

From Exceptional to Liminal Subjects: Reconciling Tensions in the Politics of Tuberculosis and Migration

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Abstract Controlling the movement of potentially infectious bodies has been central to Australian immigration law. Nowhere is this more evident than in relation to tuberculosis (TB), which is named as a ground for refusal of a visa in the Australian context. In this paper, I critically examine the “will to knowledge” that this gives rise to. Drawing on a critical analysis of texts, including interviews with migrants diagnosed with TB and healthcare professionals engaged in their care (n=19), I argue that this focus on border policing, rather than resettlement and the broader social determinants of health that drive current rates of TB, paradoxically renders migrants diagnosed with TB as liminal subjects in the post-arrival phase. This raises ethical issues about who “matters,” as well as dilemmas about what constitutes adequate care for the “Other,” both of which go to the heart of the political economy of migration.

Keywords Tuberculosis · Migration · Equity · Health disparities · Social determinants of health · Surveillance

Situating an Epidemic

The burden of tuberculosis (TB), spread via the dispersion and inhalation of the *Mycobacterium tuberculosis*,

constitutes a global epidemic (World Health Organization 2015). In low- and middle-income countries, multidrug-resistant (MDR) and extensively drug-resistant (XDR) strains continue to present challenges for TB control, with the poor most affected (Abubakar et al. 2013; World Health Organization 2009). However, in many high-income countries, the burden of the disease is borne overwhelmingly by the overseas-born and specifically immigrants (Roche et al. 2008; Das, Baker, and Calder 2006; Cain et al. 2007).

In Australia, a national caseload analysis of 2007 data found that 86.4 per cent of reported cases occurred amongst the “overseas born” population (Barry, Konstantinos, and the National Tuberculosis Advisory Committee 2009), a trend supported by more recent data analyses (Toms et al. 2015). This mirrors epidemiologic trends in the differential distribution of TB between migrants and the native-born in the United Kingdom, Canada, New Zealand and, to a lesser extent, the United States (Cain et al. 2007; Das, Baker, and Calder 2006; Minion et al. 2013). Within the state of New South Wales, the epidemiology of TB has largely resembled the national trend. It is characterized by a rapid post-WWII decline, followed by a plateau in the number of overall cases since the late 1970s. Between 1975 and 1995, for instance, the ‘overseas-born’ proportion of cases increased from 30 percent to 79 percent (Heath et al. 1998), further increasing to 87 percent in 2010 (Roberts-Witteveen, Christensen, and McAnulty 2010, 175). Accordingly, the differential distribution of TB constitutes a disparity in health between immigrants and the native-born, insofar as it is “avoidable, unjust and unfair” (Whitehead 1992, 431).

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However, TB continues to be constructed as a “risk” to health that warrants pre-emptive measures prior to the arrival of immigrant bodies, largely through health screening and border control measures. Controlling the movement of bodies is a legitimate concern for nation states, but this raises questions about the extent to which the will to knowledge driving the enrolment of these technologies in border control manifests care for the “Other” in this case, namely immigrant bodies—the key focus of this paper.

This paper is structured as follows. In the opening section, I outline the ontological framework guiding the study and the methodology employed. I then critically discuss the findings of the study, including immigrants’ experiences of TB. Finally, I offer a discussion of the ethical implications of an overbearing focus on border control as a panacea for disease control, in light of the interrelated human rights norms concerning the right to health and non-discrimination.

Ontological Approach

This paper is underpinned by an approach informed by Discourse Theory, building on the work of Laclau, Mouffe, and others. A Discourse Theory approach seeks to situate specific practices, such as healthcare seeking practices, within broader regimes, which are understood as discourses, comprising the totality of our being (Horner 2014). From this purview, such practices are seen as the product of, and implicated in, relations of conflict and contestation, marked by antagonism, rather than arising from individual agency alone (Laclau and Mouffe 1985). Indeed, the radical constructivist orientation of Discourse Theory, in ontological terms, situates “the political,” or “that realm of antagonism and conflict inherent in everyday life” (Mouffe 2000, 101), as primary.

