Bioethical Inquiry (2016) 13:31–34
DOI 10.1007/s11673-015-9697-6

SYMPOSIUM: TUBERCULOSIS

Beyond Biomedicine: Relationships and Care in Tuberculosis Prevention

Paul H. Mason · **Chris Degeling**

Received: 14 December 2015 / Accepted: 16 December 2015 / Published online: 2 February 2016

Abstract With attention to the experiences, agency, and rights of tuberculosis (TB) patients, this symposium on TB and ethics brings together a range of different voices from the social sciences and humanities. To develop fresh insights and new approaches to TB care and prevention, it is important to incorporate diverse perspectives from outside the strictly biomedical model. In the articles presented in this issue of the *Journal of Bioethical Inquiry*, clinical experience is married with historical and cultural context, ethical concerns are brought to bear on global health, and structural analyses shed light upon the lived experience of people living with TB. The relational and reciprocal dimensions of care feature strongly in these discussions, which serve as a poignant reminder that behind each of the yearly deaths from TB is a deeply personal story. No single discipline holds a monopoly on how to care for each of these people, but strong cases are made for support from mental health and social workers in addressing the kaleidoscope of needs in TB prevention. As the World Health Organization moves towards the goal of eliminating TB globally by 2050, attending to the needs of TB patients serves global interests to lower disease burden and to develop better integrated communities worldwide.

Keywords Tuberculosis · Medical anthropology · Medical history · Reciprocity · Social policy · Socio-ecological model · Care

Mycobacterium tuberculosis is an evolutionary success story. Emerging from a mycobacterial progenitor in East Africa, modern strains of the bacillus have plagued humankind since before the time of the ancient Egyptians (Hershkovitz et al. 2008; Masson et al. 2013). The "patience" of the microbiological organism is the key to its success. The slowly replicating bacillus can lie dormant for long periods in human and non-human animal hosts. When it reactivates, it can cause a prolonged chronic illness that, if left untreated, allows many opportunities for infection to spread among people and other susceptible species of mammal. Because of our long and shared evolutionary history, it has been claimed that "*Mycobacterium tuberculosis* has killed more people than any other microbial pathogen" (Daniel 2006, 1862). The impacts of tuberculosis (TB) simmer beneath human history (Upshur 2010). Unlike other significant but more acute epidemic diseases such as the plague and cholera, TB lacks an outbreak

P. H. Mason (✉)
Woolcock Institute of Medical Research, University of Sydney, Sydney, Australia
e-mail: paul.mason@woolcock.org.au

P. H. Mason · C. Degeling
Centre for Values, Ethics and the Law in Medicine, University of Sydney, Sydney, Australia

C. Degeling
e-mail: chris.degeling@sydney.edu.au

P. H. Mason · C. Degeling
NHMRC Centre of Research Excellence on Tuberculosis Control, Sydney, Australia

narrative, and so the effects on culture of increases and decreases in incidence have been less visible though no less enduring.

At various times in recent history, TB has been characterized as a disease of "capitalism" (Dubos and Dubos 1952); "incomplete civilization" (Packard 1989; Barnes 1995), and "incomplete industrialization" (Tremblay 2007). TB is quintessentially a social disease. However, as well as being a marker of the contextual impacts of disadvantage and social disruption, TB is an individual experience. The spectrum of symptoms caused by active *Mycobacterium tuberculosis* infection was known as consumption, "a disease of wasting." The identification of the causative agent of consumption in 1882 then altered what it meant to suffer from this disease and catalysed the adoption of medical models of hygiene as a means of prevention. The discovery of antibiotic treatment for tuberculosis some sixty years later solidified biomedical authority over the disease and simultaneously laid the foundations for the growth of big pharmaceutical companies organized around meeting the health needs of consumers. As a social disease, perspectives outside the strictly biomedical model offer important ways of framing how TB is defined, understood, and treated, with consequences for the lives of individuals, the making of social policy, and the organization of medical care.

