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## Commentary

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# Commentary

FILOMENO V. AGUILAR JR.

# Targeting Tuberculars Social Stigma and Public Health Campaigns

In the fight against tuberculosis one major obstacle is the social stigma associated with the disease. Stigma, which is both relational and contextual, marks the body of the tubercular as a site of danger. This essay reflects on the social history of tuberculosis and proposes that stigma's contingent history in the Philippines can be traced to public health campaigns carried out during the twentieth century, which sought to segregate and isolate the tubercular to limit contagion but could not provide an effective cure. The stigmatization of tuberculosis persists at present, and public health campaigns may need to address stigma directly.

**KEYWORDS: TUBERCULOSIS · SOCIAL STIGMA · HISTORY · DOTS · PUBLIC HEALTH CAMPAIGNS**

The World Health Organization (WHO) ranks the Philippines as having the ninth highest number of tuberculosis cases in the world and the highest in Southeast Asia. It estimates more than 14 million people live with tuberculosis, which kills 75 Filipinos everyday. Recently, big strides from the Directly Observed Treatment Short-course (DOTS) program made the Philippines one of the first four among twenty-two “high burden” countries to have met WHO detection and cure targets. Nonetheless, a study shows that clinically only 28 percent of patients with incident active TB are diagnosed and successfully treated, while 20 percent of patients will die without ever being diagnosed and 6 percent more will die after they are diagnosed because they do not receive adequate care (Peabody et al. 2005).

The relatively low rate of clinical diagnosis, case detection, and successful treatment suggests that more needs to be done to reduce the burden of tuberculosis—particularly now that the state-supported standardized treatment strategy of the WHO DOTS is seen to be effective in controlling TB. The limited success of DOTS has been attributed to the lack of political commitment, flawed organization of health services, insufficient expertise and facilities, irregular drug supply, inadequate finances, fragmentary understanding of TB’s macroeconomic consequences, and the emergence of multidrug-resistant (MDR) TB (ibid.; WHO 2007; 2008).

Also implicated in the problem of tuberculosis but given limited attention by academics and public health professionals is the social stigma associated with the disease. An extensive review of the literature reveals that, despite the “prolonged treatment course, treatment side effects, and the stigma attached to the diagnosis,” there are no studies of the social psychology of TB and TB treatment, the impact of DOTS on patients’ quality of life, and the effect of stigma on patient outcomes (Chang et al. 2004, 1639). This essay seeks to call attention to social stigma as an aspect of tuberculosis and of TB control, and reflects on the social history of TB’s stigmatization in the Philippines.

### **DOTS Treatment Partners and Stigma**

The DOTS program relies on treatment partners, usually family members of the patient enrolled at a DOTS clinic, to ensure completion of drug therapy by strictly complying with the intake of several different medications for a period ranging from six to nine months. A 2004 study where I participated

finds that family members who serve as treatment partners handle their role seriously. One 53-year-old wife describes her treatment-partner role as *nakatutok*, referring to the close monitoring of her husband’s conformity with the DOTS regimen. She also tells him to stop smoking, and reminds him about the dos and don’ts that she has learned from the DOTS clinic. A 53-year-old mother adds to her list of duties the giving of encouragement to her 18-year-old daughter to persevere and be strong willed to complete the treatment, despite the unpleasant side effects, rather than suffer a relapse. Other treatment partners “lecture” (*pinapangaralan*) or even threaten the patient about dire consequences if the medicines are not taken.

Interestingly, all treatment partners say they keep the treatment confidential because of the social stigma attached to persons with tuberculosis. Confidentiality implies a high level of secrecy. Treatment partners say they never talk about the patient’s disease in public, or when other members of the family or household are within hearing distance—in the process, concealing the illness from persons in intimate proximity to the patient. Others keep the information from spreading by simply not talking about it. They fear that household members, including the helper, might gossip (*tsismis*) and spread the information about the TB sufferer. Usually, only the most immediate family members are allowed to know the situation. The mother of the 18-year-old girl with TB even conceals the illness from her other children, and the only other person in the family who knows about it is the father.

