

SOCIAL, HISTORICAL AND CULTURAL DIMENSIONS OF TUBERCULOSIS

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Summary. Tuberculosis (TB) researchers and clinicians, by virtue of the social disease they study, are drawn into an engagement with ways of understanding illness that extend beyond the strictly biomedical model. Primers on social science concepts directly relevant to TB, however, are lacking. The particularities of TB disease mean that certain social science concepts are more relevant than others. Concepts such as structural violence can seem complicated and off-putting. Other concepts, such as gender, can seem so familiar that they are left relatively unexplored. An intimate familiarity with the social dimensions of disease is valuable, particularly for infectious diseases, because the social model is an important complement to the biomedical model. This review article offers an important introduction to a selection of concepts directly relevant to TB from health sociology, medical anthropology and social cognitive theory. The article has pedagogical utility and also serves as a useful refresher for those researchers already engaged in this genre of work. The conceptual tools of health sociology, medical anthropology and social cognitive theory offer insightful ways to examine the social, historical and cultural dimensions of public health. By recognizing cultural experience as a central force shaping human interactions with the world, TB researchers and clinicians develop a more nuanced consideration of how health, illness and medical treatment are understood, interpreted and confronted.

Introduction

Despite the widespread availability of effective treatment, tuberculosis (TB) remains the second leading cause of death from infectious disease worldwide. According to the 2014 WHO Global Tuberculosis Report, 9 million people developed TB and 1.5 million people died from TB in 2013 (World Health Organization, 2014). One-third of new cases are estimated to have been left unreported to national TB programmes. Substantial shortcomings in case-detection are not only due to the limitations in available diagnostic

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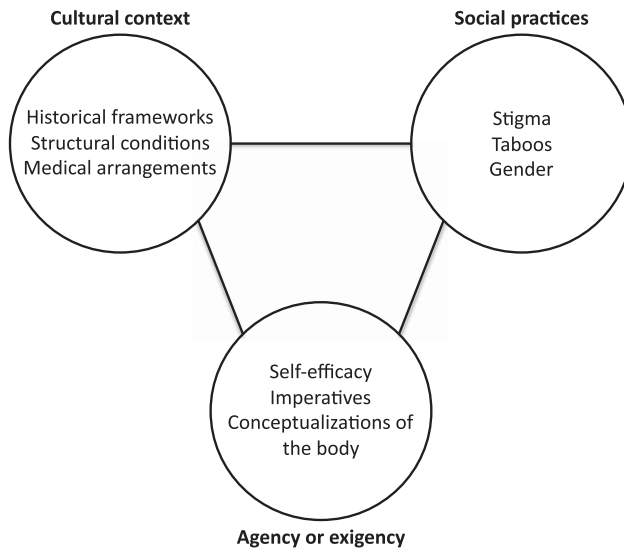


Fig. 1. Three mutually impacting spheres of human activity that factor in socio-cultural considerations of TB.

strategies and time-consuming laboratory tests (Pai *et al.*, 2012; Engel & Pai, 2013). Barriers to diagnosis and treatment also include geographical challenges, economic difficulties, communication issues (Chemtob *et al.*, 2000), fears of stigma (Nair *et al.*, 1997; Coreil *et al.*, 2010), unregulated private health care practices (Bhargava *et al.*, 2011), non-adherence to treatment (Greene, 2004) and gender biases in health-seeking behaviour (Wang *et al.*, 2008; Atre *et al.*, 2009). Often left to operate at an intuitive level, perspectives from the humanities and social sciences contribute significantly to tackling the problem of TB by providing conceptual tools to pay attention to complexity, question the familiar, reconfigure boundaries to create novel frameworks and to critically examine assumptions, arguments and false reasoning (Porter, 2006).

In this review article, key concepts are visited from the social model as they apply to TB disease as well as latent tuberculosis infection (LTBI). The concepts are organized into three sections, (a) cultural contexts, (b) social practices and (c) agency or exigency (see Fig. 1). For each concept, key articles in the field relevant to each of the explored themes are turned to. While original thoughts about TB care and prevention are presented, the purpose of synthesizing this selection of concepts and themes is primarily to set a foundational space for future interdisciplinary research. The objective, one shared by others in the field (e.g. Oshi *et al.*, 2014), is to encourage a systematic exploration of the social, historical and cultural factors that influence health seeking, treatment adherence and successful public health policies. The aim is to stimulate more social studies of TB and to open the space for more collaboration among quantitative and qualitative researchers.

In the first section, 'cultural contexts', the biomedical history of TB originating in nineteenth century Europe is explored, which, through the participation of new TB cases from around the world, is fast becoming a part of global history. While looking at the

past, whether present global health inequities are a realization of the discriminatory ideas of early twentieth century Eugenists is contemplated. Methods of disease surveillance are also called into question in a critical appraisal of TB care and prevention.

The second section, 'social practices', turns to more familiar concepts such as stigma, taboos and gender as they relate to TB. Social practices such as stigmatizing language (Frick *et al.*, 2015) and victim blaming (Lambert & Van der Stuyft, 2005) shift accountability away from the clinic and onto the patient. Victim blaming, for example, is a poor practice that misdirects attention away from assembling more qualified human resources, improving health infrastructure and building stronger health systems that co-ordinate effectively with the private sector. Unpacking social stigmas, taboos and constructions of gender allows us to gain a deeper understanding of practices that impede or facilitate productive health-seeking behaviour.

The final section, 'agency or exigency', looks at the enabling environments and cultural imperatives of socially conditioned individuals. Human bodies through social experience and within particular cultural arrangements are funnelled into following certain courses of action. A technological imperative, for example, means that technologies are sometimes used because they exist not because they are clinically necessary. The biomedical imperative to treat people at risk of developing TB disease but not yet exhibiting symptoms is also explored.

The topic of medicalization interweaves amidst the concepts discussed. Influenced by a dominant biomedical discourse, medicalization (Conrad, 1992) is the tendency to treat social issues and natural events as biological problems for which medical treatment is prescribed. At an organizational level, medicalization heavily orients policymakers to see TB as a biological problem requiring medical treatment. With due consideration to the rise in antibiotic-resistant strains of TB and the complexity of the disease, medical anthropologist Erin Koch (2013b, p. 193) asks 'are responses to disease that keep them at the center of things really 'more efficient?'' A singular focus on a particular disease can draw attention away from addressing the connections between health-related problems as well as the socioeconomic conditions and cultural contexts that foster transmission and reactivation (Park & Littleton, 2013).

At an individual level, understanding the processes of medicalization means paying attention to how people diagnosed with TB are given an imperious invitation to understand their bodies as medical objects where their social status, power relations and agency are compromised by unfamiliar medical hierarchies. Without a foreseeable and clearly identifiable exit to a medicalized identity, the isolating social experiences of a TB patient can continue much longer than medically justified (Long *et al.*, 2001). Thoughtful engagement with the social and biographical consequences of medicalization can help draw attention to the need for culturally sensitive rites of permission that give socially isolated TB patients symbolic re-entry into their community. However, medical models that put disease at the centre seem to go hand-in-hand with consumerism and isolation. Taking a step back from the dominant biomedical discourse, clinicians and researchers can critically reflect upon wider spheres of the patient experience and how non-adherence to treatment may not be a case of being a bad patient but of being a poor consumer.