Spanning individual, interpersonal, and structural levels of the socio-ecological model (see Figure 1), this symposium on TB and ethics in this issue of the *Journal of Bioethical Inquiry* includes articles written by anthropologists, bioethicists, clinicians, historians, and public health specialists. Anthropological and human rights perspectives delve into the lived experiences of health professionals and people living with TB. Ethical, historical, and political viewpoints dissect interpersonal relationships between TB patients and healthcare providers. At the structural level, clinical experience and anthropological fieldwork converge upon questions of causality, care, and compensation. No single article fits squarely within one sphere of analysis, thus demonstrating the value of interdisciplinary engagement and multidisciplinary cooperation. At the centre of each article is a moral orientation towards attending to social interactions between patient and carer within settings structured by biomedical infrastructure and global health policy. Caregiving, according to Kleinman (2015), is relational and reciprocal and has aesthetic importance. Coming before and going beyond medical intervention, at its best care is a concern for forms of human interaction that can strengthen social inclusion. At its worst, the practices of "care" can be hollowed out and systematized so as to foster the alienation of both provider and recipient (Mol, Moser, and Pols 2010). The articles in this symposium highlight how the presence or absence of different enactments or modes of care can reinforce or erode the ethical probity, acceptability, or effectiveness of measures intended to promote TB control and prevention.

Diego Armus (2016), a medical historian, recounts how TB patients in sanatoriums in Buenos Aires, Argentina, from the 1920s to 1950s grouped together to collectively negotiate for their desired medical treatments. A story of activism, Armus describes how the collectivization of interests around particular biomedical innovations did not reinforce the authority of doctors but rather became a catalyst for reordering and negotiating how TB was "managed" in Buenos Aires. With the collapse of sanatoriums after the advent of antibiotics, future research might enquire more broadly how a loss of community among people living with TB has impacted upon patient care, treatment management, and interventionist approaches to public health.

Based on fieldwork between 2001 and 2007, Erin Koch (2016), a medical anthropologist, describes local innovations in bringing a standardized TB control strategy recommended by the World Health Organization, "Directly Observed Therapy, Short Course" (DOTS), to TB patients in Georgia. Efforts to provide support that focus on the sociality and identity of those being cared for can be impeded by the limited budget for basic care items such as juice and snacks. In an ethnography that runs counter to current critiques of DOTS that focus on the absence of choice, Koch critically interprets how TB healthcare providers and people living with TB worked to improve the conditions of TB treatment through mobilizing, navigating, and negotiating the social relationships that surround antibiotic exchange.

Seiji Yamada, Sheldon Riklon, and Gregory Maskarinec (2016), a pair of clinicians and an anthropologist, piece together the distributed causality of TB in the Marshall Islands. They find the syndemic of tuberculosis and diabetes in islands of the Pacific to be a direct consequence of the history of colonialism, nuclear testing, and anthropogenic climate change as well as the increased reliance on Western food imports. Yamada et al. configure a public health polemic that

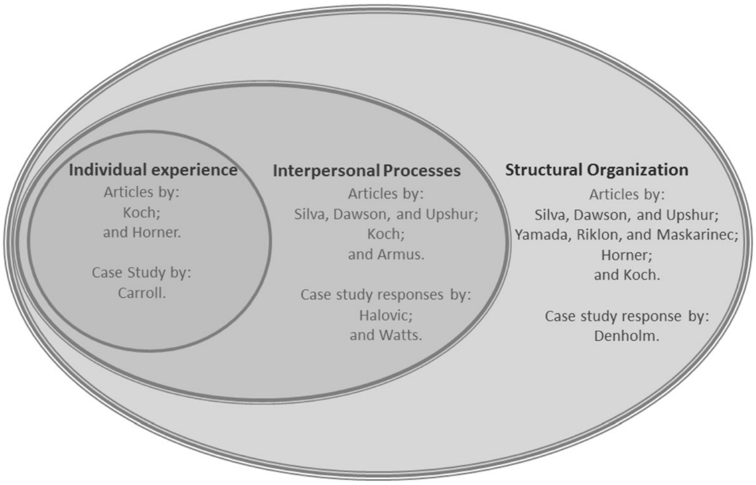

Fig. 1 Articles in this journal symposium on tuberculosis and ethics span the individual, interpersonal, and structural levels of the socio-ecological model used by Mason, Degeling, and Denholm (2015) to describe the socio-cultural dimensions of tuberculosis care and prevention.

makes us ask: when causality is distributed, do we fail to call policies, practices, and structures into account?

