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Persistent pathogen: A conference report of anthropological research on tuberculosis

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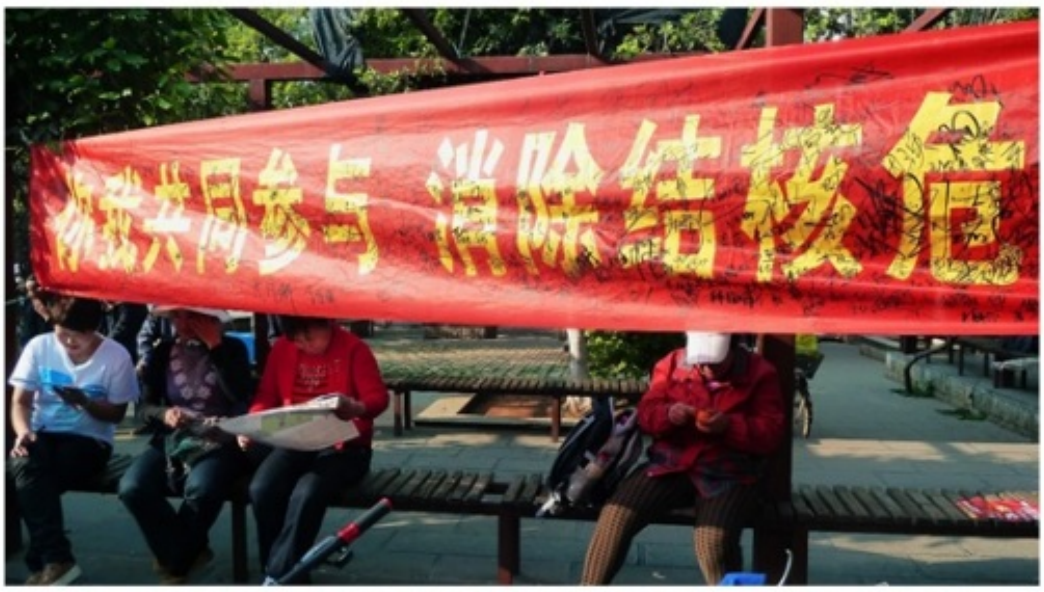
By Emilio Dirlikov



"You and me participating together, let's eliminate the threat of tuberculosis."
2013 World Health Day community outreach activities in Kunming, China
Photo credit: E Dirlikov

The 2013 World TB Day theme was “Stop TB in my lifetime,” calling attention to both the goal of virtually eliminating tuberculosis (TB) by 2050, as well as the Stop TB Partnership, established in 2000, through which global antituberculosis activities are coordinated. Despite this valiant slogan, tuberculosis control is at an important crossroads. In 2012, there were an estimated 8.6 million incident cases of TB, of which approximately three million went undiagnosed (World Health Organization 2013a). That year, 1.3 million deaths were caused by TB (World Health Organization 2013b). Beyond health, TB continues to stymie productivity and negatively impact economic development (Jamison et al. 2013). Challenges such as increasingly drug-resistant strains, co-infection with HIV, and unsustainable funding structures threaten the gains made towards the Millennium Development Goals (MDGs) targets set for 2015 (Dye et al. 2013).

Despite its epidemiological and economic significance, TB has garnered scant anthropological attention, although a few notable exceptions bear mention. Erin Koch has examined the implementation of the DOTS

strategy in post-socialist Georgia (Koch 2006, 2011, 2013a, b). The physician-anthropologists of Partners in Health (PIH), such as Paul Farmer and Salmaan Keshavjee, have used anthropological insights from their work in places like Haiti, Peru, Tajikistan, and Russia to create and advocate for better treatment programs (Farmer 1997, 2001, Keshavjee et al. 2008, Keshavjee et al. 2011). Ian Harper's work on control efforts in Nepal has come through long-term support of program implementation (Harper 2006, 2010). Recently, anthropological interest on TB in a diversity of contexts around the world has notably increased. This trend has been buoyed by several doctoral projects, as well as Master-level research.

In order to bring together this burgeoning group of anthropologists, Ian Harper (University of Edinburgh) and Helen MacDonald (University of Capetown) formed a panel entitled "Infectious disease and wealth: exploring the links between tuberculosis and the political economy," for the 2014 United Kingdom Association for Social Anthropology (UK ASA) conference, held from June 19-22. Panelists were asked to move beyond a simple linkage between social inequality, poverty, and TB in order to address:

> "To what extent do or can attempts to control tuberculosis address the issues of underlying poverty around which the disease flourishes? How has the focus on drug treatments overshadowed other ways of addressing the control of the disease and what are the implications of this? What role does anthropology have in thinking about the relations between culture and economy with regards to tuberculosis, and how might these insights be important for policy and practice in the control of the disease?"

