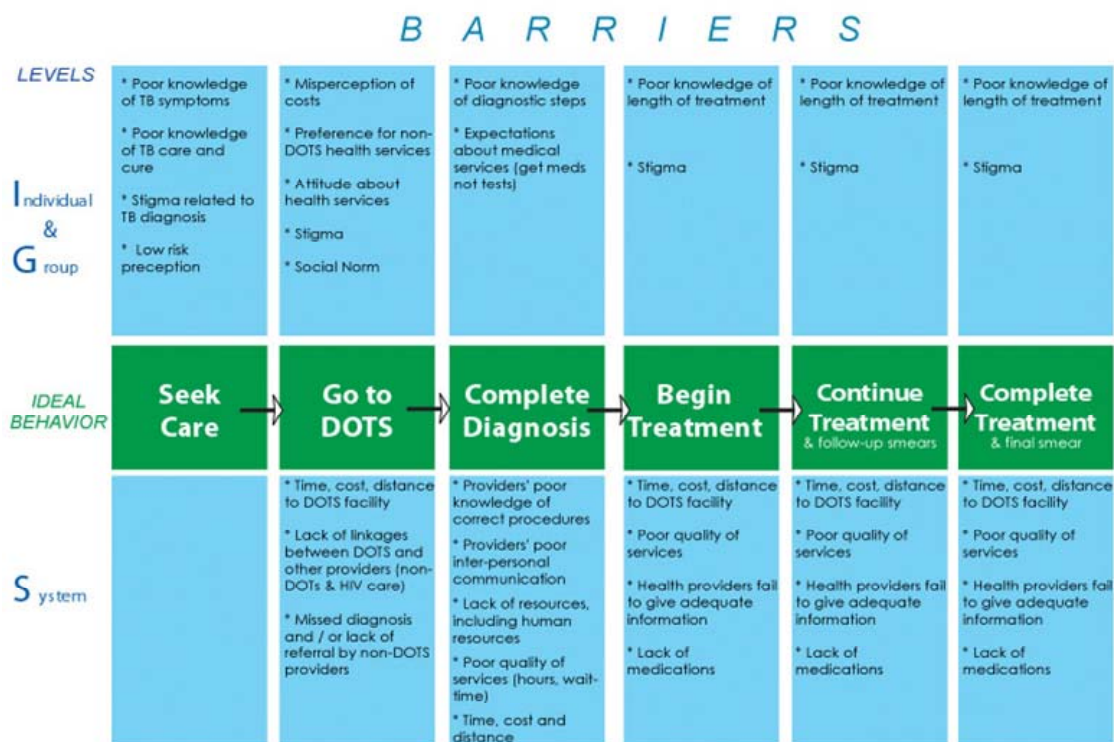
Another lesson is that conventional communication programs that aim to increase knowledge may have impact as long as other behavioral barriers are low. Thanks to interpersonal and mediated communication activities, patients may be equipped with more information to recognize symptoms, know routes of contagion, and be aware that TB care and cure is available. However, better knowledge per se would not necessarily prompt them to seek care or complete treatment. Stigma, low risk perception, and economic and physical difficulties may continue to delay care-seeking and cause default.

The literature also suggests that BCC programs need to prioritize gender, stigma and other socio-cultural issues (e.g. care-seeking practices, medical beliefs). Many studies provide evidence that TB patients suffer from social exclusion and discrimination, and that TB is a highly stigmatized disease, particularly in communities with high HIV/AIDS. Women, particularly, confront severe difficulties: stigma, low education, and local care-seeking practices largely account for longer delays in getting diagnosed at DOTS clinics. Socio-cultural factors also partially account for the persistent difficulties of TB control programs to reach migrant populations in both developed and developing countries.

Cough to Cure Pathway:

As the result of this literature review, it becomes clear that successful tuberculosis control requires specific behaviors from patients and health providers as well as a conducive environment that facilitates those behaviors. Understanding patients' behaviors is fundamental to design interventions to strengthen tuberculosis control programs, including communication interventions. Communication interventions need to identify key problems, reasons, and intended audiences. To assist in identifying these barriers it is useful to them map out along a preferred behavior continuum from the first sign of symptoms (cough) to treatment completion (cure). Using the results of this review, the following chart maps the identified behavioral and societal barriers along a preferred behavioral continuum.

From Cough to Cure: A Path of Ideal Behaviors in Tuberculosis Control



Application

In applying this pathway, communication programs in support of TB could use the path of ideal behaviors as a diagnostic and planning tool to identify barriers that make ideal behaviors difficult. Barriers exist at three levels:

- *Individuals* may lack knowledge, have care-seeking preferences and expectations as well as attitudes about health services that result in delay or in their going to providers or facilities that don't provide adequate care, or they may not perceive the risk of inadequately treating a cough.
- *Groups* (including families, neighbors, communities, and local organizations) may have attitudes and opinions that influence individual decisions and behaviors by affecting stigma, social norms, and risk perception.
- *System* characteristics, including time, cost, and distance to DOTS facility, the availability of diagnostic tools and medicines, health providers' knowledge and interpersonal communication skills, insufficient human resources, weak monitoring may affect program success.

To use the path and design appropriate behavior change communication interventions, four set of questions need to be asked:

Questions

1. Where is the greatest

Example of application:

How many people fail to seek care at any provider within a

- dropout? short time of developing a chronic cough?
How many go to a private provider but never get to a DOTS provider?
2. What are the reasons for the greatest drop-out? Is this more or less than the number of people who fail to persist with treatment after they have started it?
(If the greatest drop-out occurs at step 2, going to a DOTS provider) examine access, referral by non-DOTS providers, stigma
3. What barrier(s) need to be addressed? Is access a bigger problem than non-referral?
4. What interventions will best address the selected barrier(s)?
(If access is a problem, possible solutions include transport subsidies, increasing the hours DOTS providers are open, increasing the number of DOTS providers, emphasizing the importance of community support for people undergoing treatment...
Which of these interventions are a) feasible given program funding and expertise; b) likely to be effective within the short to medium term; c) sustainable?

In going forward, communication programs in support of TB control need to think beyond the prevailing "information/knowledge" paradigm that typically reduces patient delay and default to poor information. A wider perspective is needed to understand how they can contribute to minimizing behavioral barriers to improve case-finding and treatment adherence rates, particularly among at-risk populations.

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