With a close attention to discourse and Foucauldian theory, Jed Horner (2016), a social policy and public health researcher and analyst, examines TB and immigration law in contemporary Australia. Horner finds that Australian border policing and migrant TB screening neglect to attend to conditions of resettlement, thus exposing and predisposing newly arrived migrants to becoming liminal subjects. It is perhaps surprising that social scientists studying TB have not drawn more heavily upon Foucault, when his ideas about political control over individual bodies provide a provocative analytical framework to study DOTS, sanatoriums, and the structural violence that still leads to deaths from TB.

Zooming out to a more global scale, Diego Silva, Angus Dawson, and Ross Upshur (2016), a team of clinicians and bioethicists, address the issue of reciprocity in international TB care and prevention. Silva et al. examine how TB care and prevention will require the valorization of reciprocal relationships among vulnerable communities, sufferers, and national and global institutions. Their conclusion is compelling:

> [T]hat under a principle of reciprocity, not only must compensation and support be provided to those TB patients who abide by public health measures but also … that reciprocity may provide further arguments in favour of the moral obligation to rectify the background conditions that lead to contracting and developing TB in the first place (Silva, Dawson, and Upshur 2016, ¶1 under "Conclusion").

In addition to the research articles, this symposium also includes a hypothetical case study by Jane Carroll (2016) about a migrant, Xiang, who became sick with multidrug-resistant TB after a period of work in Australia. Researchers in both the biomedical and social sciences submitted responses to this case study. Due to page constraints, only three responses could be published within the print version of the journal (with the others available via the journal's website at bioethicalinquiry.com). Krista Watts (2016) writes about the medicalization of people living with TB and argues for greater involvement of social workers to support TB patients. Shaun Halovic (2016) offers complementary perspectives about the importance of providing psychological support to patients like Xiang. Drawing upon professional experience, Justin Denholm (2016) shares insights into the clinical, ethical, and programmatic dimensions of Xiang's situation. The emotive responses from researchers worldwide were a potent reminder of the issues faced by TB patients globally.

From pre-Péron Argentina to post-Soviet Georgia, from the post-colonial Republic of the Marshall Islands to the Commonwealth of Australia, this symposium on TB and ethics covers a selection of disparate geographical areas over different time scales and time periods. The articles offer an entry point into a variegated patchwork of social science research into TB. Taken collectively, the articles in this symposium do not have one unified message but indicate that no single approach can hold a monopoly on TB research, healthcare, and prevention. Disease causation, microbial and human agency, and the legal and medical frameworks that surround TB control are critically analysed in ways that challenge contemporary approaches. The reductionist approach of personalized medicine aimed at disease elimination will undoubtedly need to turn to more complex models of disease care and prevention that incorporate socially-informed perspectives (Farmer 2003; Degeling et al. 2015). With the potential of climate change to compromise food security and push human populations into even more overcrowded urban centres, particularly in the poorest regions of the world, the urgency to address infectious diseases such as TB is heightened. The continuing need to control the spread of TB and to limit the devastation that it still causes opens the door to all manner of regulations, secular moralizing, and surveillance procedures that find their way into the most intimate aspects of peoples' lives. Appreciating the social history, cultural life, and ethical dimensions of TB is an important way of understanding how the disease is classified, how its causes are conceptualized, and how it has been brought under control in some parts of the world but has continued to spread and evolve in others.

