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INTRODUCTION TO SPECIAL ISSUE

Globalised tuberculosis control in local worlds

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Despite a steady global decline in the incidence of tuberculosis (TB), progress towards health targets has been slow and a crisis of drug-resistant strains of TB continues unabated. The United Nations high-level meeting on TB in September 2018 resulted in a renewed push to invest in drugs, diagnostics and vaccines to “reach” those most vulnerable to the disease. Yet, an overriding focus on biomedical technologies to manage TB at the expense of meaningful engagement with the social threatens to further consolidate its reputation as a “silent killer.” Drawing on anthropological contributions from South Africa and one from neighbouring Zimbabwe, this special issue explores how human action produces, shapes, names, experiences and resists the disease in its fullest breadth within local conditions. The articles recognise TB as a “global” object of biomedical knowledge and intervention, on the one hand, and as intricately tied to a legacy of colonial and apartheid governance, on the other. Each article deals with different aspects of understanding the interface between global and national policies and their unintended effects in local worlds.

**Keywords**: antimicrobial resistance; ethnography; global health; participatory methods; tuberculosis; South Africa

TB on the global stage



Figure 1: Silent Killer. Permission granted by artists Chris Moyce and Wayne Beukes, and commissioning funder, UCT’s ‘Swallowing the World’ project

TB is not a drama queen. It kills silently and slowly. Nevertheless, it”s an extremely effective killer. — Aaron Motsoaledi, South African Minister of Health, 2018

On September 26, 2018, heads of state gathered for the first ever United Nations (UN) high-level meeting on the global tuberculosis (TB) epidemic. While arguably no longer a “neglected” disease (see Parker and Allen 2012), TB had not until then generated the same level of urgency that previously propelled HIV and AIDS and, more recently, Ebola and antimicrobial resistance (AMR) onto the UN’s main stage. In fact, were it not for the persistent cajoling and nagging of Aaron Motsoaledi, South Africa’s Minister of Health, this historic meeting may not have taken place at all (Motsoaledi 2018). With the legacy of Nelson Mandela celebrated at the UN Peace Summit but two days before — himself a TB survivor and fierce advocate for TB control — the assembled members unanimously endorsed the first UN declaration on TB.

Although the declaration committed heads of state to a significant increase in expenditure (US$ 13 billion per annum for TB prevention and care by 2022), it was seemingly little different in kind to programmatic approaches that preceded it. In a powerful address, the UN Deputy Secretary-General Amina Mohammed stressed that TB and the proliferation of drug resistance are fuelled by “poverty, inequality, urbanisation, migration and conflict,” requiring an “all-systems approach that accounts for the social drivers that perpetuate its spread.” She went on to call for “a new way of working, beyond singular streams of work, beyond single disease-specific siloes, and single goals” (UN 2018). Yet for all the talk about systemic drivers and inhibitors at the meeting, the five “key asks”1 in the declaration remained highly biomedical in approach, focused on “reaching” “vulnerable” people with drugs, diagnostics and vaccines. Motsoaledi’s intention in bringing TB into the limelight was to undo its apparent power of silence (see epigraph). But without meaningful engagement with the social, this extension of biomedical technology might only further consolidate that power, ensuring that the proverbial tape (see cover image) — or, more literally, a facial mask (Abney 2018) — remains firmly over the mouths of the afflicted.

The “re-emergence” of TB

TB is, in many ways, the archetypal disease of poverty (Farmer 2000). The disease finds traction in exactly those spaces where life is most abject: cramped and overpopulated housing, lack of sanitation, mal- and under-nutrition, and syndemic interactions with other infectious diseases (Singer and Clair 2003). TB largely slipped beyond view in the industrialised nations of the global north following improvements in living conditions and the discovery of effective anti-TB drugs. Hopes of consigning TB to the history books dwindled in the 1990s following a recognition that TB was again on the rise in both high and low- and middle-income countries, increasingly in drug-resistant forms (Farmer 1997). However, the discourse of “re-emergence” neglected the fact that TB had never disappeared in the developing world (Packard 1989; Farmer 1997) where rates of the disease steadily rose in the decades following the discovery of antibiotics. In 1993, Hiroshi Nakajima, the World Health Organisation (WHO)’s director-general, finally declared TB a “global health emergency” (Lawn and Zumla 2011; Nakajima 1993).