Through its insistence on the political as constitutive, this theoretical standpoint dissolves tensions between the supposedly material and discursive during the process of analysis (Horner 2014; Torfing 1999), situating discourse as decisive. In accordance with this ontological framework, a number of qualitative methods were adopted to inform this paper, including a genealogical analysis of the Australian border control regime, as well as an analysis of print media constructions of TB. Additionally, semi-structured interviews were conducted in a clinical setting with migrants diagnosed with TB

(n=14) and healthcare professionals engaged in their care (n=5). Ethics committee approval was granted (HREC/12/LPOOL/256) for this purpose.

Tuberculosis and the “Will to Knowledge”

Elevated rates of tuberculosis amongst the overseas-born, seen through the prism of governmental concern, have structured a particular “will to knowledge” about what is of paramount importance and, hence, which subjects matter most (Foucault 1994). A will to knowledge is characterized by

[t]he demarcation of a field of objects, by the definition of a legitimate perspective for a subject of knowledge, by the setting of norms for elaborating concepts and theories. Hence, each of them presupposes a play of prescriptions that govern exclusions and selections (Foucault 1994, 11).

This will to knowledge has implications for how TB is managed and has, as its focus, the prevention of the transmission of TB from immigrant bodies to the “Australian community”—a politically powerful referent (Horner and Rule 2013; Horner, Wood, and Kelly 2013). In 2013, for example, a report by an Australian Parliamentary Committee inquiry identified cross-border health risks as an emerging challenge to Australia’s health (House of Representatives Standing Committee on Health and Ageing 2013). This concern has been simultaneously evident in Australian print media coverage of TB, particularly in relation to drug-resistant forms of the disease; coverage that has emphasized the risk posed by porous borders in the Torres Strait treaty zone, for example (Parnell 2011; Elks 2011). A 2007 article that appeared in Australia’s national newspaper, *The Australian*, rendered these fears tangible, commenting:

A health crisis is looming in Australia’s far north, where thousands of Papuans have been crossing the Torres Strait to access medical services, bringing with them disease and spreading fears of an HIV outbreak (Parnell 2007, ¶1).

This particular will to knowledge, which has TB as its object but the “Australian community” as its key referent, has also envisioned and enrolled particular technological means to achieve this end, including

epidemiological analyses, as well as mechanisms for migrant health screening (Horner 2015). However, it unfurls within particular political-historical contexts. It should therefore be situated, as Laclau and Mouffe (1985) remind us, within a broader landscape of political antagonism. This includes the tensions engendered by invocations in political discourse(s) that immigrants are responsible for disease transmission, ranging from TB, to HIV, SARS, and, more recently, Ebola. These tensions become palpable when people are discriminated against, or identified as a source of disease because of *who* they are, particularly during times of crisis (King 2003). This reminds us that the will to knowledge, and the political discourse(s) it is implicated in, can have visceral effects on the bodies of specifically constituted subjects.

Against this backdrop of enduring disparities in health, and the particular will to knowledge, Gandy and Zumla (2003) have noted the pervasive tendency for TB treatment and “control” measures to be couched in the language of nationalism and xenophobia, rather than addressing structural factors, such as poverty, which have been shown to impact on the incidence of TB, as well as its prevalence within specific population groups (Rasanathan et al. 2011; Murray et al. 2013; Lonroth et al. 2009).

Indeed, as a result of the prevailing will to knowledge, even where TB policies identify specific populations that are affected by the disease, they often do not go further than naming these groups as a source of potential disease. The Australian national plan for TB control, for instance, states that “[t]he burden of TB in Australia will depend on future immigration policy, the control of TB in new arrivals, and the detection of TB as migrants age” (National Tuberculosis Advisory Committee 2012, 286). This particular construction of TB control as contingent primarily on migration and border policing reveals how entrenched this particular will to knowledge is in the Australian context and how other risk factors can be maligned.