Thinking about medicalization at a broader level means paying attention to the social, historical and cultural dimensions of biomedical practice. Medical labels, for

instance, have social consequences both for the patients who are subject to them as well as the doctors and researchers who use them to think with. One example is the way that the word 'patient' is drifting from a term referring to active TB cases to a term encompassing LTBI cases. Another example of consequential medical labelling is the discriminatory naming of different strains of TB according to distinct geographical locations. Harper (2006) has identified a clinical example in Nepal where standardized TB case definitions, a necessary measure for programmatic comparative purposes, led paramedical staff to deny pharmaceutically complicated patients access to services because they did not neatly fit into tight criteria. Harper (2006, p. 62) writes:

...the desire for accurate cohort information and the tightening of definitional and diagnostic categories may also be a part of the problem itself as the social processes that generate the facts, through processes of exclusion, simultaneously distort the nature of the reality it seeks to represent.

Taking a step back from these labels and critically reflecting upon their social life ensures that practitioners and researchers are mindful of the social and political worlds within which they operate. Greater competency in understanding the social and cultural dimensions that impact TB patients presenting to doctors contributes to developing ways to reduce diagnostic delay, increase effective TB health care delivery and stop the spread of TB disease.

Cultural contexts

History, structural violence and medicalization

A number of social histories of TB document the period covering the discovery of the *tubercle bacillus*, the development of vaccinations and the advent of antibiotic treatment (see Fig. 2). The discovery in the late nineteenth century of bacilli responsible for consumption gave rise to the notion that these micro-organisms must be eliminated wherever they might be and that the body must be strengthened to fight against them. Vaccines and antibiotics were absent, so practices of hygiene became a moral imperative to avoid bodily pollution. Lacking proven techniques to kill TB bacilli in the body, people turned to methods of killing them in the environment. Tuberculosis was seen to be residing in the dust and dirt that accumulated in houses and homes, and the contagion had to be removed. Joseph Lister (1827–1912) showed that sterilization was a reliable and effective means of reducing deaths in hospitals. His methods were transposed to other living environments. TB reshaped people's morality, sociability and daily habits, and was a significant driver of a new medical pedagogy that focused on hygienic participation in the world. In some cities, a diagnosis of TB gave public officials cause to invade and thoroughly decontaminate a patient's home. Dirt became a taboo. Substances such as soil needed to be cleansed from the body. That this categorization of dirt was a symbolic system, not necessarily a scientific one, is demonstrated by the fact that one of the first antimicrobials for TB, streptomycin, is a chemical derived from soil-dwelling fungus.

The feverishly growing cities of the industrial and agricultural revolution were smelly places with incomplete public sanitation. Louis Pasteur's (1822–1895) experiments

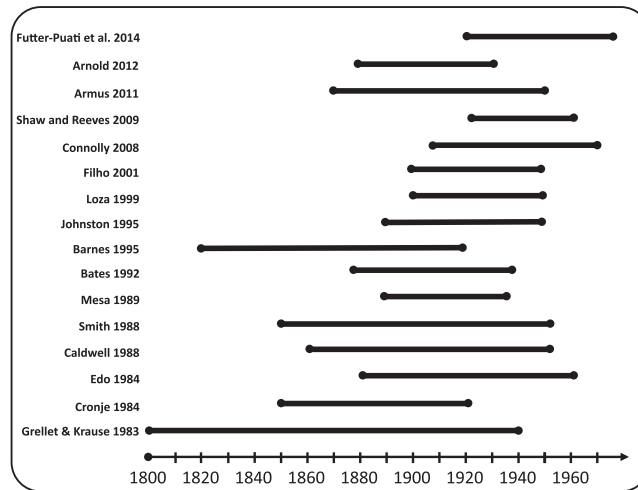


Fig. 2. A selection of social histories of TB. Authors and publication dates are listed along the *y*-axis and the period covered along the *x*-axis (Grellet & Krause, 1983; Cronje, 1984; Edo, 1984; Caldwell, 1988; Smith, 1988; Mesa, 1989; Bates, 1992; Barnes, 1995; Johnston, 1995; Loza, 1999; Filho, 2001; Connolly, 2008; Shaw & Reeves, 2009; Armus, 2011; Arnold, 2012; Futter-Puati *et al.*, 2014).

demonstrating the clean air of Mont Blanc versus the putrid air of the city offered scientific justification for the necessary escape from densely overcrowded settings. Sanatoria were erected in exotic locations to satisfy demand. Sanatoria became sites of health pilgrimages where the unclean migrated to be trained in burgeoning values of hygienic citizenship. However, not everyone agreed with the construction of sanatoria. Eugenists such as Karl Pearson saw TB as a disease that would remove ‘degenerates’ from the human gene pool:

Eugenists really have something better to propose. No one can study the pedigrees of pathological states, insanity, mental defect, albinism, etc., collected by our Laboratory, without being struck by the large proportion of tuberculous members – occasionally the tuberculous man is a brilliant member of our race – but the bulk of the tuberculous belong to stocks which we want *ab initio* to discourage. Everything which tends to check the multiplication of the unfit, to emphasise the fertility of the physically and mentally healthy, will *pro tanto* aid Nature’s method of reducing the phthisical death-rate. That is what the Eugenist proclaims as the ‘better thing to do’, and 1,500,000 pounds spent in encouraging healthy parentage would do more than the establishment of a sanatorium in every township. (Pearson, 1912, pp. 45–46)

In a chilling application of eugenic theory, the SS of Nazi Germany used mobile X-ray machines to diagnose and exterminate 100,000 TB cases in occupied Poland and the Soviet Union (Bynum, 2012).

In many developed countries in the twentieth century, declining TB rates preceded the discovery of a cure (Magill, 1955; Grigg, 1958; McKeown & Record, 1962; McKeown, 1976; Wilson, 1990; Davies *et al.*, 1999; Ostry & Frank, 2010) and would

have continued to decline even without the discovery of antibiotics (Holloway *et al.*, 2014). All the same, antibiotic treatment for TB solidified medical authority over the disease and completed a cultural trajectory of individualization. New TB cases were increasingly treated not in groups but as individual patients. The consumptive was turned into a consumer (for example, see Mooney, 2013) and mass-produced TB antibiotics fuelled a fast-growing pharmaceutical industry (see Pringle, 2012) that readily turned its attention to any condition it was able to commodify.

