

BETTER HEALTH BRIEFING 44

Tuberculosis: looking beyond 'migrant' as a category to understand experience.

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Key Messages

- 1** Tuberculosis (TB) remains a significant public health issue globally. In the UK, the burden of disease is unequally distributed with immigrant populations and those from black and minority ethnic (BME) groups disproportionately affected.
- 2** Although compared with developing countries, rates of TB in England are low, they are higher than in many other European countries and the USA. In response to England's relatively high incidence of TB and with an aim to achieving the WHO target of reducing TB incidence by 50% by 2025, a national strategy was launched in 2015. This included the introduction of primary-care led systematic screening of recent immigrants from high TB incidence countries for latent TB infection (see <https://www.youtube.com/watch?v=tKwAHJ7JeV0> for a patient-friendly video).
- 3** Whilst England's national TB strategy attempts to improve access to TB services, a wider 'hostile environment' includes mechanisms that restrict access to healthcare and housing for migrant populations, which heightens the exposure rate of TB to those already most at-risk of TB.
- 4** Although TB, along with many other infectious conditions, is exempt from NHS charging, research shows that the perceived threat of charging, and specifically, the requirement to provide identification to access healthcare as well as the fear of deportation deter people from seeking help when they are unwell.
- 5** National surveillance data need to recognise the complexity of the migrant experience in order to generate a better understanding of ways in which health care can be improved amongst this population.
- 6** Healthcare providers and civil society must work together both to challenge and circumnavigate the current adverse conditions that migrants face accessing healthcare.

Introduction

The 24th March each year marks World TB Day - the date in 1882 on which Dr Robert Koch presented his famous paper that demonstrated that tuberculosis (TB) was not an inherited disease as some thought (Gerrish, Naisby & Ismail, 2012) but rather caused by a bacterium – *Mycobacterium tuberculosis*.

Globally, it is estimated that one in four people are infected with TB (Houben & Dodd, 2016). According to the World Health Organisation, TB kills more people than any other infectious disease worldwide, despite being completely treatable. In 2016 alone, 10.4 million people fell ill with TB disease and over 1.3 million people died (World Health Organisation, 2017). Whilst the number of cases of TB in the UK is relatively low, particular populations bear a disproportionate burden of disease (Public Health England, 2017a).

TB transmission

TB bacteria are transmitted in air-borne droplets expelled via, for example, coughing, from a person who has TB disease affecting their lungs or upper airways (TB Alert, 2018). TB can occur anywhere in the body but it is only infectious in those who have disease affecting the lungs or larynx. In England, just over 50% of cases occur in the lungs and are therefore potentially infectious (Public Health England, 2017a). After entering the lungs, the bacteria can spread to anywhere in the body via the blood and lymphatic systems. On encountering the immune system three things may happen: the immune system may clear the bacteria completely leaving no trace that the body has encountered TB, the individual may become unwell with TB (active TB); or the bacteria may enter a state of equilibrium with the immune system in which the person remains well and the bacteria remain present but 'dormant' – this is latent TB infection (LTBI) (Ernst, 2012). Individuals born or living in countries where TB is more common are more likely to have LTBI than those born in low incidence areas.

Latent TB infection

People who are well, with no previous history of TB disease, but who have immunological evidence of previous exposure to TB (such as a positive tuberculin skin test or a positive interferon gamma release assay blood test) are said to have

LTBI (Lalvani et al., 2001). When the balance between the dormant bacteria and the immune system is altered the bacteria start causing disease resulting in signs and symptoms of active TB: this is called reactivation. Approximately one in ten people with LTBI will go on to develop active TB in their lifetime (O’Garrra et al., 2013). Reactivation of LTBI is commonly associated with factors that impair the immune system such as diabetes, renal disease, pregnancy, the very young or very old and HIV. People with HIV are at particularly high risk of getting TB: approximately 15% of all new TB cases globally are co-infected with HIV (Kwan & Ernst, 2011).

Active TB disease

The classical symptoms of active TB disease include weight loss, fevers and drenching night sweats, and fatigue (CDC, 2003). Beyond these cardinal features, symptoms often reflect the site of the disease. When it affects the lungs, a cough, with or without the production of blood (haemoptysis), may be present. Pleural effusions (excess fluid between the lung and the lining of the lung) are common and may cause breathlessness. Although TB can affect any part of the body, other common sites of disease include: lymph nodes – which can present as swelling, commonly in the neck, central nervous system, bones, and visceral organs. Symptoms often develop insidiously over the course of weeks and months rather than days.

When people with active TB have difficulties accessing healthcare, diagnosis is delayed, contributing to a higher risk of disease transmission, worsening morbidity and mortality, and higher costs for both the patient and the NHS (Storla, Yimer, & Bjune, 2008; Leung, Leung, & Tam, 2007; Potter et al. 2015).