Without denying that her husband is unwell, one wife says her husband has “diabetes,” a disease that is somehow more socially acceptable than TB. Another treatment partner reports that only the immediate family members know, and she takes precaution by hiding in a “safe” location the treatment records of her sister-in-law who is undergoing medication. A volunteer barangay health worker, who attends to five patients as their treatment partner, also dissimulates and tells others that the anti-TB drugs are “vitamins”; she also never fills up the requisite DOTS forms in public, as others might inadvertently find out about the patients’ condition.

Treatment partners resort to concealment, dissimulation, and camouflage because they are fully aware of the social stigma that befalls a person known to be afflicted with tuberculosis. Tuberculosis is perceived to be an embarrassment. *Nakakahiya malaman ng iba*, as one treatment partner puts it. In another study, tuberculosis is described as *batik sa pamilya* (stain or blemish on the family) (Nichter 1994, 655). Because of fear of contagion,

people avoid (*iniiwasan*) someone known to have tuberculosis. Treatment partners hope to spare the patients they are assisting from the ostracism that befalls TB sufferers. They also do not want the patients to become objects of pity (*habag*), which could mar their self-esteem.

The stigma associated with tuberculosis has found its way in one of the short stories written by Manuel E. Arguilla, which like his other stories were originally disseminated in the 1930s through widely circulated magazines. In “Caps and Lower Case” the overworked typesetter Alfredo Santos is a tubercular. His body is described in these terms: “bony chin, the hollow cheeks, and the damp clammy forehead.” According to Philip Holden (2007, 330) the tubercular in Arguilla’s story seems at first “to dramatize the iniquities of colonial capitalism in Manila, but the story seems to suggest that Santos’s tubercular body parallels a moral failing—here a lack of courage in confronting his superiors about salary and working conditions.” Tuberculosis is not just a physical ailment but also a metaphor and symbol of moral depravity. In fact one study finds that, among African Americans in the United States, TB is “seen as a powerful, fast-moving disease which is embarrassing and dirty” and it “attacks ‘bad’ people more often than it attacks particularly ‘good’ people” (Jenkins 1966, 421). The stigma attached to TB can be truly profound.

### Dimensions of Social Stigma

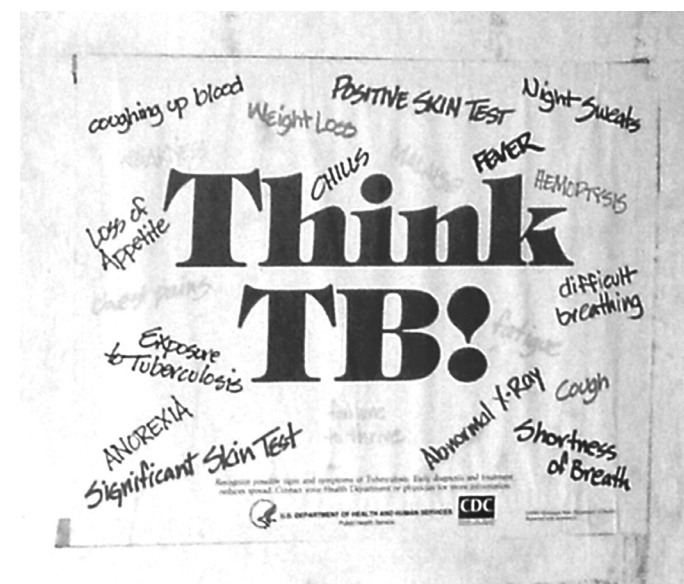
The classic work of Erving Goffman (1963) illumines stigma as a sign or a mark that designates the bearer as “spoiled” and consequently as valued less than “normal” people. This powerful phenomenon links two fundamental components: (1) the perception of difference based on a distinguishing characteristic or “mark,” and (2) the consequent diminution of personal worth.

From this perspective, persons with tuberculosis who are stigmatized are seen as flawed; they constitute as a blemish (*batik*) on the social group. Ill persons are seen as deviants from a certain putative standard of health. That the disease is shameful (*nakakahiya*) suggests that the tubercular acquires the “uncomfortable feeling that accompanies awareness of being in a socially unacceptable position,” in the classic terms of Frank Lynch (1973, 15, italics in original). The person with tuberculosis is thus made to feel inferior. Moreover, the avoidance that attends their bodies excludes them from the social. However, unlike persons with leprosy, those with tuberculosis are not banished to the social and spatial fringes. Some family members may shun a tubercular,

but most do not resort to outright rejection. A relative or friend who arrives in one’s house “would be treated as a guest and not asked to leave” (Nichter 1994, 655). Although tuberculars may not necessarily be treated as outcasts, some sufferers who understand that they are vectors of the disease may anticipate the reaction of other people and isolate themselves or be secretive about the disease, as we have seen among DOTS treatment partners (cf. Kelly 1999).