Following the advent of multidrug therapy, vulnerable populations too poor to participate in a consumer market – people once labelled ‘degenerate’ – became subject to a new form of violence subtler than the plans of the eugenicists or the actions of the Nazis. Johan Galtung, the pioneering professor of peace and conflict research, coined the phrase ‘structural violence’ to describe the failure to address TB worldwide (Galtung, 1969). Extending the concept of violence to encompass avoidable harm, Galtung stated:

Violence is here defined as the cause of the difference between the potential and the actual, between what could have been and what is. Violence is that which increases the distance between the potential and the actual, and that which impedes the decrease of this distance. Thus, if a person died from tuberculosis in the eighteenth century it would be hard to conceive of this as violence since it might have been quite unavoidable, but if he dies from it today, despite all the medical resources in the world, then violence is present according to our definition. (Galtung, 1969, p. 168)

The concept of structural violence continues to powerfully illustrate the connections between TB, poverty and social inequality (Farmer, 2004; Green, 2011, 2012). Unlike physical violence such as soldiers losing their lives at war, structural violence refers to the avoidable loss of life from preventable and curable diseases such as TB during so-called peacetime. Structural conditions enact a violence against certain populations in ways that adversely affect their quality of life, health care outcomes and life-expectancy. The structural violence enacted upon the ‘missing 3 million’ who go unreported to national TB programmes every year is a confronting situation that warrants our full attention.

Even though we have discredited eugenics and cleaned language of labels such as ‘degenerate’, violence against populations once considered ‘degenerate’ persists. Countering this structural violence, the global expansion of TB health care delivery to increase the consumption of medical therapy invites those infected with TB to assume medicalized identities: an invitation not to be refused. In accepting this invitation, the consumptive, over the course of a lengthy treatment, is trained how to be a consumer. Even though medication might be offered for free, patients still need to find ways of meeting all the ancillary and not unsubstantial costs of treatment. The structure of TB treatment conscripts patients into the lowest rungs of a medical hierarchy where they are subsumed into a dependent relationship with the providers of health and where the dominance of the biomedical model is reinforced. Tuberculosis is an excuse to co-opt the poorest classes into participating in global networks of consumerism.

An engagement with history can reveal the political nature of science, such as how the bourgeois Selman Waksman (1888–1973) was awarded a Nobel prize for his student Albert Schatz’s (1922–2005) discovery of streptomycin (Pringle, 2012), or how the work of Jean-Antoine Villemin (1827–1892), a lowly military doctor authorized to treat soldiers and

horses, was never appreciated as much as the work of Robert Koch (1843–1910), whose elite standing even allowed him to circumnavigate the social consequences of fatal experimental mishap on human subjects. Beyond studying the doctors, scientists and patients, an engagement with historical research can be used to examine the context of public health decision-making. Without critical reflection, the decisions of the past can often be taken for granted in the present. For example, rifampicin is administered in doses of 600 mg because the cost of the drug was prohibitively expensive when it was first introduced (Van Ingen *et al.*, 2011), but should this economic argument find continuation today? Shifting our critical gaze to other TB drugs, we may also ask why pyrazinamide is weight-banded when a simplified fixed-dose regimen has been shown to be feasible (Sahota & Pasqua, 2012). In a climate of desperate need for TB treatment, how much evidence-based decision-making has been bypassed? Many of these historical decisions should be reassessed. Revisiting history reveals details to be re-examined and frameworks to be questioned.

Perhaps no other disease has catalysed the rise of medicalization as much as TB. The history of consumption and medicalization demonstrates how so many contemporary TB initiatives are biased towards developing new vaccines, biomarkers and drug treatments. Addressing the problem of TB also involves mobilizing communication strategies and existing medical infrastructure to more effectively reach vulnerable populations, adapting globally standardized approaches such as DOTS more suitably to localized contexts, and addressing the social and economic conditions that foster the spread of TB. Not all societies share the Euro-American history of medicalization, but current TB epidemics across the developing world enable their societies to begin sharing this history. While medical services for TB are often the focus of aid programmes, redressing the socioeconomic factors that perpetuate the disease are rarely on the agenda for TB control. If medical facilities withdraw, a resurgence of TB in these disadvantaged settings is inevitable. Is medicalization a form of outsourcing social problems in a way that produces dependence and perpetuates economic inequities between the consumer and the provider, the consumptive and the doctor? As international donors withdraw from countries that make the shift from low- to middle-income classification, history has yet to record whether their citizens will become proficient consumers of good health.

Surveillance and supervision

George Orwell completed his critically acclaimed dystopian novel *Nineteen Eighty-Four* between a stay in a sanatorium in Aylesford, Kent, where he was first diagnosed with TB, and a sanatorium in Cranham, Gloucestershire, shortly before his death in 1950. Sanatoria were highly controlled institutions where the hygienic practices of TB patients were exhaustingly supervised, treatment and nutrition was highly monitored and ambulation and mobility was heavily surveyed. Strong echoes of the sanatorium experience are found in *Nineteen Eighty-Four*, where an oligarchical government exerts ubiquitous power, controls information and closely monitors the activity of citizens.

Tuberculosis treatment has travelled away from sanatoria, but the principle of surveillance has remained. In 1994, WHO launched DOTS – a five-point policy package designed to address the global TB emergency that it had declared the year prior. The hallmark feature of this policy, and the feature that the policy package as a whole was named after, was Directly Observed Treatment (DOT). Under DOT, a doctor or other

health care worker supervises every dose in a patient's treatment regimen to ensure the complete regimen is adhered to correctly. DOT had been recommended as a strategy for treating TB since the advent of effective chemotherapy in the 1950s (Bayer & Wilkinson, 1995), but it was not until WHO launched DOTS (Directly Observed Treatment, Short-Course) that direct observation became the global standard for administering TB treatments.

Supervision of TB treatment has always been driven by a considered public health imperative to manage the transmission of disease and ensure that patients complete their treatment regimens. The call for strict patient management, however, has frequently been accompanied by moralizing judgements that blame the persistence of TB on the therapeutic infidelity of patients. Medical historian Barron Lerner (1997, p. 1424) noted that uncooperative TB patients have been regularly excoriated as dangerous ever since the disease was found to be contagious. Lerner further demonstrated that in the early 20th century, the image of the 'careless consumptive' was more often than not associated with undesirable social, moral or class categories (such as immigrants, alcoholics and the homeless), which painted TB sufferers as a menace to public health and helped to justify forced incarceration (Lerner, 1997, p. 1426), marital prohibitions, the removal of their newborn children and sanitary and hygienic disinfection interventions in their homes (Armus, 2011). Moralizing associations have continued into more recent times. Following an unprecedented TB outbreak in New York City in the early 1990s, health professionals and media commentators often blamed the outbreak on the non-adherence of individual patients to their treatment regimens. This continued into academic discourse surrounding the global TB crisis more generally. Patient non-compliance was the most oft-repeated explanation for the persistence of the plague and the rapid increase of drug resistance (see Farmer, 1997), and the sufferer was portrayed as 'a breeder of bacteriological weaponry, threatening the population at large' (Draus, 2004, p. 197).