Here, I reflect on the full day of presentations in order to synthesize insights and distill the major themes that emerged from the conference papers. I focus on four themes:

1) Emphasis on History;

2) Importance of the Local;

3) Impact of the Global; and

4) Opportunities for Collaborations.

These themes were cross-cutting, and many of the panelists touched upon elements of all four in their presentation.

Theme I: Emphasis on History

Tuberculosis lends itself to taking a *longue durée* perspective in order to understand the impact of this ancient scourge on the contemporary. As opposed to historians of science and medicine, who have produced histories of TB in various contexts (e.g., Condrau and Michael 2010, Johnston 1995, Bryder 1988), anthropologists require a different relationship with historical antecedents, conditioned by encounters made possible through fieldwork.

For example, **Bharat Venkat (Princeton University)** moved between past and present, recounting the history of the pivotal 1950s Madras Study, which shifted the treatment paradigm away from the sanatorium to out-patient care, through an interview with Dr. Radhakrishna, one of the study's key statisticians (Tuberculosis Chemotherapy Centre 1959, Ramakrishnan et al. 1961). Venkat argued that the logic of the study was an attempt to move from "the unknowable temporality of the cure to the predictable future of the cure rate." ?Yet the enduring promise of the cure, like all promises, is fragile because of the twinned possibilities of? resistance and relapse.

In my presentation, I examined what I term the "price of free" in China—that is, the price of TB diagnosis and treatment despite current government programs that provide these services free of charge. Though the high costs patients reported could be interpreted as a major failure of the national program, I contextualized present control practices into a history of TB as the social disease. I argued that Chinese government policies instituted since 2000, such as the TB double free program and welfare reforms more generally, signal the emergence of a truly nationalized problem of tuberculosis in China, in terms of both scale and conceptual underpinnings.

Theme II: Importance of the Local

Tuberculosis continues to be a disease associated with poverty, as borne out by statistics. At the global level, TB is disproportionately found in low– and middle-income countries (LMICs). At the national level, TB proliferates along the fault lines of society, appearing primarily in disenfranchised communities, such as the poor, homeless, prisoners, minorities, immigrants, and indigenous groups (Lönnroth et al. 2010). In line with anthropology's commitment to document social suffering and the experiences of the subaltern, panelists provided insightful accounts of at

risk groups and patient perspectives that might be missed by other disciplines.

Drawing from research conducted in Mumbai, Ramila Bisht (Jawaharlal Nehru University) examined the risk of TB faced by healthcare workers. While media reports highlight doctors' risk, she reveals that lower level healthcare workers, such as nurses, maintenance staff, and NGO outreach workers, are often more at risk, chancing exposure to TB out of fear of losing their jobs. Bisht advocates accounting for the health system as a whole in addressing the vulnerable situations all health workers who interact with TB patient find themselves confronting.

Working from Bilaspur district of Chhattisgarh state in central India, **Helen MacDonald (University of Capetown)** investigated the revealing and concealing power of numbers. She juxtaposed the deluge of statistics used in public health reports and media reports to more experiential understandings held by doctors at *Jan Swasthya Sahyog*, a non-profit organisation that treats TB patients. These doctors produced new metrics, which included body weight among other socioeconomic measures, in order to increase patient adherence and lower default rate. Such expanded metrics fit within a unique form of "care" and "empathy" not captured by state statistics.

Carina Truyts (University of Capetown) broadened the scope to consider the lived experience of TB patients in the suburbs of Cape Flats, South Africa. Her focus on the everyday was accompanied by a theoretical and methodological attention to the violence suffered by patients. This included the use of photographs and drawings made by patients in order to capture the unspoken or unsayable and avoid the potential violence of submitting patients to straight-forward interviews. Truyts concludes that the daily hardships experience by TB patients were compounded by structural inequalities that perpetuated cycles of violence.

Panelists faced the challenge of addressing macro processes that impact the TB epidemic while also attending to individual practices that facilitate transmission and activation of disease. In attempting to overcome this divide, **Oriana Bras (Universidade de Lisboa)** explored the social dimensions of TB in Rio de Janeiro at three distinct levels: structural, collective, and individual. Drawing on ethnographic examples, she illustrated that attention at each of these levels renders different problems and solutions. Combined, they offer a more robust, holistic approach to breaking the pathways through which the bacteria promulgates.

Theme III: Impact of the Global

In 1993, WHO Director-General Hiroshi Nakajima declared a “Global TB Emergency,” reviving attention to a disease that had largely fallen off the global agenda (Nakajima 1993). Since then, new antituberculosis organizations have proliferated, many of which work on a global scale. Several panelists positioned their research to investigate such organizations and accompanying global processes.