Following the declaration of emergency, the WHO’s primary response to the epidemic was to advocate the worldwide implementation of directly observed therapy, short-course (DOTS), a complex system of treatment checks and balances that provided high cure rates for TB at a low cost. Focusing on five main elements and nine key operations DOTS included: 1. diagnosis by sputum smear microscopy; 2. standardised supervised treatment; 3. uninterrupted drug supply; and 4. recording and reporting system. Motivated by poor patient “adherence” and substandard public health interventions, DOTS was promoted by key actors in the WHO and the World Bank as the solution to TB control (Ogden, Walt, and Lush 2003, 180). It involved a transportable package of interventions built upon four key pillars: diagnosis by sputum smear microscopy of individuals presenting at public health facilities; standardised supervised treatment; an uninterrupted drug supply; and a recording and reporting system. A steady global uptake of DOTS TB control services followed in the ensuing years, facilitated in part by the development of national treatment programmes in many nations. Established on the recommendation of the WHO, these programmes were designed to implement the direct observation of treatment and reinforce other DOTS components. In 2006, under the guise of the WHO’s Stop TB strategy, DOTS was further expanded and refined to promote its continued scale-up, integration with broader health systems, and ability to manage complex forms of TB, such as HIV-TB co-infection and multidrug-resistant (MDR) TB. To the present day, the direct observation of standardised drug regimens remains the central component of the global TB response.

While DOTS and subsequent iterations have contributed to a reduction in the global TB incidence, this downward trend is highly partial, with efforts considerably less successful in addressing drug-resistant TB. Nonetheless, and still committed to the possibility of eliminating TB, the WHO’s ambitious End TB Strategy aims to reduce TB incidence by 80% and deaths by 90% between 2015 and 2030 (WHO 2015). Speaking of the modest progress made under the strategy thus far, Mohamed informed the delegates of the high-level UN meeting: “it has been uneven, it has been slow, and it is extremely fragile.” This comes shortly after the WHO’s latest Global TB Report stated that, in 2017, 10 million people developed TB globally and it killed 1.6 million people — more than 4 000 people each day. Additionally, only 25% of the estimated 558 000 drug-resistant (DR-TB) patients were treated, and only half of those had successful outcomes (WHO 2018). Motsoaledi’s drive to make TB the subject of a high-level meeting was borne of intimate experience with TB in South Africa and the clear insufficiency of approaches thus far. But how, despite being curable since the mid-twentieth century, does TB continue to resist its control? Now increasingly visible on the global stage, why does it continue to elude? How might this ancient yet eminently modern disease be better engaged?

Medical anthropologists have arguably been suggesting answers to these questions since the disease’s “re-emergence.” Paul Farmer, a particularly outspoken physician-anthropologist, has long contested the appropriateness of narrow, standardised treatment protocols to fix what is essentially a disease of poverty. Using ethnography, especially patients’ illness narratives, Farmer’s studies have shown that DOTS and attendant biomedical discourse narrowly frame TB and its treatment as a matter of individual “compliance” and “adherence,” obscuring structural determinants of TB and placing blame upon impoverished individuals for their own ill health (Farmer 1997, 2000, 2001, 2004). Ian Harper, also a trained physician, has built upon Farmer’s work by exploring numerous dimensions of TB control through his work in Nepal, such as the dangers of narrow case definitions (Harper 2006); tensions between “compliance” and drug resistance (Harper 2010); public-private partnerships (Ecks and Harper 2013); and the (anti)politics of the Global Fund for AIDS, TB and malaria (Taylor and Harper 2014). The work of Farmer, Harper and a growing number of other anthropologists (e.g., Das and Das 2007; Human 2011; Koch 2013a, 2013b; Hunleth 2017; Engel 2015; Dixon and Tameris 2018; Macdonald and Harper forthcoming) advocate for a broad understanding of the social that goes beyond the poverty of patients to the broader political-economic systems that fail to deliver adequate TB care. Such systemic factors include the preference in contemporary global health for narrow, vertical, technologically-driven disease programmes at the expense of comprehensive primary healthcare and intersectoral efforts (e.g., Biehl and Petryna 2013; Prince and Marsland 2014; Packard 2016). Yet, while implicating global processes, anthropological studies also show that effective, sustainable solutions must be tailored to the particular contexts and histories in which TB is entwined. This issue focuses primarily on South Africa, which has a long, turbulent history of racialised domination and control and, consequently, one of the world’s most severe TB burdens.