The purpose of Direct Observation Therapy is to ensure that patients are adhering correctly to each dose of their treatment regimen. Despite the overwhelming support for DOT as a standard of treatment (see, among others, Bayer & Wilkinson, 1995; Morse, 1996; Reichman, 1996; Floyd *et al.*, 1997), it was not until the late 1990s that DOT had been tested under the style of controlled conditions to which other clinical methods were subject, with the first randomized control trial assessing the efficacy of direct observation published in 1998 (Zwarenstein *et al.*, 1998). This study, along with subsequent studies, have produced conflicting results about minimal benefit in specific contexts (Garner & Volmink, 2003).

A number of anthropologists have pointed out some of the shortcomings of certain DOTS programmes (Harper, 2010; Koch, 2013b). In a study of compulsory DOTS clinics in Florida, Coreil *et al.* (2010) found that many of the Haitian migrants under the programme found the clinics comparable to being in prison, and found that both stigma and the prolonged absence from kin and the workforce enforced by the programme discouraged at-risk patients from seeking diagnosis and care. In post-Soviet Georgia, the monitoring of the DOTS protocol was described as 'more stereotypically Stalinist in its implementation than the former Soviet system' (Koch, 2013b, p. 90). Medical anthropologist Ian Harper has also argued that the rigid reporting structures of WHO's DOTS strategy meant that patients who do not fit into the patient categories defined by WHO were often denied access to treatment – the most severe and complex

cases of TB were excluded from care (Harper, 2010). Examples such as these suggest that standardized approaches to improving adherence can be counterproductive if they are implemented with a rigid or heavy handed approach.

The fundamental problem underlying many approaches to patient surveillance in TB control is that they are founded on two premises: namely that the therapeutic infidelity of patients is to blame for the persistence of TB worldwide, and that attempting to rigidly define and control patients will stem this problem. Medical anthropologist Paul Farmer has argued that attempts to account for the global spread of TB and its drug-resistant strains by pointing to the dispositions of individual patients amounts to 'immodest claims of causality' that do not address the true roots of disease and suffering (Farmer, 1999). For Farmer (1999), the prevalence of disease amongst the poor and marginalized represents the 'biological expression of social inequalities' (p. 262) whereby 'fundamentally social forces come to be embodied as biological events' (p. 14). By aiming to further understand the sociocultural and economic/structural factors that impact a patient's ability to complete treatment, targeted initiatives can be developed that offer comprehensive support to patients.

There has been a gradual shift in recent years, largely due to the criticisms above, from clinic-based DOTS to community-administered approaches, with community engagement now listed as one of the key points of WHO's StopTB strategy (World Health Organization, 2006, p. 15). 'Community-based' health initiatives have been adopted for decades, but the use of community health care in TB treatment has been slow to be included in WHO's approach. One prominent example of community-based treatment practices in contemporary TB control is the DOTS-plus model. Under the DOTS-plus model, a community health worker provides patient treatment support rather than a doctor or nurse, and care is generally brought to the patient rather than the patient needing to constantly return to the clinic. In addition, the DOTS-plus model incorporates a range of psychosocial, financial and structural supports to help patients both during treatment and after they are cured, such as assisting patients seek accommodation and employment after they have completed treatment (Shin *et al.*, 2004). Such an approach shifts the focus from being a punitive measure to enforce compliance towards a support structure to assist patients to complete treatment.

The community-based approach now advocated is a positive development, and illustrates a great deal of distance from the prison-like conditions of many sanatoria. However, community-based approaches to treatment and surveillance have attracted their own criticisms. Anthropologists Coral Wayland and Jerome Crowder (Wayland & Crowder, 2002) argued that WHO's current definition of community 'ultimately homogenizes what may be heterogeneous groups' by assuming that an aggregate of individuals in a given location will automatically share a 'form of social organization and cohesion...as well as interests and aspirations, including health' (pp. 232–233). This creates issues when, for instance, community health workers are of a higher caste than patients and are reluctant to assist patients in swallowing their tablets (Harper, 2006, p. 62). Nevertheless, continued attention and scrutiny may help ensure that community-based developments in therapy truly result in benefits for patients rather than merely being a palatable slogan.

DOTS is one example of TB surveillance; other scales of surveillance include the contact investigation of active TB cases (Fox *et al.*, 2013; Shah *et al.*, 2014), the molecular genotyping of TB to determine transmission networks (Sintchenko & Gilbert,

2007; Sintchenko *et al.*, 2007; Gallego *et al.*, 2010) and the border control practices of screening migrants for TB (Ho, 2003; Welshman & Bashford, 2006; Kehr, 2012; Reitmanova & Gustafson, 2012; Horner & Rule, 2013; Horner *et al.*, 2013; Warren, 2013). Surveillance has historical significance in many settings, particularly among vulnerable populations. With regards to TB among immigrant populations, anthropological research has moved the focus of attention away from a narrow concern with the country of birth, and towards a concern with the conditions of settlement and the circumstances that promote the reactivation of latent TB infection in migrant communities, including poverty and discrimination, life history and the experiences of migrants in transit and after arrival (Littleton *et al.*, 2008). While monitoring TB at the border is important, anthropologists have advocated that support for migrants, their social participation, access to health care and rights to freedom from discrimination are also key to reducing reactivation of TB (Park & Littleton, 2007). Applying a critical social and cultural lens to biosurveillance is necessary to ensure that important public health measures do not in the process compromise the dignity and well-being of sufferers themselves, and that the darkest elements of an Orwellian future are avoided.

Social practices

Stigma and taboo

The ways in which people react to illness or disease are strongly connected to broader social and cultural processes. Stigma is a useful concept to analyse some of the issues facing people with diseases such as TB. Sociologist Erving Goffman defined stigma as 'something unusual and bad' about someone (Goffman, 1963, p. 1). Stigma may also refer to 'any condition, attribute, trait, or behaviour that symbolically marks the bearer off as "culturally unacceptable" or inferior' (Williams, 1987, p. 136). Stigma, as these definitions make clear, carries a connotation of deviance. Certain signs, behavioural patterns and attributes are labelled 'deviant' and negatively regarded by society while others are labelled 'normal'. Deviance, which is 'deeply discrediting,' inversely defines the 'usualness' of normalcy (Goffman, 1963, p. 3). The social relationship between deviance and normalcy is crucial to comprehending stigma.

Despite the availability of an effective cure, TB patients experience strong social stigma in many parts of the world due to the 'discrediting' status they receive from family and community because of the illness (Courtwright & Turner, 2010; Juniarti & Evans, 2011). The close association between AIDS and TB in many parts of the world only serves to exacerbate social stigma. People go to great lengths to avoid an infected person (Somma *et al.*, 2008). When a person in a family is diagnosed with TB, she or he may be subjected to a form of social exclusion (Scambler, 1998); that is, the illness may encourage separations in familial and social relations (Johansson *et al.*, 2000). The effects of stigma can be unpredictable and can include shame and embarrassment, fear of or actual job loss, fear of contagion and social isolation (Getahun & Maher, 2000; Khan *et al.*, 2000; Somma *et al.*, 2008; Juniarti & Evans, 2011).