Presenting via Skype, **Nora Engel (Maastricht University)** outlined the difficulties of introducing newly developed TB diagnostics at points-of-care, with particular reference to India. She argued that although developers focus on the simplicity of diagnostic tests in order to maximize their applicability, paradoxically, this simplicity mutes the complexity of the situation at the primary health level. Engel proposes a greater inclusion of local expertise in the development and implementation of new technologies.

Ian Harper (University of Edinburgh) examined the modalities of financing mechanisms introduced by the Global Fund to fight AIDS, TB, and Malaria (Global Fund), focused on programs conducted in Nepal since 2002. He explained how under the Global Fund, new metrics have shifted the focus from program impact to program targets. While such metrics are designed to promote program efficiency and transparency, on the ground, the new modality for gathering data is not always productive and may create conflict within established local bureaucracies.

Justin Dixon (Durham University) presented the case of a long-term clinical trial of a new TB vaccine being carried out in South Africa. While the new vaccine has recently been shown to confer no added protection over the current vaccine, BCG, through the trial close to 3,000 underserved children were provided healthcare services. Dixon highlighted the relational and ethical predicaments of conducting clinical trials, especially in considering the legacy of inequality and structure of power that gives rise to TB.

Curiously, the geographic focus of presented papers may further reflect a destabilization of the old centers of “the global” by drawing attention to the growing significance of the BRICS countries (i.e., Brazil, Russia, India, China, and South Africa). BRICS are important for TB global control for at least three reasons. First, all five countries are part of the 22 designated high-burden countries (HBCs), and combined account for 46% of incident cases of TB, and 40% of global mortality (Creswell et al. 2014). Controlling TB in these countries thus impacts global progress. Second, individually, BRICS countries have historically championed innovative health programs, at times going against established norms and global paradigms. While challenges to health remain (Marten et al. 2014, Rao et al. 2014, McKee et al. 2014), novel strategies and technologies developed in these countries

could be used elsewhere. Finally, since July 2011, BRICS' Health Ministers have produced five joint communiques and one declaration on shared health challenges, and propose areas of collaboration. The January 11th 2013 meeting of the Ministers galvanized a commitment to combat TB, with a focus on multidrug-resistant (MDR) forms, demonstrating high-level political commitment (BRICS Health Ministers 2013). Anthropological research conducted in BRICS countries, such as the panelists' working in Brazil, India, China, and South Africa, sheds light on the shifting importance of these countries for global TB control.

Theme IV: Opportunities for Collaborations

"How can anthropology be useful to overcoming inequalities [that give rise to TB] and to identify new intervention strategies to eradicate TB?," asked Elisa Vasconi (L'Università di Siena). She posited: "the role of anthropology should go beyond the study of local knowledge and practice to stand to be a tool of political critique and transformative action." Using long-term ethnographic fieldwork conducted in Ghana's rural Western Region, Vasconi explored an innovative TB control program that made use of traditional medical practitioners for service delivery. Yet, which practitioners were employed, how they were trained, and issues that emerged in diagnosis and treatment present challenges to the success of control efforts. Ethnographic research, such as Vasconi's, reveals these difficulties, providing insights that could be addressed through policy reform.

Vasconi was not alone in her search for the broader applicability of anthropological research. Indeed, most of the panelists conducted research through affiliations with antituberculosis health organizations, ranging from the global scale (i.e., Harper with the Global Fund, Engel with the Gates Foundation, Dixon with an international pharmaceutical company, and I worked with WHO and Family Health International 360), local hospitals (i.e., Bisht in Mumbai and Bras in Rio de Janeiro), and local NGOs (i.e., MacDonald in Bilaspur district, Bisht in Mumbai, and Truyst in Cape Flats). In effect, panelists shared a commitment to going beyond isolated anthropological investigations in order to collaborate with public health experts and policy makers towards improved programs and patient outcomes.

Harper's work highlights the value of productive collaboration beyond the academy. Previously, he managed a TB control project in Nepal for three and a half years, and has also worked with NGOs in India for two years supporting community health programmes. More recently, in 2008, he worked in the Nepal National Tuberculosis Programme assisting with the

implementation of the Global Fund program. Harper's dedication to both anthropological research and programmatic support exemplifies the importance of establishing productive collaborations across multiple disciplines and sectors.

Conclusion: Towards the Anthropologies of Tuberculosis

What lessons can we, as anthropologists, take away from research and discussions about TB?

As seen, TB provides fertile ground for anthropological exploration. Here, I have highlighted themes that emerged from the presented papers, such as: the importance of history in anthropological research; a focus on local diversity and the experience of those affected by the disease; attention to global processes; and areas where anthropologists can work collaboratively with health organizations and beyond.

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