That there is discursive but only situational avoidance of people with tuberculosis alerts us to the contextual and dynamic nature of stigma. Studies suggest that the most central dimensions in the stigmatizing process are the elements of (1) peril, or the perceived danger of the stigma; (2) concealability, or the visibility of the stigma; and (3) origin, or the controllability of the stigma (Heatherton et al. 2000, 6).

As long as a person is not coughing persistently and spitting blood, and is not skin and bones, the condition of the tubercular can be concealed. (The photo below shows a poster in a DOTS clinic that identifies various symptoms of tuberculosis.) Because tuberculosis is commonly associated with coughing up blood, without this telltale sign patients are passed off as *mahina ang baga* (with “weak lungs”), which is not stigmatizing. Without



Poster at a DOTS clinic indicating the various symptoms of tuberculosis

the expectoration of blood, the disease is often glossed as “weak lungs,” even by clinicians. However, precisely because TB is associated with coughing up blood—that is, the disease is linked to an advanced stage—the very mention of the word tuberculosis conjures death. Indeed, for many a diagnosis of tuberculosis is often tantamount to a death sentence.

Expectedly, in popular health culture the origin of tuberculosis in an individual is not well understood. A study by Mark Nichter (1994, 653–54) in Oriental Mindoro finds that people think of tuberculosis in terms of “pre-disposing factors,” such as lack of food due to poverty (*pasma sa gutom*); overwork and exposure to the elements (“letting sweat dry on one’s back”), which weaken the body and disrupt the hot/cold balance; and excessive habits, particularly smoking, drinking, and sex. Heredity is also seen as an important factor, with tuberculosis said to be transmitted through the “blood” of a parent. Given these contradictory perceptions, a tubercular may be seen as personally responsible and liable for contracting the disease and thus stigmatized, in a similar vein that someone afflicted with HIV-AIDS is stigmatized. But a tubercular may also be seen as having little control over the disease, because of heredity for instance, consequently attenuating responsibility and modulating the stigma. The association of tuberculosis with poverty, however, heightens stigma because to be abjectly poor and go hungry is widely seen as the consequence of one’s own actions (regardless of structures of injustice that social scientists may emphasize).

The peril associated with tuberculosis appears to be a central pivot in the persistence of stigma. Whatever their perceptions of its cause, most people think that tuberculosis is contagious. The body of the tubercular is cast as inherently flawed and affects not only the person but also others who are near to the diseased body. Contagion is seen to come from “contact with blood, saliva, food or breath” of the sick person (*ibid.*, 654). That one has the “potency” to make others sick places the tubercular on the level of the *mangkukulam* (sorcerer), who is believed to have such potency. Interestingly in Ghana tuberculosis is known in the Asante Twi language as *nsamanwa* or ghost cough, with all of its malevolent and spectral associations (Lawn 2000, 1190).

However, because social stigma is relational, the person who assigns stigma to the tubercular is implicated in the very process as he or she senses his or her own body’s vulnerability in the presence of the tubercular. We can say that the perceived danger is always in relation to the one who is not sick rather than

to the sick. As a result, the more visible the “mark,” the more will people feel threatened, and the greater will be the behavior of avoidance.

An important deduction is that stigma is not a universal constant. Rather it is dynamic, contextual, and relational. Moreover, stigma is socially and culturally defined: “there is considerable variation across cultures and across time about what marks are stigmatizing” (Heatherton et al. 2000, 5). To understand the stigmatization of tuberculosis in the Philippines, its social history needs to be excavated.

## Tuberculosis Before Stigma

A time in the Philippine past existed when no stigma was attached to tuberculosis. In fact, during the entirety of Spanish colonial rule, a disease specifically called “tuberculosis” was unknown.