Most studies addressing stigma and TB seem to understand stigma based on the notion of a 'spoilt identity' of the TB patient. Seeing the affected person as the exclusive carrier of stigma, however, provides limited understanding of the multifaceted realities

of stigma. In examining the complex nature of stigma, one must also examine how it is situated in the social networks of stigmatized individuals, rather than (or only) in relation to the individuals themselves (Das, 2001, p. 1). Because the 'self' of an individual is not necessarily located in the individual body *per se*, but rather located in the person's cultural and social relations. For example, unequal gender relations may mean the experience of stigma by female TB patients is worse than their male counterparts (Long *et al.*, 1999; Karim *et al.*, 2007).

An examination of various social taboos that people with TB have to endure also contributes to understanding the synergistic effects of stigma and social situation. Studies conducted in Zambia, South Africa and Kenya show that family members maintain various social taboos such as not sharing food, kitchen utensils and beds with TB patients (Liefoghe *et al.*, 1997; Edginton *et al.*, 2002; Godfrey-Faussett *et al.*, 2002). In other words, dealing with the social ramifications of TB disease requires exploring local conceptualizations of TB and cultural interpretations of the illness (Nichter, 1994). The study of taboos, thus, allows us to gain insight into the social practices that accompany stigmatizing medical labels such as TB. Taboos, as Douglas (2002, p. xiii) illustrated, help to maintain social order by threatening specific dangers:

Taboo is a spontaneous coding practice which sets up a vocabulary of spatial limits and physical and verbal signals to hedge around vulnerable relations. ... Some of the dangers which follow on taboo-breaking spread harm indiscriminately on contact. Feared contagion extends the danger of a broken taboo to the whole community.

A cultural minefield of taboos can be opened up by the discrediting symptoms of active TB disease, which in some contexts may be strongly associated with physical contamination and unacceptable contagion. But dominant taboos can weaken over time (Chambers, 1960). Learning to understand the social basis of stigma and the social practice of taboos in any particular setting can help TB clinicians and researchers to navigate and contest the isolating social practices that impact negatively upon health-seeking behaviour and treatment compliance for a disease that is actually treatable and unnecessarily stigmatized.

Addressing the broader social and structural forces that shape the TB patient's experience of stigma will lead to positive transformations of TB care and prevention. Focusing only on the individuals can be limited and opportunistic; instead, developing new technologies and restructuring social organization can be effective strategies of stigma reduction. Addressing what individuals can do instead of what they cannot do allows us to shift health issues from being private problems to becoming public concerns. If we start addressing the practical barriers that restrict someone's inclusion in the community, then we are fundamentally questioning the structural violence against stigmatized people.

Gender

Tuberculosis control is a gender issue that has been neglected by the tuberculosis-control programmes. 'Gender' refers not only to the physiological differences between sexes but also to the variety of behaviours, expectations and roles that exist within a social, economic, and cultural context. (Diwan & Thorson, 1999)

Gender remains an area that has received inadequate attention in social studies of TB (Weiss *et al.*, 2008). Our social interactions with each other and the environment shape our knowledge and interpretation of gender. The social construction of gender can variably influence lifestyle factors, health-seeking behaviour and ultimately life chances. A consideration of the role of gender is important when addressing TB screening, diagnosis and treatment adherence. The responsibilities associated with specific gender roles prescribed by a society might place some individuals more at risk of contracting and developing TB, affect compliance to a lengthy treatment programme or restrict the willingness to produce sputum for diagnostic procedures. In differing circumstances, gender dynamics can impact upon life chances by making some individuals more vulnerable to disease exposure and other individuals at risk of non-compliance to treatment. Gender is thus an important consideration in mapping the distribution of health and illness in a population.

Although TB cases and deaths now disproportionately affect male populations globally, it has not always been so and is not the case in all settings. Regularly discordant with patterns of incidence, social fears about TB have led to moral and political discourses about women wearing corsets (Armus, 2011, pp. 161–173), riding bicycles (Strange, 2002, p. 613) and engaging in migrant domestic work both nationally (Gergely, 2004, p. 511) and internationally (Yeoh & Annadurai, 2008, pp. 549–550). Fears of TB have also compounded women's domestic duties in some settings (Armus, 2011, p. 156). Conversely, notions of the resilient male body have put men to work in high-risk settings such as coal mines, encouraged men to engage in high-risk behaviours such as alcohol and tobacco consumption that increase the risk of developing TB disease (Slama *et al.*, 2007; Lönnroth *et al.*, 2008) and urged men to dismiss symptoms until the disease reached a serious stage (Johansson *et al.*, 2000). Moralizing and politicizing gendered behaviour through the lens of TB has not been helpful to combating stigma nor has it increased participation in TB treatment programmes.

Tuberculosis is a major cause of death in men during their early and productive years; the impact on women has included risk of infection from their husbands (Durham, 1990, p. 352), making them widows who may be left solely responsible for finances (Helmbold, 1989, p. 46), exposed to social obstacles and unprotected from the inappropriate behaviour of other men (Goodman, 1998, p. 451). A study of health-seeking behaviour among Indian male and female TB patients in the capital of Maharashtra found that married men and single women experienced a greater level of family support to initiate and complete treatment (Nair *et al.*, 1997). Diagnosed with TB, men worried about loss of wages, financial difficulties, reduced capacity for work, poor job performance and the consequences of long absence from work, while women were faced with concerns about the reduced chances of marriage or rejection by their husband and harassment by in-laws in addition to their concerns about dismissal from work. Married women attempted to hide their disease condition for fear of desertion, rejection or blame. However, maintaining secrecy was difficult particularly when movement outside the home was subject to routine social monitoring. The pressures of housework and the strain of secrecy among women were significant obstacles to treatment adherence. Subsequent research in rural Maharashtra found similar trends (Atre *et al.*, 2009). Highly dichotomized gender roles throughout Maharashtra meant that a diagnosis of TB together with a patient's interaction with the local treatment

facility may be a severe challenge to socially acceptable gender practices and culturally assigned gender identities. Gender is part of a matrix of social relations that include age, marital and parental status among other relational characteristics. These concomitant considerations are important to understanding health-seeking behaviour and the agency of TB patients in diverse cultural contexts.