Crystallizing a Will: Charting a History of Tuberculosis and “Othering” in Australia

The historical antecedents for this particular will to knowledge in tuberculosis lie in Australian political discourse, where the disease has long been associated with migration and contagion (Bashford 2010; Horner,

Wood, and Kelly 2013; Horner and Rule 2013). Throughout Australian history, TB has come to feature as an object of political concern, during both its endemic phase and once it was articulated as an “imported” disease (Bashford 2010). As recently as 2006 the notion of “TB importation” featured prominently in a federal election campaign and led to a comprehensive review of migrant health screening by the Australian National Audit Office (Horner and Rule 2013, 464). Quoted in major daily newspapers, former Australian political leader, Pauline Hanson, was reported to have remarked, in relation to the risk of TB transmission arising from the Torres Strait border crossing:

PNG [Papua New Guinea] has serious problems with AIDS, TB and other exotic diseases, and these sick people seeking medical treatment are coming into north Queensland from the western province of PNG where on a good day it is a quick trip in a motorised canoe (*The Courier-Mail* 2007, ¶4).

So strong has the precedent of TB been in Australian history that some of the more punitive, exclusionary, and stigmatizing responses mooted to HIV in the early 1980s, including mass screening, mandatory notification, detention, and quarantine, drew directly on the legacy of TB treatment regimes (Sendzvik 2003, 84, 94–95, 183). These mooted responses were, however, later jettisoned in favour of partnership models that entailed working with directly affected populations to tailor messages and approaches to prevention and treatment. The very invocation of such responses during public debate, however, indicates the salience of concerns over TB and the manner in which it evokes strong public memory. In this respect, the tendency in Australian political discourse to identify the figure of the migrant as a TB carrier is equally evident in the extant international literature on the politics of TB (Littleton et al. 2008; Reitmanova 2009; Craig 2007; Craddock 2008).

The tendency to identify the figure of the migrant as a TB carrier is also enshrined in migration law itself (Bashford and Power 2005). This carries implications for people who occupy the subject position(s) “immigrant” and particularly “non-citizen,” insofar as the law is performative—and identifies a threat that it necessitates constant vigilance against (Horner and Rule 2013), thus warranting a focus on immigrants as potential disease carriers. For example, Australian migration

law and regulations have long prescribed a “no excuses, no exceptions” policy insofar as TB is concerned, barring people with active TB from entry (Bashford and Power 2005). As Horner, Wood, and Kelly (2013) have noted, in an analysis of select cases concerning Australian migration law and TB, the use of legislative sanctions, including cancellation of visas and deportation, is not limited to offshore visa applicants seeking entry to Australia but extends to certain categories of persons who gain entry to Australia under specific circumstances. This results in an exclusive focus on what King (2003) has referred to as “the movement of bodies across borders” and not immediately following (re)settlement. As Horner and Rule argue, this focus

ultimately serves to (re)inscribe the problem, and foreground the “threat” of “immigrant TB,” absent any attempt to examine the complex ways in which this “threat” materialises in the lives of migrants themselves, who bear the greatest burden in terms of risk of exposure to TB and the actual incidence of the disease, whether through a new primary infection or reactivation, for instance (2013, 469).

The logic of border control as a panacea for disease control that arises from the prevailing will to knowledge concerning TB in the Australian context has been questioned by Denholm and McBryde who, on the basis of modelling, have presciently commented that “[p]ublic health strategies targeting latent tuberculosis infection in immigrants may substantially reduce tuberculosis incidence in a low prevalence region. However, immigration-focused strategies cannot achieve the 2050 MDG [Millennium Development Goals] and alternative or complementary approaches are required” (Denholm and McBryde 2014, 78).