TB in South Africa

Packard’s (1989, xvi) influential history of TB in South Africa demonstrates powerfully how the disease is linked to “fundamental political and economic transformations that have been associated with the rise of industrial capitalism in South Africa,” particularly the rapid rise of the mining sector. The mining industry has long relied upon cheap migrant labour both from within and outside of South Africa. Workers are subjected to grim working and living conditions, and substandard access to healthcare, and are simply replaced when they develop disease (see Mutendi and Macdonald 2018; Ncube 2018). Among Packard’s (1989) most important observations is that the appearance of waxing and waning TB rates through the nineteenth and twentieth centuries was an illusion. Apparent drops in TB were merely the result of the disease being pushed beyond the visibility of medical statistics, as the non-white majority was systematically removed, relocated and excluded from urban centres and access to healthcare through successive colonial and apartheid regimes (see also Reynolds 2013).

Following the dismantling of apartheid, access to healthcare among those historically most deprived has improved alongside broader attempts to overturn centuries of racialised domination. Yet, patterns of exclusion have endured through the democratic transition and, indeed, despite hopes invested in a “new” South Africa, living and working circumstances have only worsened for many. The adoption of neoliberal macroeconomic policies; the rise of HIV and AIDS and the associated “knowledge wars” (Epstein 1999; Levine 2012); an overstretched, under-resourced and fragmented healthcare system (Coovadia et al. 2009; see also Dixon and Tameris 2018); accelerated labour migration; and numerous political and economic failures — these interlinked factors have conspired to keep over half the country below the national poverty line and engendered a larger and more complex burden of disease. A gradual decline in TB incidence in South Africa may reflect actual rather than fictive inroads into the epidemic unlike the earlier trends unmasked by Packard (1989). Yet, TB continues to cause more deaths than any other disease among the general population, and in 2017 there were an estimated 322 000 new TB infections in the country (WHO 2018). Additionally, there were over 16 000 laboratory-confirmed drug-resistant TB cases, including 747 extensively-drug-resistant (XDR) cases — not even considering the significant number that went undetected.

Concerned by the continued preference for narrow, targeted biomedical interventions, since 2010 medical anthropologists at the University of Cape Town led by Helen Macdonald have been researching TB in South and Southern Africa. Under the umbrella of the “Social Markers of TB” project, over 20 ethnographic projects have been conducted by a strong core of postgraduate anthropology students (Macdonald et al. 2016). Placing at the heart of their analyses the social modalities through which the disease is recognised, lived and made sense of, these ethnographic studies have made valuable contributions to understanding the TB epidemic as both a “global” object of biomedical knowledge and intervention, on the one hand, and as intricately tied to a legacy of apartheid governance, on the other. Themes explored include: connections between “dirt,” poverty and stigma (Abney 2011; Winterton 2010); the experiences of miners and migrants (Mutendi 2014, 2018; Ncube 2015; Macdonald and Mutendi 2017); disruptions to motherhood and childhood (Ndzendze 2012; Abney 2014; Schooling 2014); gang life and substance abuse (Versfeld 2017; Dixon 2017); interactions between food and treatment (Truyts 2013; Schmidt 2012); and the emergent role of clinical trials as sources of healthcare (Dixon 2017, 2018).

In addition to ethnography, Macdonald’s recent project, “Swallowing the World,” explores novel participatory methods for “giving voice” in ways that resist invoking imaginings of a “suffering stranger” (Butt 2002), through collaborations with photographers, graffiti artists, fashion designers, actors, scientists and TB patients. These efforts have begun to draw attention in the biomedical world. The entrance foyer of the Fifth South Africa TB Conference in Durban this year was graced by a photo exhibition by Chloë Shain in collaboration with research scientists (Shain 2016, 2017); each day of the conference was opened by poetry by Njabulo Cele and Dr Zolelwa Sifumba from the Aspiration collective2; and Macdonald gave a plenary address dressed in fashion created by Refiloe Gava’s “Wear Your TB” project.

The current special issue stems from and builds on this emerging body of anthropological and engaged scholarship. The contributors share the contention that an aetiological and pharmaceutically-driven approach to the treatment of TB masks the diverse variability in social, economic and political disturbances driving disease incidence. By neglecting the multiple forms of exclusion and the social and political precarities that make TB prosper, but treating those sickened by the disease, public health efforts to control TB amount to the “symptomatic treatment of a social disease” (Kehr 2016, 383). The works presented here represent the viewpoints of a multiplicity of figures within the social spheres of TB treatment, including patients and “high-risk” groups (Abney; Mutendi and Macdonald; Ncube; du Plessis, Tshefu and Nazier; Müller; Prah) and also, importantly, doctors, nurses and other health workers (Dixon and Tameris; Ehrlich, van de Water and Yassi). Each article deals with different aspects of understanding the interface between global and national policies and their unintended effects in local worlds. Together, they show how the social realities into which TB is absorbed can be so resistant to biomedical interventions and highlight the counterproductive outcomes that can result, such as drug resistance, the perpetuation of stigma, and further marginalisation of the afflicted.