References

Armus, D. 2016. On TB vaccines, patients' demands, and modern printed media in times of biomedical uncertainties: Buenos Aires, 1920–1950. *Journal of Bioethical Inquiry* 13(1). doi: 10.1007/s11673-015-9692-y.

Barnes, D.S. 1995. *The making of a social disease: Tuberculosis in nineteenth-century France*. Berkeley: University of California Press.

Carroll, J. 2016. The ethics of isolation for patients with tuberculosis in Australia. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-015-9685-x.

Daniel, T.M. 2006. The history of tuberculosis. *Respiratory Medicine* 100(11): 1862–1870.

Degeling, C., C. Mayes, W. Lipworth, I. Kerridge, and R. Upshur. 2015. The political and ethical challenge of multi-drug resistant tuberculosis. *Journal of Bioethical Inquiry* 12(1): 107–113.

Denholm, J. 2016. Ethics, tuberculosis, and compassion: Lessons from praxis. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-015-9693-x.

Dubos, R., and J. Dubos. 1952. *The white plague: Tuberculosis, man, and society.* Boston: Little, Brown, Boston.

Farmer, P. 2003. *Pathologies of power: Health, human rights, and the new war on the poor*. Berkeley: University of California Press.

Halovic, S. 2016. Effective therapeutic relationships using psychodynamic psychotherapy in the face of trauma. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-016-9701-9.

Hershkovitz, I., H.D. Donoghue, D.E. Minnikin, et al. 2008. Detection and molecular characterization of 9,000-year-old *Mycobacterium tuberculosis* from a Neolithic settlement in the Eastern Mediterranean. *PLoS One* 3(10): e3426. doi:10.1371/journal.pone.0003426.

Horner, J. 2016. From exceptional to liminal subjects: Reconciling tensions in the politics of tuberculosis and migration. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-016-9700-x.

Kleinman, A. 2015. Care: In search of a health agenda. *The Lancet* 386(9990): 240–241.

Koch, E. 2016. Negotiating "the social" and managing tuberculosis in Georgia. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-015-9689-6.

Mason, P.H., C. Degeling, and J. Denholm. 2015. Sociocultural dimensions of tuberculosis: An overview of key concepts. *International Journal of Tuberculosis and Lung Disease* 19(10): 1135–1143.

Masson, M., E. Molnár, H.D. Donoghue, et al. 2013. Osteological and biomolecular evidence of a 7000-year-old case of hypertrophic pulmonary osteopathy secondary to tuberculosis from Neolithic Hungary. *PLoS One* 8(10): e78252. doi:10.1371/journal.pone.0078252.

Mol, A., I. Moser, and J. Pols. 2010. Care: Putting practice into theory. In *Care in practice: On tinkering in clinics, homes and farms*, edited by A. Mol, I. Moser, and J. Pols, 7–26. Bielefeld, Germany: Transcript-Verlag.

Packard, R.M. 1989. *White plague, black labor: Tuberculosis and the political economy of health and disease in South Africa*. Berkeley: University of California Press.

Silva, D.S., A. Dawson, and R.E.G. Upshur. 2016. Reciprocity and ethical tuberculosis treatment and control. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-015-9691-z.

Tremblay, G.A. 2007. Historical statistics support a hypothesis linking tuberculosis and air pollution caused by coal. *International Journal of Tuberculosis and Lung Disease* 11(7): 722–732.

Upshur, R. 2010. What does it mean to "know" a disease? The tragedy of XDR-TB. In *Public health ethics and practice*, edited by S. Peckham and A. Hann, 51–65. Bristol, UK: Policy Press.

Watts, K. 2016. MDR-TB, isolation, and anomie: Has anyone referred to social work? *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-016-9707-3.

Yamada, S., S. Riklon, and G.G. Maskarinec. 2016. Ethical responsibility for the social production of tuberculosis. *Journal of Bioethical Inquiry* 13(1). doi:10.1007/s11673-015-9681-1.