Policing Immigrant Bodies—the Border, the Clinic, and the Community

In an era of increasingly diffuse border control practices, the will to knowledge concerning tuberculosis has particular implications at an everyday level (Horner 2015; Weber, Wilson, and Wise 2013). Increasingly, the monitoring of immigrant bodies extends beyond the border, to the clinic and the “Australian community” as a whole. Weber, Wilson, and Wise (2013) have termed these

“nodal cartographies” of immigration policing, reflecting shifts away from the notion of unified dividing lines as the basis for managing the presence of migrants in Australia. Medicare cards, which determine access to publicly funded healthcare services, referrals from other agencies, and interactions with police on occasion, including when someone is apprehended, thus become sites to assess a subject’s right to belong.

For example, Horner, Wood, and Kelly (2013) have examined how the policing of the migration health criteria in the Australian context extends beyond the realm of the airport as a site of entry. They argue that due to the performativity of migration law, and visa subclasses once migrants are physically inside Australian space, the reach of migration law, and indeed concern for controlling the movement of potentially infectious bodies, extends to educational providers, schools, hospitals, and other areas of public life where immigrants interact with members of the “Australian community” (Horner, Wood, and Kelly 2013). Drawing on case studies involving non-citizens with TB, they illustrate the way in which a diagnosis with TB can expose specific subjects to visa cancellation, specifically if they are found to be non-compliant with the law in other ways (such as failing to disclose it upon arrival, as they first enter Australia).

Immigrant Experience(s) of Tuberculosis: A Situated Account

But what of the people who occupy the subject-position immigrant, often legally designated as “non-citizens,” and who are diagnosed with TB in Australia? How are their experiences of illness registered in the midst of these discourses of TB that frame it as a threat and continue to implicitly problematize the “migrant with TB”? As Lupton (1999) has argued, there is a tendency to privilege the construction of discourse(s), whilst at the same time affording little attention to the manner in which specific subjects negotiate these discourses. This is the issue I address in this section.

Many of the participants I interviewed within the chest-clinic reported not encountering immigration-related barriers at all, owing primarily to their status as either long-term permanent residents or citizens. However, some participants, and particularly newer arrivals, reported social and financial factors that affected timely access to diagnosis, treatment, and care more broadly—

findings consistent with the international literature (Tomas et al. 2013). Participants attributed these factors to a number of issues including: (a) differences in exposure to TB and TB symptoms for local medical practitioners, in rare cases resulting in misdiagnosis and, in some cases, delayed diagnosis; (b) barriers in social care once they were diagnosed (particularly for the recent mothers I interviewed); and (c) out-of-pocket expenses arising from treatment adherence through directly observed therapy (DOT), which relies on presentation on-site for an extended period of time. Some of these barriers are undoubtedly experienced by others who are diagnosed with TB and who are navigating the healthcare system. One participant in this study, Winston, remarked that issues can arise in terms of transporting oneself to the clinic: “The only problem here is the parking spaces outside. Because if you don’t get a place to park your car, you get booked.” Another patient undergoing treatment for TB, Mariella, similarly remarked: “I have to get off at [an area] and get the train, and, you know, one time the trains were cancelled.”

For some, these issues were overlaid with experiences of TB-related stigma. Such experiences included managing the potential for adverse responses at an interpersonal level, including between friends, members of their own ethnic or national community in Australia, and the broader community. TB stigma here was embedded in what King (2003) terms “origin narratives,” which denote powerful tropes that attribute the presence of a disease to membership of a particular social group, in this case migrants. These origin narratives often become performative—shaping our disease imaginaries, including the manner in which migrants diagnosed with TB rationalized their diagnosis. A TB nurse, Sharon, remarked how this impacts on the lives of people with TB, asserting that

[s]ome feel there’s a stigma, because they still look at it as a dirty person’s disease. They think, where did I get it [TB] from? They say but my mom and dad don’t have it and we try and explain it’s not genetic.