Ethnographies of a silent killer

The opening article by Dixon and Tameris focuses on the experiences of nurses working in three public clinics in the Western Cape. After offering a historical overview of the major shifts that have occurred in the landscape of primary healthcare since 1994, the authors set out to understand why nurses often resort to practices of scolding and disciplining patients. The answer, they contend, lies in a fundamental dissonance between the discursive framing of healthcare relations (premised upon patient rights and responsibilities) and the material realities in which they must actually deliver care. For nurses, TB is experienced most sharply by an *absence*, with patients seemingly not coming to the clinic when sick and frequently “defaulting” on treatment. Scolding, the authors contend, needs to be understood not simply as “uncaring” but as a desperate attempt to stitch biomedical interventions onto impossibly turbulent social worlds. At the same time, it is through the work of these frontline agents of the state that constructions of unruly, irresponsible bodies are reproduced, deflecting attention away from the systemic failures that drive the spread of TB and DR-TB.

Taking a closer look at the kinds of marginalisation inadvertently produced by biomedical interventions, Abney focuses on TB patients and the N95 masks that they must wear whilst they are infectious. Using the notion of “containment” as theoretical lens, Abney shows that, while masks are designed to contain TB bacteria and prevent the spread of the disease, as social and material objects they also “contain” other properties. Drawing on prolonged ethnographic engagements with patients in Khayelitsha, Cape Town, she shows how masks “contain” stigma and when worn instigate a process of “losing face.” Losing face, Abney shows, refers at once to the literal swallowing of the face by these large, ominous-looking masks and also an embodied process in which mask wearers experience a profound loss of self and social status. This serves to undermine the preventative value of masks as patients, understandably, often do not wear them, particularly in social situations where mask-wearing might provoke scorn or aggression.

Mutendi and Macdonald’s article shifts attention to the mines in the north of the country — the cornerstone of the South African economy and home to the highest rates of TB in the world. Based on fieldwork in two mineworker communities, the authors demonstrate that miners understand TB not in terms of biological causative agents but rather in terms of conditions of life working underground. The metaphors evoked by their respondents to understand the impact of TB on their lives — notably “dust” and “we are like bubble gum” — constitute a powerful critique of the capitalist relations of production in which they are caught. Sent underground, chewed up and spat back out when they have lost their “flavour,” miners see TB as an often inevitable outcome of living precariously as eminently disposable tools of the mining industry. Mutendi and Macdonald’s analysis serves as a stark reminder that the political economic inequities implicated by Packard (1989) as driving the TB epidemic in South Africa have not been redressed and, consequently, TB is more rampant than ever.

Ncube’s article powerfully demonstrates the consequences of migrant living amidst South Africa’s TB epidemic on the families of migrants back home, in this case in Matabeleland South, Zimbabwe. Ncube’s analysis focuses on a deeply unsettling phenomenon in which families, dependent on remittances from South Africa due to economic hardship in Zimbabwe, find that it is not only money and goods that are sent home. With migrants in the diaspora finding that not all is golden in the “City of Gold” (colloquial name for Johannesburg since the Gold Rush), they and their children often live in precisely the conditions under which TB thrives. In the event that they, or their children, get sick, the latter are often “posted home” via *omalayitsha* [informal couriers] alongside, or instead of, anticipated remissions. Ncube therefore highlights the insidious capitalist processes through which TB is transmitted across borders and the complex burden of care engendered as a result.

While miners and migrants are especially high-risk groups, Ehrlich, van de Water and Yassi’s article reminds us that health workers are also highly vulnerable to infection, experiencing higher rates of TB and especially DR-TB than the general population. Drawing on previous research and the voices of health workers, Ehrlich, van de Water and Yassi show that, while TB is recognised as an occupational disease with various rights and protections afforded to health workers, insufficiencies in the system have resulted in a situation in which health workers are often unaware of their rights and, if diagnosed with TB, fear a lack of confidentiality and abandonment by the system and colleagues. Diagnosed health workers are therefore often reluctant to disclose their status, contributing to an under-counting of TB and the multiple layers of silence in which the disease is shrouded. Along with Dixon and Tameris’ article, Ehrlich, van de Water and Yassi show that health workers are subjected to numerous forms of structural violence in their professional lives, which has often been neglected in anthropological work on TB that has tended to prioritise the suffering of lay people (see Ecks and Harper 2013).