Men and women follow different pathways to seek diagnosis and treatment and in some settings these labyrinthine pathways can lead to a huge shortfall in the number of people who should be turning up at TB clinics. Worldwide, TB cases among men exceed those found in women by a ratio of 2:1. However, these global data conceal the local diversity of sex differences in TB rates. According to the notification rates reported by country in the 2013 WHO Global Tuberculosis Report, male-to-female ratios of TB can vary from 1:2 in Afghanistan, to 1:1 in Pakistan, to around 2:1 in India, and at its most extreme 3:1 in Vietnam. Comparing TB notification rates to TB prevalence data, however, reveals even more intriguing disparities. In Vietnam, for example, the national prevalence survey data from 2006–2007 indicate a male-to-female ratio of 5:1. If the prevalence survey data and notification rates are comparable, then this means that two out of every five Vietnamese men with TB are not reporting themselves to national tuberculosis programmes and are probably not receiving proper treatment. Visibly, male health-seeking behaviour in Vietnam contributes significantly to diagnostic delay and shortfalls in TB treatment. Unseen in these statistics is whether women might also be under-reporting to TB clinics. Interventions to reduce diagnostic delay and create more direct health-seeking pathways for men are likely to look quite different to those for women. Innovative ethnographic strategies to conduct participant observation with infectious patients need to be developed and implemented to address these issues thoroughly.

An explanation of disparities based solely on gender as a sociocultural determinant influencing access to TB care may be incomplete without an account of the biological determinant of sex (Ottmani & Uplekar, 2008). Tuberculosis researchers have identified an absence of information about sex-specific biological mechanisms that may account for sex differences in TB rates (Neyrolles & Quintana-Murci, 2009) and debated whether sex differences are an artefact of reporting bias, attributable to confounding variables such as co-infection or connected to variations in sex-specific disease progression from latent to active TB (Rhines, 2013). A systematic consideration of biological sex and the socially constructed aspects of gender is more than just determining the numbers of male and female TB cases. The sex distribution of notified TB cases is likely to result from diverse biological, social and cultural variables, including access to care, structural factors, ethnicity, the particular strain of TB and co-epidemics such as HIV/AIDS (Ottmani & Uplekar, 2008). Furthermore, while race, ethnicity and socioeconomic status feature almost automatically in epidemiological research studies about TB, diverse gender identities are rarely included as variables. Current epidemiological data about male and female TB provide quantitative statistics about two biologically defined categories, but documenting does not necessarily capture the relevance of social and cultural dimensions of gender for TB care and prevention (Weiss *et al.*, 2008). To broaden current models, anthropological fieldwork may interpret critically the qualitative experience of gender and how socially constructed and socially vulnerable gender roles influence agency, health seeking and treatment compliance. In the absence

of conclusive data about the biological predisposition to TB disease due to sex, TB policies and programmes should try to address the known obstacles created by gender norms, such as integrating flexible clinic hours to increase women's access to TB treatment services (Oshi *et al.*, 2014). Capturing epidemiological data about sex and ethnographic data about how gender is constructed, performed and challenged in the social spaces where TB diagnoses are revealed and concealed will lead to transformative health care practices that promote the social inclusion of all TB patients.

Agency or exigency

Agency

Agency is the capacity of an individual to exert influence over their environment by choosing their course of actions (Bandura, 2009). A useful model for conceptualizing human agency is Albert Bandura's Social Cognitive Theory (Bandura, 1997), which situates behavioural, environmental and personal factors in a relationship of reciprocal determinism. Understanding a patient's experience requires not only an observation of their behaviour (e.g. presentation for treatment, adherence to medication), environmental factors (e.g. social support structures, access to transport, exposure to a disease) and personal factors (e.g. knowledge of TB, expectations of treatment, belief about one's competence to manage treatment) but also consideration of how these three factors impact upon each other. Personal factors, specifically self-efficacy beliefs, are central to human agency and to the capacity to exercise control over one's life (Bandura, 1997). Bandura (1986, p. 391) defines self-efficacy beliefs as:

People's judgments of their capabilities to organize and execute courses of actions required to attain designated types of performances. [Self-efficacy] is concerned not with the skills one possesses but with judgments of what one can do with whatever skills one possesses.

The role of self-efficacy has been examined in a number of health areas including asthma, diabetes, hypertension and HIV (Ogedegbe *et al.*, 2003; Campbell *et al.*, 2006; Gerber *et al.*, 2006; Gleeson-Kreig, 2006; Sarkar *et al.*, 2006; Johnson *et al.*, 2007; Ngamvitroj & Kang, 2007; Erlen *et al.*, 2010; Dowse *et al.*, 2014). Studies have linked self-efficacy to various health promotion behaviours such as treatment and medication adherence for HIV (Ammassari *et al.*, 2002; Johnson *et al.*, 2007). A limited number of studies, which are reviewed here, have begun to examine self-efficacy among TB patients.

Adopting participant-observation methods and applying Social Cognitive Theory, Wyss and Alderman (2006) studied 23 Hispanic migrant farm-workers with LTBI. They examined environmental and personal factors that were barriers to screening participation, TB diagnosis and treatment completion. Environmental factors included financial status, long working hours, clinic not being open for evening hours, limited access to transport to visit the clinic and seasonal work requiring moving from location to location. Additional environmental factors focused on social domains including availability of health professionals, family support, co-workers and community members. The environmental barriers, long working hours and limited transport directly influenced health-seeking behaviour. Moreover, reduced self-efficacy for asking for additional support limited the individual's capacity to utilize available resources to

adhere to treatment. Implementing simple yet thoughtful measures, the clinic created an enabling environment. It opened two evenings a week and began running a bus service to pick up patients from the farm and take them to the clinic. Operationally conceptualizing the environmental and personal factors using Social Cognitive Theory offered effective solutions to increase patient attendance, adherence to medication and consequently treatment completion.

Further interventions in this case example would focus on personal factors (Wyss & Alderman, 2006). Educational activities could be utilized to increase health and disease knowledge and also target feelings of lack of control over the disease and self-efficacy beliefs. Knowledge creates the precondition for change but it is self-efficacy beliefs that play an integral role in personal change and health behaviours (Bandura, 1998). When people believe their actions may produce desired change, they are motivated and have an incentive to act and persevere in the face of challenges (Bandura, 1998). Wyss and Alderman (2006) greatly desired to empower the patients and reinforce to them that personal actions can affect their future. Later interventions utilized Spanish translators who accompanied patients on the bus and in the clinic to explain the process of health treatment and test results. Optimizing the time spent on the bus was aimed at increasing patient knowledge and possibly even self-efficacy beliefs to navigate the health system. The impact of self-efficacy beliefs was not directly measured or tested in this study.

Morisky and colleagues (2001) examined the role of self-efficacy beliefs and peer counselling in LTBI interventions with adolescents. Adolescents were randomized into four treatment groups: peer counselling, incentives from parents, combined peer counselling and parental incentives, or treatment as usual. Researchers investigated the contribution of self-efficacy for taking medication, general mastery beliefs (e.g. what happens to me in the future mostly depends on me) and self-esteem to predict medication adherence. Self-efficacy for taking medication was the strongest predictor for medication adherence. Regarding the effect of peer counselling vs incentives, the percentage of patients that completed treatment was highest for the combined group, followed by peer counselling, usual care and the incentives programme, but the differences were not statistically significant. However, peer counselling was significantly associated with higher self-efficacy and mastery scores for adolescents. Importantly, peer counselling was offered by 'models' who had previously successfully completed the TB treatment. Counselling was offered every 2 weeks and focused on encouraging medication adherence and helping patients problem-solve any challenges in completing treatment. Bandura highlighted modelling as one of the important mechanism for increasing self-efficacy. Understandably, the manipulation of an environmental factor, in this case offering a social support structure such as peer counselling, was associated with increased self-efficacy for taking medication, increased mastery beliefs and a greater sense of agency. Not only does Social Cognitive Theory offer predictors of health behaviour but also the mechanisms to increase and enhance relevant predictors, i.e. increasing self-efficacy via modelling procedures (Munro *et al.*, 2007).