For some participants diagnosed with TB, their concerns also centred on the manner in which TB was managed, particularly during initial presentation with symptoms, in healthcare settings outside of the confines of the dedicated chest-clinics in NSW, which all participants recounted provided high-quality, and non-

stigmatizing, care. For instance, Sarah, a migrant from Southern Africa living with TB and undergoing treatment, commented that the initial process of isolation in a hospital setting, and the lack of social and psychological support that followed, was both disconcerting and de-personalizing, because “[b]y the time you go in the ward all the other nurses are wary, you no longer have your name or your number—it’s TB.”

Sarah contrasted the level of support available to people diagnosed with TB to those diagnosed with HIV, the latter of which has pre- and post-test counselling, as well as a range of social support options available, particularly in the Australian context. Similarly, Sonal, a mother from India, remarked how difficult the experience of isolation was, with her limited social support base, which was compounded by her inability to have close contact with her children:

It’s really very difficult because my baby was not living with me and it was very tough time for me, that living without my baby. I used to meet recently only in hospital but still they are not allowed me to take—you know like, it’s like ... I had to just look at the baby through the door in the hospital.

These comments from participants highlight how migrants themselves, in the process of rationalizing their diagnosis, both reverted to, and privileged, explanations centred on demographic, rather than what Ho (2004) has termed “environmental,” risk factors, such as living or working conditions. Says Ho, in relation to the extant literature dominating the public health imaginary of TB:

[E]nvironmental considerations are not extended to immigrants, whose tuberculosis is regarded as the result of infection in their home countries rather than the product of high-risk environments in the US (2004, 757).

Paradoxically, whilst these people *are not* the concern of immigration authorities, it is often by virtue of being immigrants in the first instance that they encountered such barriers to timely diagnosis and early treatment, many of which are outside the ambit of their control. Nonetheless, all of the migrants I interviewed reported that they continued treatment and were on course to complete it. Some of these findings disrupt the proximal/distal distinction adopted in public health, which has been critiqued by scholars (Krieger 2008). They point to seemingly structural and intermediary

barriers, including institutional policies, or indeed assumptions of sameness arising from universalism, having an immediate impact on the lives of migrants diagnosed with TB, as they arguably do in the lives of others diagnosed with TB, albeit sometimes to differing degrees. Critically, however, they also mark a transition from an exceptional subject, and potential carrier of TB, when a person crosses a border, to a liminal subject of healthcare domestically, once people are within the border(s) of the nation-state.

Towards More Ethical Encounters: Tuberculosis Control in the (Re)Settlement Phase

It is clear that the will to knowledge concerning tuberculosis in Australia—at least through the prism of official regulation—results in an overbearing focus on border control as a panacea for stemming TB rates. Indeed, the management of TB across international borders poses significant challenges to nativist assumptions, namely: protecting “locals” from infection. Owing to its focus on protecting some, and its neglect of the social determinants of health—factors that impact on disparities in TB—this approach also delivers the least to those who stand to benefit most, namely the “overseas born” in many high-income countries. Instead, it arguably increases stigma, by associating the disease largely with migrants, and imposes obligations on officials to police this immigration edict (Kulane, Ahlberg, and Berggren 2010).

This reveals the operation of a visceral politics of who *counts* in Australia when it concerns TB—the “Australian community” (Casper and Moore 2009). This prevailing approach, engendered by a particular will to knowledge, manifests an example of what Krieger et al. have termed the “inverse hazard law,” denoting how the bodies of those most at risk receive the least attention, at least as *subjects* (Krieger et al. 2008, 1970).

As such, a new ethical engagement in the terrain of TB in these contexts is needed, one that carefully balances various interrelated human rights, such as the right to non-discrimination and health, and a concern for addressing TB. Such an approach is necessitated by the *International Covenant on Economic, Social and Cultural Rights* (ICESCR), which calls for the control of epidemic diseases through measures that protect the autonomy of the person, to the furthest possible extent.

For example, article 12.2(c) of the ICESCR imposes on state parties an obligation to take measures concerning “[t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases.”