Aiming to unsettle

The remaining articles share a vision of “working in and out of disciplines” with participatory methods. As scholars of TB, we are attempting to ask new questions, push new boundaries and develop new tools to address South Africa’s TB epidemic. Carina Truyts, one of the many researchers who have contributed to “Swallowing the World,” took as a starting point a line from Salman Rushdie’s seminal novel *Midnight’s Children*: “To understand just one life, you have to swallow the world” (Rushdie 1981, 109; see Truyts 2013). In the novel, Rushdie’s narrative inscribes India’s history onto the body of protagonist Sinai. In an effort to gain understanding of the multifaceted context and thread of experience that pours life into man and country, Rushdie (and Truyts) choose to invoke the verb of swallowing (to ingest, to take in and absorb) as the main vehicle for understanding. As an airborne disease, TB can only ever be breathed/swallowed into the body. To swallow a person’s life also mirrors the process of ethnographic fieldwork, where information comes in disjointed bits and pieces which are slowly brought into meaning through long term sustained participant observation or “deep hanging out.” In turn, we invite audiences to “swallow” the final articles and in the process become a site for academic transformation.

In the White Paper for the Transformation of Higher Education (South Africa, Department of Education 1997), the type of academic engagement termed “responsiveness to societal interests and needs” is considered as one of the three roles of a university, and one which should be fully integrated with mainstream teaching and research. Twenty years after the release of the 1997 White Paper, questions still remain about the nature and extent to which higher education institutions have responded to the call to avail their “expertise and resources” to meet the challenges of local communities and constituencies through community engagement. Given the renewed calls for the transformation, especially from student-led activism, South African scholars are beginning to ask: “What might an anthropology that shifts the relationship for the university from one of vertical paternalism to horizontal collaboration look like?”

Efua Prah, known for using the expressive, revealing quality of theatre to produce ethnographic accounts of children’s experiences (see, for example, Prah 2013), was well placed to interview Australian scholar Paul Mason on his educational book, *Phuong and An go to the Doctor* (Mason 2016). Using an online crowd-funding platform, the book was published in Vietnamese and distributed throughout the province of Ca Mau. Currently published in 30 different languages, Mason shows scholars that it is possible to step outside the ivory tower of the university (with limited resources) to question for whom it is that academics write. If we want to reach people who are not already in the conversation, we should be able to explain it to anyone.

Pieter du Plessis (2017) used his honours research to work closely with undergraduate photographer Siv Tshefu and in consultation with research participant Flavia Nazier to bring Flavia’s experience with TB to life through their collaborative photo essay. As someone who identifies as a transgender sex worker, Flavia desires to be “made human.” Their piece avoids visually documenting inequality, discrimination and violence surrounding TB stigma (crucial in its own right) that can inadvertently produce unintended invisibility (see Butt 2002). Alex Müller responds to their photo essay by welcoming Flavia’s “staring back” to render legible her rich and complex world. In her concluding comments, Müller states that work of this kind “might be even more important for the health sciences, where imaginings of powerless patients abound, and stories highlighting patients’ agency and tenacity are hard to come by.”

To return to Aaron Motsoaledi’s opening quote and its linkages to the beautiful images photographed by Siv Tshefu, TB is an extremely effective killer and kills silently and slowly. Nevertheless, we can and must bring drama and insights from the humanities and social sciences to bear on TB. Chris Moyce and Wayne Beukes’ live-art performance as part of the “Swallowing the World” project pulled pedestrians in from all walks of life — young and old — to talk about TB. Their graffiti did not stand alone because, alongside it, were displayed the projects of graduate students that beautifully articulated the experiences of TB patients in our South African context. Children provided a platform to join the conversation with their own graffiti performance. Anthropologists have an important role to play in engaging this “modern plague” (Farmer 2001). We must prise off the tape so that it no longer continues to evade, elude and kill in the shadows.

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Notes

1. The “Key Asks,” the priority actions demanded by a resolution, include priority targets under five key themes: reach all people by closing the gaps on TB diagnosis, treatment and prevention; transform the TB response to be equitable, rights-based and people-centred; accelerate development of essential new tools to end TB; invest the funds necessary to end TB; and commit to decisive and accountable global leadership, including regular UN reporting and review.
2. In July 2017, the *Aspiration: Journeying with TB* collective launched their applied and interactive theatre piece using multi-media, poetry, body maps, photos and life stories. This was facilitated and performed by Pam Sykes and Louise Westerhout together with TB activists and survivors Zolelwa Sifumba, Pat Bond and BoyBoy Solomzi.

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