Other studies have applied Social Cognitive Theory as a useful model to frame personal, behavioural and environmental factors in LTBI and TB treatment (Liefoghe *et al.*, 1999; Weildland *et al.*, 2013). Using a combination of participant-observation methods and broad conceptual frameworks, these studies led to useful interventions that enhanced the patient experience and led to more effective treatment delivery. Although many studies have

focused on measuring patient adherence factors it is also constructive to examine clinician TB knowledge and self-efficacy (see Benkert *et al.*, 2006). Recognizing that agency is distributed among a variety of social actors and environmental factors, holistic models can be used to create medical facilities where patients are not pathologized and treatment infrastructure is enabling.

Imperatives

Cultural values influence the imperatives of medical practitioners and patients. When, where and how bodily conditions are diagnosed and treated are all questions open to cultural influence. For example, personal comfort levels shaped by familiar cultural practices, socially sanctioned beliefs and historically propagated conceptualizations of the body may lead to a preference for diagnostic methods that use one kind of body sample, such as blood, over another, such as sputum, regardless of their relative accuracy. Cultural imperatives can strongly influence diagnostic and treatment decisions and should thus be questioned, because cultural imperatives sometimes lead people to follow measures that are unnecessary, discriminatory or possibly even harmful. Doctors and patients can be driven by technological imperatives, geographical imperatives and surgical imperatives to name but a few.

While surgical imperatives for TB became uncommon with the advent of antibiotic treatment (see Gillard, 2010), technological and geographical imperatives remain. A technological imperative refers to how patients and health professionals can feel strongly compelled to use available technology even when it is excessive, futile or detrimental (see Wolf & Berle, 1981). Using technology because it exists rather than because it is clinically necessary can lead to problems. In India, suboptimal tests are administered to diagnose TB because they are available, not because they are effective and recommended by the WHO (Bhargava *et al.*, 2011). In the absence of enforceable regulatory frameworks, the financial benefits enjoyed by various stakeholders, including the producers, distributors, laboratories and clinicians, help to keep such substandard products on the Indian market despite potentially disastrous consequences for patients. Attachment to particular technologies can become so strong that even when scientific evidence indicates that technologies are ineffectual, or even harmful, such evidence may be disregarded or strongly resisted. The implementation of technology is not simply driven by its efficacy but mediated by social, economic and political processes. The examination of these dimensions of health care technology is important because the adoption and application of technology is an intensely political and profitable activity. When technology is used regardless of whether it is useful, superfluous or injurious, the technological imperative needs to be assessed to ensure ethical, accurate and economically sound decisions.

In the case of TB, the consequences of the technological imperative are an important consideration because diagnosis relies upon the combination of symptomatology with radiology and laboratory testing. Diagnostic tools include smear microscopy, culture and molecular tests, each with their own strengths and weaknesses, and test sensitivity and specificity. An over-reliance on one diagnostic tool and the under-utilization of complementary diagnostic tools may result in anti-TB treatment being administered, or not administered (see Bhargava *et al.*, 2011). For example, using a diagnostic tool such

as GeneXpert as a screening method in the Mekong Delta might be a practical decision based on the geographical challenges of the region, but an over-reliance on this technology could potentially lead to a false-positive result from a sensitive and specific test for TB such as GeneXpert being trusted more than sputum-smear, X-ray results or symptomatology, which involve more subjective human observations. The illusion of objectivity in a test such as GeneXpert can also mean that clinicians forget that the process of sputum collection for testing is not uniform and can involve highly subjective interpretations in production methods and assessment. The difficulty of attaining outright objectivity in any medical test is further reason to critically examine the imperative to use one kind of intervention over another.

Imperatives surrounding technology do not simply relate to over-use and over-reliance. The use of medical technologies within hierarchical and authoritative social structures creates another type of imperative, where certain technologies are coveted by those in power or used discriminatively according to fixed and rigid protocols. The exclusive use of GeneXpert for HIV patients in some settings, for instance, can exclude other vulnerable populations from the benefits of this technology. Examining the technological imperative in TB control involves a thorough assessment of which populations are excluded as well as a rigorous evaluation of which technologies are favoured and which are discounted, which technologies are used and which are not, and which technologies receive support from influential players and which do not.

Geographical imperatives can lead patients to believe that they have to travel great distances before they can reach or earn effective cure. Travelling to sanatoria outside the cities of 19th and 20th century Europe was seen as a health pilgrimage by some and as enforced exile by others. Today, TB patients in rural areas of the developing world might see travel to big cities as offering greater access to reliable medical resources that evoke the image of modernity. Similarly, seeking to pay for medical treatment as opposed to using free services may be seen as preferable and more conducive to a successful health outcome. Economic imperatives can make some patients believe that they are not receiving optimal treatment if they are not paying for it. However, seeking private health care as opposed to public health care might be a misguided imperative in some contexts. In Vietnam, for example, the National Tuberculosis Programme boasted 86% treatment success for patients treated under DOTS as opposed to patients treated in unregulated private clinics in Ho Chi Minh City, who only achieved an average of 48% treatment success (Lönnroth, 2000). On the flipside of the geographical imperative to travel towards treatment can be the imperative of patients to travel away from places where they can infect others. The imperative of isolation distorts a patient's view of themselves, their feelings of shame and their experience of being stigmatized by others. Understanding the geographical and economic imperatives of patients can be used to create public health education and communication strategies that reduce stigma and orient patients towards effective treatment.

In the science laboratory, the momentum of medicalization can shape the imperatives of researchers to seek better diagnostic tools, more reliable biomarkers of disease to detect illness and track recovery, more effective vaccines to protect individuals and human populations using novel delivery methods, and cheaper, less toxic drugs that can be administered in lower doses over a shorter time period. However, too much emphasis on medical interventions can blind health specialists and funding organizations

to the importance of addressing the social conditions that foster the spread of TB disease; from the ability to mobilize existing medical interventions by developing better communications strategies; and from the need to adapt globally standardized approaches such as DOTS more cohesively with local operations.

By articulating medical imperatives, we can question them and orient TB control efforts towards well-balanced programmes. A dominant biomedical discourse drives the imperative of doctors to treat patients and the imperative of patients to seek treatment. But amidst a swirl of geographical, economic and technological imperatives, the question remains, which imperatives should be favoured? By proceeding from an imperative of ensuring social inclusion, health practitioners, health seekers and health researchers can embrace the ethical and practical factors that surround medical intervention. While economic factors are often prime considerations when determining which imperatives should be favoured, perhaps the most ethical imperative to keep in mind when dealing with TB is the imperative of social inclusion.