In Europe the tubercle had been described in 1650, its presence as a common factor in all forms of the disease argued in 1819, the disease given the label “tuberculosis” in 1839, a tubercular’s sputum known to be infective of animals in 1865, and the tubercle bacilli discovered by Robert Koch in 1882 (Sakula 1982). The Spanish introduced the term *consumción*, or “consumption,” which was how the disease was popularly known in Europe because it was said to “consume” a person from inside the body. However, consumption was an imprecise label as it referred to many types of fevers. Other labels from Europe were also introduced, including *peste blanca* (white plague); *tisis*, from phthisis (Greek for consumption); and *escrófula* (scrofula), which described the condition of a compromised lymphatic system manifested in swollen neck glands (cf. Philippine Islands Antituberculosis Society 1922; Calderon 1927). It should be stressed that, despite Koch’s exposition of the etiology and transmission of tuberculosis in the late nineteenth century, “the concept of the infectiousness of the disease spread very slowly” (Pope 1938, 327).

Among the Tagalog a disease called *pagkatuyo ng katawan* (drying up or withering of the body) was known. It was described extensively in a book titled *Ang Mahusay na Paraan nang Pag-gamot sa Manga Maysaquit Ayon sa Aral ni Tissot*. The book was a local appropriation—an “improved and expanded” version (*hinusay at dinagdagan*)—of an original *Aviso al Público*, by Samuel Auguste David Tissot, a noted eighteenth-century Swiss physician. The Tagalog version was authored by Fray Manuel Blanco, a former provincial of the Augustinian order, who also authored in 1837 *Flora de Filipinas Según el Sistema de Linneo* (*Flora of the Philippines According to the System*

of *Linnaeus*). Because the edition to which I have access from the University of Michigan Digital Library is dated 1916, the date of the original *Ang Mahusay na Paraan* cannot be ascertained. However, since Tissot died in 1797 and Blanco in 1845, the first *Mahusay na Paraan* could have appeared in the early nineteenth century. On page 4 of the prologue, Blanco claimed that, as soon as he obtained a copy of *Aviso al Público*, he proceeded immediately to produce a Tagalog version (*la que inmediatamente empecé á traducir al tagalog, ansioso de comunicar á estos pobres indios un tesoro tan rico*).

For the disease called pagkatuyo, the symptoms of which included persistent coughing for months, fever, spitting of blood, and lethargy, Blanco's (1916, 66–68) work presented a very broad notion of “causes”: inhaling melting lead (*tanso*); persistent fatigue (*parating pagod*); profuse sweating (*parating pinapawisan*); discharge of blood in the anus; excessive menstruation; protracted breast-feeding; being kicked by an animal, which produced a swelling in the abdomen; lack of sleep; drinking too much alcohol; working, like dressmakers and shoemakers, with the head bowed constantly; for women, threading abaca; prolonged playing of the flute; eating spicy, salty, and aromatic foods; a caregiver being infected by the person being looked after (*ang ungraabay sa maysaquit, na dahil doon siya,i, nasalanan nang caniyang saquit*); and heredity, to which immediately was added “in which case nothing can be done about it” (*Cun minsan naman itong saquit ay minamana, na cun gayo,i, ualang magagauang gamot doon*).

Apart from the diversity and ambiguity of causative factors, this text is instructive in that pagkatuyo was not necessarily seen as contagious. The remedies suggested for a patient who was at an early stage of the disease included moving to a new location and riding on horseback, presumably to inhale fresh air and exercise the lungs. For ease of digestion, the patient was advised to limit food intake to vegetables and milk. Blanco (*ibid.*, 70) added, “Here in the Philippines the milk of a female horse is potent” (*Dito sa lupa nang Filipinas magaling ang gatas nang cabayong babayi*). The patient must drink two glasses of freshly expressed horse milk four times a day. If one could find a nursing mother, then the patient was told to breast-feed directly (*ibid.*). Blanco also stressed that in the Philippines it was advisable to drink tuba from coconut or sugar palm (*tuba sa niyog ó sa caong*) and eat raw oyster (*talaba*) (*ibid.*, 71). Significantly these suggested remedies did not indicate the need for seclusion, isolation, or segregation. The ill person was not advised to avoid others nor were others told to avoid such a person.