But this requires moving beyond the provision of curative services alone and extends to addressing the underlying social determinants of health, which structure patterns of disease morbidity and mortality, as well as access to healthcare services within—and between—countries (Committee on Economic Social and Cultural Rights 2000). Yet it is these same underlying determinants that are frequently overlooked in many high-income countries (Rasanathan et al. 2011), where the epidemic is situated amongst migrants and the focus is on policing mobility, particularly across national borders (Horner, Wood, and Kelly 2013; Horner 2015; Kulane, Ahlberg, and Berggren 2010).

As a result of the provisions of the ICESCR, state parties have an obligation to ensure that legal and policy frameworks, as well as investment priorities, contribute to reducing disparities in the incidence of communicable disease, as well as the underlying inequities in the distribution of the social determinants of health, that drive these disparities. Critically, though, the right to health, particularly with regard to communicable diseases, also engages the related right to non-discrimination, by virtue of the persistent stigma and discrimination experienced by people diagnosed with TB.

How, then, might we strike such a balance in addressing disparities in TB in high-income countries, particularly given the nature of the will to knowledge concerning the disease in these same contexts?

Firstly, the involvement of members of affected populations is critical. Engaging with people directly affected by TB can yield important insights into barriers to diagnosis, circumstances that impact on timely access to treatment and care, and the realities of stigma at an everyday level—considerations central to drafting legislation, designing policy, and delivering services. The UN Special Rapporteur on the Right of Everyone to the Attainment of the Highest Standard of Health has commented, for instance:

The right to health further requires the participation of affected individuals and communities in all decision-making processes impacting their health during the formulation, implementation, monitoring and evaluation of health-related laws and policies (Grover 2013, 10).

We would do well to heed this call for direct engagement with affected populations in crafting more attentive responses to the tuberculosis epidemic; responses that must surely go beyond narrow ideas of border control as the ultimate panacea to control the spread of tuberculosis.

Secondly, consistent with the findings of successive studies, we should prioritize settlement support and healthcare access for migrants following (re)settlement, rather than focusing on detection of illness and disease through migrant health screening alone (Wickramage and Mosca 2014; Littleton et al. 2008). It is the (re)settlement phase, and particularly access to employment, adequate housing, and responsive primary and tertiary healthcare, that plays an important role in determining migrants' future health trajectories within countries, including in relation to communicable diseases such as TB (Lee, Kearns, and Friesen 2010; Asanin and Wilson 2008).

These twin factors, much of which remain within the remit of the healthcare system and the social services sector, engender the potential to provide greater support for, and engagement with, migrant experiences of TB than migrant health screening alone.

Conclusion

Discourses of tuberculosis in Australia, which suffuse both popular perceptions and public responses to the disease, continue to centre largely on the movement of bodies designated as infectious and posing a “risk” across national borders. However, few studies have examined the antecedents to this approach, or the “will to knowledge” undergirding it (Foucault 1994).

Situating seemingly “natural” differences in TB as a disparity in health between immigrants and the native-born in Australia, this paper has called into question pervasive discourses that privilege measures aimed at “controlling” the disease by policing the movement of immigrant bodies alone. Not only does this tendency, manifest through a specific will to knowledge, give rise to issues in terms of addressing a persistent disparity in health but it also engenders broader ethical issues concerning how immigrant bodies are constructed, treated, and fundamentally, who ultimately counts as a subject of concern in a given context (Casper and Moore 2009).

Engaging with TB, as a persistent disparity in health, I argue, thus entails reorienting our focus away from immigrant bodies as sources of disease towards a concern for engaging with members of populations directly affected by TB, as well as the broader determinants of disease. These determinants structure exposure to, activation of, and presentation with TB, and shape the treatment experience(s) of people diagnosed with the disease. Such a reorientation constitutes a new optic attuned to peoples lived experience(s) and is critical to dislodging the will to knowledge that currently privileges the health of other population groups, without reference to the needs of directly affected populations, who bear the burden of disease in any given context.

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