The liminal body

The availability of antimicrobial treatment for TB has extended the medical gaze to include people with a latent infection. Latent tuberculosis infection (LTBI) results from exposure to *Mycobacterium tuberculosis* but carries no symptoms, is not contagious and, in the majority of individuals, does not progress to disease. Nonetheless, people at risk of developing active TB disease, but not yet exhibiting symptoms, have been encouraged by medicalization to understand their bodies as sites of necessary sanitation.

Latent tuberculosis infection means that a person carries the microbes that, in high-risk individuals, can multiply and cause active TB disease. High-risk groups include people who are immunocompromised (e.g. HIV/AIDS patients) or using immunosuppressants (e.g. for organ transplantation, ankylosing spondylitis, Crohn's disease, rheumatoid arthritis, psoriasis or diabetes). Treating LTBI in these cases is a recommended preventative measure given the likelihood of developing active disease. However, these people only constitute a small subset of the total number of people with LTBI. The WHO estimates that 2 billion people worldwide have LTBI.

In her preface to the 2002 reprint of her seminal work *Purity and Danger*, Mary Douglas reflects on how the fear of pollution has come to dominate modern thinking: 'We became afraid of contamination of the air, water, oceans and food. The topic of risk had been sleeping quietly since the seventeenth-century interest in gaming probabilities. A new academic discipline emerged – risk analysis...' (Douglas, 2002, pp. xviii–xix). The case of treatment for LTBI in low-risk individuals demonstrates how fear of contamination has extended beyond the air, water, oceans and food of Douglas' imagining and into the deepest recesses of our bodies. Theories of attendant harm, according to Douglas, control threats to established classification systems. With regards to LTBI, the risk of impaired health bolsters biomedical classifications of the world. In societies where LTBI is a threat to the sanctity of human health, perfunctory rituals of purification sustain propriety, morality and the local consensus on how the world is categorized. If the rituals are not respected, the danger of impaired health and contagion persists. For some, treating LTBI is part of hygienic citizenship – a ritual cleansing process that acts as a rite of permission for re-entry into the world.

People diagnosed with LTBI are diagnosed as being ‘at risk’ of an illness without showing any signs or symptoms of disease. Being in a liminal state between health and illness, a person with LTBI could be conceptualized as having a liminal body (Mason, 2014). Treatments for LTBI are available but why would a person seek treatment for a curable disease they do not yet have? Treating LTBI might be preferable to waiting for active disease to potentially develop because, although most cases of TB are curable, TB symptomatology is obscure, diagnostic measures are not always accurate and the treatment is long and potentially hepatotoxic. Latent tuberculosis infection treatment is not without the possibility of adverse drug effects and some people refuse treatment because of their low risk of developing the disease, their apprehension about antibiotics, their personal or religious beliefs or their ongoing risk of TB exposure due to living or working conditions. Medicalization biases the liminal body towards the inclination to expunge infection even in low-risk individuals. In a liminal state between health and illness, the threshold to determine who is a patient is not always determined by the presence of active disease. Decision-making processes are swayed by cultural ideals. In many contexts, medicalization brings a set of specific obligations to the liminal body. Empowered by the ongoing commercialization of the body (Savard, 2013), medical imperatives can become the norm.

The situation becomes complicated when a person is suspected of being infected with multidrug-resistant or extensively-drug-resistant TB, but many questions are open to debate. Is someone with LTBI a patient? Is LTBI a category of illness? What are a person’s moral obligations to find out if they have LTBI? How does a diagnosis of LTBI affect someone’s social inclusion or workplace opportunities? What are the priorities of clinicians and public health specialists in dealing with LTBI? Latent tuberculosis infection and active tuberculosis are on a continuum. The threshold between latent tuberculosis infection and active tuberculosis is constructed by the choice of biomarkers used, the sensitivity and specificity of the diagnostic technologies available, the quality of the bodily sample produced and the subjective judgment of the doctor. Koch uses the word ‘threshold’ in a qualitative sense to talk about TB as a zone of contested practices where arrangements of resources, medical expertise, forms of illness and standards of biomedical response materialize through social, political and economic transformations (Koch, 2013a). Perhaps nowhere is this qualitative threshold more apparent than in the consideration of whether or not LTBI requires intervention. The differential sorting of groups by diagnostic categories, hygienic imperatives and stigmatizing labels has given rise to contested notions of illness and the question of which bodily conditions oblige medical intervention.

Conclusion

Agency, cultural imperatives, gender, history, the liminal body, medicalization, stigma, structural violence, surveillance, taboo and threshold with respect to TB incidence, research and treatment have been discussed. These concepts are a reminder of context, relational interactions and the biases in dominant discourses about TB. People exposed to *Mycobacterium tuberculosis* cannot be reduced to infected organisms that need antimicrobial cleansing. How a patient’s condition is understood and treated is framed by their local historical context. The surveillance measures used to detect and track illness

can be conducive or subversive to good health outcomes. More than just a physical condition, illness is a social category that relates to experiences of stigma, accompanying taboos and socially constructed gender roles. Cultural imperatives can moralize illness and create overbearing trends towards certain courses of actions. As medical solutions become increasingly successful in overcoming acute and chronic diseases, they start being applied to more liminal bodily conditions. In this regard, TB has been a powerful catalyst for the growth of medicalization. This article has discussed how stigma, taboos, gender practices, cultural imperatives, patterns of surveillance, historical forces and environmental features heterogeneously intersect with variable personal and behavioural factors to shape an individual's sense of agency. With a central concern for social inclusion, an integrative holistic framework is advocated, which challenges the structural conditions that sustain social stigma, gender discrimination, unquestioned cultural imperatives, unhelpful taboos, disruptive surveillance and historical oversights.

From the viewpoint that TB is not simply an object of concern but a site of contested practices (Koch 2011, 2013a), researchers and clinicians are invited to recognize that medical perspectives are one voice among many. A dominant biomedical discourse regularly leaves public health policy swayed by statistics, but we can easily forget that statistics, just like medical labels, play into social and political frameworks. As epidemiologist John Porter (2006) writes, 'Certain disciplines currently hold more weight within public health discussions and in particular when discussing "evidence-based practice".' This article has attempted to bring key concepts from the social model to bear on the problem of TB in order to encourage more balanced discussions and a space for researchers to share a common vocabulary. Taking a holistic view, the social model helps to see accountability as distributed rather than residing in any single part or agent of the system. Applying social science concepts to contemporary practices in TB clinics and research laboratories will not necessarily have a measurable, immediately quantifiable impact, but questioning our paradigms is a transformative process. Transformation is necessarily qualitative and it translates into the lived experiences of patients, health practitioners and biomedical researchers.

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