Norbert Vecchiato (1997) observed an analogous absence of social stigma in rural Ethiopia in the 1990s. Vecchiato's ethnomedical investigation indicates that the disease known as *balamo* is the most feared in the village he studied, explaining thus: “The reason the Sidama fear tuberculosis may be linked to the long-term debilitation and discomfort it produces in contrast to other short-term infectious diseases, and to the threat it poses to the economic stability and health of the entire family” (*ibid.*, 188). The Sidama's etiological framework associates tuberculosis to overwork, inadequate nutrition, and contagion through the use of personal belongings or through sexual contact. Herbal medicines, which induce vomiting, are preferred over modern medicine. Other treatments include good food (porridge, milk, meat) and cautery. Despite the fear of the disease, Vecchiato is unequivocal that as far as *balamo* is concerned “no social stigma is attached to tuberculosis” (*ibid.*).

From the Spanish Philippines and contemporary rural Ethiopia it may be deduced that, where the etiological paradigm is loose and has no micro-organismic explanation, there are no strictures to prevent contagion and there is also no stigma. It appears that, paradoxically, the modern scientific understanding of the cause of tuberculosis provided the context in which the disease became known as TB and simultaneously stigmatized. But this modern understanding had to be pushed and promoted until a semblance of it became pervasive—the unintended consequence of public health campaigns.

### Segregation and the Making of Stigma

Koch's work on the etiology of tuberculosis and related ideas of disease transmission influenced American health officials in the Philippines in their search for an approach to contain and control this endemic disease beginning in the 1910s. Colonial officials were also at the forefront of disseminating their own understanding of the disease to debunk notions such as those given currency by Blanco. Significantly, the disease now had a “new” name—tuberculosis—that applied to a specific type of illness. Although labels such as consumption and pagkatuyo were still in circulation by 1918 (see fig. 6, Moralina this issue) these have now been erased in the Filipino's collective memory, replaced by the word tuberculosis.

With the new name, shortened to TB, came strong negative associations that, in no small measure, were generated by colonial authorities. The American colonial state's public health measures as discussed in detail by Aaron Moralina (this issue) included methods of surveillance, exclusion, and segre-

gation in the civil service, the nursing profession, in public schools, the prison system, and among motor vehicle drivers and female participants in dance halls. Segregation and exclusion would have fomented ideas about a diseased person's potency to infect others, hence that person's loathsomeness.

Spitting was outlawed, and saliva was demoted to the level of an abomination—when for centuries spitting was otherwise the natural thing to do as one chewed and munched on betel nut. The saliva itself became a bodily discharge to be feared, such that utensils used by a tubercular must be washed and soaked in boiling water. Contact with the tuberculous person, and all appurtenances, had to be avoided altogether.

American health authorities introduced a particularly evocative symbol of segregation: the sanatorium, which was founded on the idea that “altitude and dryness of the atmosphere [were] essentials in the treatment of tuberculosis” (Pope 1938, 328). In time the “sanatorium movement” in the United States was seen as providing “the first substantial promise of recovery to the stricken individual,” a method of treatment that “promised to lift the age-long fatalism” that attended tuberculosis (ibid., 327). The San Juan hospital-sanatorium was built in 1910, closed down in 1916, and replaced by a new sanatorium in Santol, Santa Mesa, in 1918. The Santol Sanatorium would later be expanded and in 1938 renamed as the Quezon Institute (Q.I.). The remoteness of its location can be gauged even today by how excessively receded the Q.I. buildings are from the main road. The sanatorium was intended to provide the best possible medical care to patients, teach them how best to carry on with their lives, but also to contain the spread of infection by isolating and segregating the obviously infective patients. Wittingly or not, moving into the sanatorium, and later the Q.I., was akin to a death sentence, as hardly did patients leave it healthy and alive. In the popular imagination it was a dreadful place of banishment.

The crucial aspect of this still sketchy history is that, while the public health authorities of this period had a modern scientific view of disease causation, there was no corresponding cure. Despite the initial excitement about tuberculin that Koch introduced in the 1890s and continued to refine by 1907, no cure was in sight. “Eventually, Koch gave up completely the use of tuberculin as a cure” (Sakula 1982, 250). Although the Bacillus Calmette-Guerin (BCG) vaccine was available by the 1920s, the American colonial officials in the Philippines were not keen to adopt it. Moreover, although BCG has proved effective in preventing severe forms of childhood tuberculosis, the vaccine “appears

to protect individual children, but has little effect on those already infected and contributes little to reducing the transmission of TB” (Nichter 1994, 650). Streptomycin would enter the scene only in 1947. And even when available, it was not always affordable.