Social determinants of TB

TB has long been associated with poverty (Farmer, 1997; Suk, Manissero, Büscher & Semenza, 2009; Barr, Diez-Roux, Knirsch, & Pablos-Méndez, 2001). and conditions associated with poverty such as overcrowding, poor nutrition and lack of access to appropriate health services. It was improvements in these ‘social determinants of health’ (Dahlgren & Whitehead, 1993) that were responsible for the steady decline in mortality from TB in the early 1900s, well before the advent of a vaccine or effective antibiotic treatment. The benefit of such changes was even acknowledged at the time: In an address made at the 1909 Whitechapel Tuberculosis Exhibition in East

London, Rt Hon John Burns MP stated that TB “can be fought by many forces in many ways, led by general well-being, higher wages, cheap and abundant food, better housing [and] increased sobriety” (Burns, 1909).

Mortality risk further improved following the introduction of effective antibiotics in the mid- 20th century. By 1993 however, fuelled by the HIV epidemic and globalisation amongst other factors (Davies, 2000), TB was declared a global emergency (World Health Organisation, 1994). In high-income, low-TB burden countries the distribution of disease shifted with most cases occurring amongst migrants.

Particular health challenges are encountered throughout the migratory journey (Bhopal, 2007) and these differentially affect disease risk (Krieger, 2008). The ‘healthy migrant effect’ describes the fact that most migrants arrive at their destination in good health (Vissandjee, Desmeules, Cao, Abdool, & Kazanjian, 2004; Anikeeva et al., 2010). However, this advantage deteriorates after arrival (Abraído-Lanza, Chao, & Flórez, 2005). This is likely to occur because of stresses that accompany the experience of being a migrant such as those associated with the acculturation process (Bhuga, 2004), language barriers, employment struggles and lack of social support (Wilkinson & Marmot, 2003). In the case of TB, both direct transmission of active disease or reactivation of latent TB may be facilitated by the particular stressors and environmental conditions experienced during (Ho, 2003) and after the migration process (Ho, 2004). Thus migration in and of itself has recently been labelled as a social determinant of health (Davies, Basten, & Frattini, 2009; Fleischman, Willen, Davidovitch, & Mor, 2015; Dhavan, Dias, Creswell, & Weil, 2017) .

TB in the UK

In 2017 there were 5,137 cases of TB in the UK, 71% among the non UK-born population (Public Health England, 2017b). Countries of origin amongst foreign-born patients reflect both migrant flows and the global distribution of TB, with the highest numbers of cases amongst people from South Asia and Sub-Saharan Africa (Public Health England, 2017a). Evidence suggests these cases occur largely as a result of reactivation of latent infection originally acquired abroad rather than through recent transmission (Walker et al., 2014; Kruijshaar, Abubakar, HR, Pedrazzoli, & Lipman, 2013).

To reduce the number of individuals entering the UK with active, infectious TB, pre-entry screening is now undertaken for all those moving to the UK for 6 months or longer from a country with a TB incidence >40/100,000 population as part of the visa application process. A recent study demonstrated that those screened in this way “pose a negligible risk of onward transmission” but remain at increased risk of tuberculosis from reactivation of LTBI.

TB control strategies in the UK centre around three key principles: early diagnosis, effective treatment and preventative treatment for those at high risk (including both treatment for LTBI and vaccination) (Public Health England, 2015). In 2015 Public Health England and NHS England launched the joint national tuberculosis strategy with an aim of achieving a year on year reduction in TB incidence. The strategy highlights ten key areas for improvement including: access to services and early diagnosis; comprehensive contact tracing; improved BCG vaccination uptake; tackling TB in underserved populations; and the new entrant screening programme which is the only area to come with additional financial support (Public Health England, 2015).

Beyond the national TB strategy

Over the past 5 years successive governments have employed techniques to create a ‘hostile environment’ for those living in the UK illegally (Kirkup & Winnett, 2012). These strategies include restricting access to services that have an effect on a range of the social determinants of health for migrants and in particular are detrimental to TB control efforts (Removals & Instructions, 2018). For example, overcrowding is a known risk factor for TB transmission (Clark, Riben, & Nowgesic, 2002; Baker, Das, Venugopal, & Howden-Chapman, 2008). However, policies that restrict housing access for some migrants such as the ‘right to rent’ checks force vulnerable people into low budget, poorly maintained and often over-crowded accommodation. In relation to healthcare access, successive policy and legislative changes have reduced the number of people eligible for free NHS care and increased the mechanisms through which chargeable patients are identified (for a detailed overview and analysis see elsewhere (Potter, 2018)).

Furthermore, data sharing as part of the Memorandum of Understanding between the Home Office and NHS digital threatens healthcare access, comprehensive contact tracing, the ability to tackle TB in underserved populations and accurate

surveillance and monitoring systems (Potter, 2017). At the recent health committee hearing in parliament on this issue, evidence was presented that clearly demonstrates the threat of deportation deters people from seeking help when they are unwell (House of Commons, 2018).

Data sharing also threatens public trust in clinicians' ability to provide a confidential health service. Stigma is strongly associated with the experiences of TB patients and especially for migrants with TB (Boudioni, McLaren, Belling, & Woods, 2011); as such, fears surrounding confidentiality may further impede health-care access amongst this population. Data sharing therefore both undermines attempts at reducing diagnostic delay but also the potential effectiveness of the latent TB screening programme which is reliant on migrants registering with a Primary Care General Practice.

As part of the NHS Visitor and Migrant Cost Recovery Programme, on 23rd October 2017, upfront charging was introduced for those ineligible for free NHS care requiring non-urgent treatment. Whilst TB is exempt from such charges, routes to diagnosis are often circuitous (Abarca et al., 2013) and patients are not always aware of their rights (Poduval et al., 2015) (in the UK treatment by a GP and within A&E are free). Further, to determine eligibility, identification documents are required. This process may not only deter those fearful of deportation from seeking healthcare (Hacker, Anies, Folb, & Zallman, 2015) but also those who cannot easily access such documents like those who are homeless (Hiam & McKee, 2017). Furthermore, according to the Office for National Statistics, one in six people living in the UK do not currently have a passport (ONS, 2011).

The potential for these policies to harm was clearly documented in the case of Sylvester Marshall (originally given the pseudonym Albert Thompson) who was denied cancer treatment as it was deemed non-urgent by doctors and he could not pay the £54,000 bill upfront (Gentleman, 2018). In this particular case, Mr Marshall was not in fact chargeable for NHS care in the first place but struggled to prove it, like many others from the Windrush Generation who became caught up in 'hostile environment' policies.

Considering the effect of such policies on the diagnosis of TB, a recent study of over 2000 TB cases showed evidence of a significant association between the roll out of

the Visitor and Migrant Cost Recovery Programme and worsening delays in diagnosis amongst the non-UK born population in a high burden setting in London (Potter et al., 2017).

A better understanding of TB in migrants

UK-based research on health services accessibility amongst migrants has often considered the influence of ethnicity rather than other possible migrant classifications, such as why people migrate, how they migrate, where they migrate from, and immigration status in the destination country (Jayaweera, 2010). Although theoretically ethnicity might at least include where an individual migrates from, it is often poorly defined and, in cases where it is self-assessed, it is variably understood (Senior & Bhopal, 1994).

National data are collected on all TB cases but only include country of birth, year of entry to the UK and ethnicity. Data are then re-presented as non UK-born versus UK-born with incidence stratified by ethnicity. Prescribed ethnic groups mirror those used in the UK national census. This categorisation fails to account for the diversity of migratory experience amongst these populations, for example lumping in Italian-Bangladeshis who have spent much of their lives living in a low incidence country, some born in Italy, with Bangladeshis born in Bangladesh who move directly to the UK.

Globalisation has contributed to changing populations, and particularly those within cities, are becoming increasingly diverse. It is therefore vital to understand better the experiences of these 'superdiverse' (Vertovec, 2007) populations in order to evaluate disease risk and improve healthcare for 'at-risk' populations. In particular, more research is required to examine which variables would be useful to collect at a national level that would improve our understanding of TB diagnosis and treatment amongst migrants in the UK. As important, patients require confidence in handing over such data, and particularly, their immigration status which has already been demonstrated to have an effect on TB care (Heldal et al., 2008).

Conclusion

In the 21st century, despite being completely treatable, TB remains a disease of the marginalised, thriving in spaces where human rights have not been realised. Some

have argued (Reitmanova & Gustafson, 2012; Horner, 2016) that with an increased understanding of how TB is spread and the medicalisation of its treatment, strategies to rid the world of TB focus too heavily on control and surveillance, with underinvestment in mechanisms to improve the wider social and political determinants of TB (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2010)

The national TB strategy has laudable goals but its implementation is being challenged by anti-immigrant government policies that construct 'adverse conditions of care' (Kehr, 2012) for migrant TB patients in the UK. Although the risk of TB to the general public is currently low (Aldridge et al., 2016), diagnostic delay threatens the health and life of individuals infected with TB as well as heightens the exposure risk of others to the disease. Incidence will rise if we do not develop policies that benefit the public health of the entire nation, including those most vulnerable to TB and other infectious diseases.

We stand a far greater chance of designing effective policies once we start to examine disease-risk in general and the experience of migrant patients in particular with increasing granularity. We must leave behind "calcified"¹ epidemiological categories and find others that better reflect the experiences of modern, 'superdiverse' populations in which we live. Finally we must design policies that enable individuals to realise their right to healthcare and challenge those that do not.

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¹ Jenny Phillimore used the term calcification to describe stayed epidemiological categories in her key note address 'Superdiversity, population health and health care: opportunities and challenges in a changing world' at the 1st World Congress on Migration, Ethnicity, Race and Health, Edinburgh, May 17th 2018.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk



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