Meanwhile, with no real remedy, a diagnosis of tuberculosis meant certain fatality, and the best that could be done was to isolate the patient. Initiatives to segregate the tubercular consolidated social stigma. Tuberculous persons were thus marked without being cured. Moreover, the campaigns might have unintentionally associated tuberculosis (particularly blood in the saliva) with moral depravity. Criminals and individuals of ill repute contracted the disease: TB was seen to happen to “bad people” or the morally impure. Tuberculosis was at the intersection of interrelated attempts at medicalization and de facto criminalization and moralization.

### **Curability and Stigma's Intransigence**

In 2007, on the occasion of 125 years since Robert Koch's discovery of the tubercle bacillus, the *European Respiratory Journal* asked in an editorial, “Is ‘science’ enough to tackle the epidemic?” (Migliori et al. 2007). Despite the achievements in TB control programs worldwide, the journal editors expressed serious concern borne of rising cases of MDR TB and extensively drug-resistant (XDR) TB, conjoined with the spread of HIV/AIDS, which cannot be cured through DOTS. At the end of the editors' list of seven suggestions was the recommendation: “Initiation of advocacy, communication and social mobilisation activities” (ibid., 426). The question in the editorial's title, however, fell short of exploring public health issues beyond biomedical science. Debunking stigma is not on the agenda. Moreover, while it is recognized that MDR TB is already a global pandemic, as “the world's leading infectious cause of adult deaths, most . . . are due not to multidrug resistant tuberculosis but to lack of access to effective treatment for drug susceptible tuberculous disease” (Farmer and Kim 1998).

Calls have been made to shift from a strictly biological to a multidisciplinary understanding and collaboration in seeking the successful control of “ordinary,” i.e., drug susceptible, tuberculosis. Health belief models have been proposed and discussed to analyze difficulties with patient adherence to treatment and lengthy delays in seeking professional care (Rubel and Garro 1992). Popular perceptions are factors implicated in discontinuing and defaulting on treatment, relapse, and the rise of MDR, and now XDR,



tuberculosis. Among these social and cultural factors is the social stigma attached to tuberculosis.

This essay suggests that public health campaigns have been the creators of stigma in the past and may be complicit in its perpetuation at present. Medical practitioners today, influenced by the stigmatization of this disease, often unwittingly make the control of tuberculosis ineffective. In order “not to offend” the patient and to show sensitivity to the wishes of the patient’s family, clinicians hesitate to use the negatively laden term TB; instead they resort to using the ambiguous term “weak lungs” in their diagnosis, without minding its epidemiological implications. Private practitioners therefore become “weak links” in tuberculosis control (Uplekar et al. 2001).

Under the weight of stigma, a treatment partner of a patient enrolled in a DOTS clinic will conceal the disease, risking the infection of others in the family and the patient’s social circles. As a result, the case statistics in DOTS reports do not capture this aspect of the fight against tuberculosis.

The history of the disease suggests that, even after the cure became available, the force of the stigma has been etched in the collective psyche. Once embedded, the stigma resists easy extraction. Even among some population groups in the United States, it has been observed that “the availability of a biomedical cure does not overcome the community stigma or prevent the negative responses experienced by patients . . .” (Kelly 1999, 239). Note, however, that in the U.S. those who stigmatize tuberculars are not aware that tuberculosis is treatable. A study in Pakistan shows that the stigmatization of TB is linked to its perceived incurability (Liefoghe et al. 1995).

Although the curability of TB is stressed in the educational components of DOTS, stigma persists. It is as though DOTS operates in a world of its own, which patients and treatment partners leave aside when they confront the force of cultural perceptions and practices in the wider world beyond the DOTS clinic. Despite the emphasis on curability among direct participants in DOTS programs, the general population continues to harbor ideas that link peril, infection, and incurability in a solid chain. This wider world in which TB patients and treatment partners lead their daily lives need to hear the message that tuberculosis is curable and that it is not a moral scourge. An educational program that addresses these issues in popular health culture may be considered as a key plank in a holistic, integrated, and interdisciplinary fight against tuberculosis. Although there are no facile solutions, stigma can be frontally addressed in public health campaigns to control tuberculosis.

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