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EDITORIAL

“Born Like This / Into This”: Tuberculosis, Justice, and Futuristic Dinosaurs

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I was born of disease.

Not in the same circumstances as too many still today and so many others in the past, but my existence—or at least key narratives from life courses entwined with my existence—are rooted in disease. Had it not been for the “Spanish flu,” I would cease to exist. For it was the death of my paternal grandfather’s first wife during the 1918–1919 influenza pandemic that left him a widower, with three young children to raise. Out of this tragedy came marriage to my grandmother and ten more children, my father eighth in that line, eleventh in the blended family overall.[1] And had it not been for tuberculosis, my grandparents never would have met. For it was my great-grandfather’s affliction with TB that brought this small immigrant family of three—him, my great-grandmother, and my barely born grandmother—from New York to Denver. They came West, into the dry, thin High Plains air of Colorado, where the sun reputedly shines three-quarters of the year (Colorado Climate Center 2010) and the climate was a prescriptive for what was then called “consumption” and those ill with it “lungers” (Lewis 2015).

Perhaps this health history somehow found its way, Lamarckian-style, into my being. For I am otherwise not

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[1] I once recounted this story at a Society for Public Health Education (SOPHE) training on crisis and emergency risk communication, during a session in which we used the possibility of an avian flu pandemic as a case study. To emphasize the far-reaching effects of epidemics, the instructor asked us to consider the influenza pandemic of 1918–1919 and urged us to share how events from ninety years prior had personally affected us. She was, perhaps, at first taken aback that, in this tragic way, I had disease to thank for my father’s life and, thus, my own. It is this randomness of circumstance, being “born into this,” that political philosopher John Rawls attempted to address in his *A Theory of Justice*, first published in 1971.

sure from where my lifelong interest in medicine and the health sciences springs. I didn't grow up in a household of healthcare workers. My parents, before I knew them, were both schoolteachers, and all of my life they owned and operated a local furniture manufacturing company.[2] There were no aunts or uncles as doctors or nurses, no family friends in the business of sickness and health or the production of well-being. Yet, since I was small, all I wanted to do was read about medicine. True, these early books consisted mostly of those by Michael Crichton and Robin Cook (which also might explain my ongoing interest in the rise and persistence of the detective narrative). And while these novels weren't the bastions of great philosophical or medical depth (although authored by scientists/modern medicine men), they hooked me into seeking more, and soon I was reading non-fiction about the rise of hospitals, evolutionary theory, the pharmaceutical industry, the history of science and technology. Anything related to medicine. And the politics of health. And morbidity and mortality.

Towards the end of high school, I enrolled in science seminar as well as a medical careers class, where we met after school with a dedicated teacher who led discussions and arranged field trips to hospitals and the University of Colorado's Health Sciences Center. At the age of sixteen, a classmate and I even observed several surgeries from the floor of an operating room. Practically from over his shoulder, we watched as the orthopaedic surgeon and his team talked us through each procedure, working as one, serious and collegial, clearly enjoying their work while caring for their patients. Nearly thirty years later, I remember this experience vividly, gratefully, aware then as now of the opportunities that being able to attend a well-funded school provides. Through science seminar, I was offered an internship at National Jewish Medical and Research Center (now called National Jewish Health), whose doors opened in 1899 as National Jewish Hospital for Treatment of Consumptives. Under the guidance of world-renowned pulmonologists, I learned about TB, *Mycobacterium avium-intracellulare* (MAI), and drug resistance and participated in research exploring drug-susceptibility testing.

I gave no thought to it at the time, but, for a brief moment anyway, I was part of an institution that once treated my great-grandfather, connecting me to him in ways beyond just our genes.

But it's not only our own families who count. It's all families. As I now write, reflecting on TB and these odd (and rather morbid) webs of social and historical ties, memories are dredged from my primary school days as well, when our forearms would be pricked with the tuberculin tine test, the area circled in pen, and we'd be handed index-sized cards with variations of raised bumps with which to compare our own possible reactions over the next several days. I remember these cards well. I was intrigued by them. Almost mesmerized. And I would spend considerable time running my fingers over the uneven, artificial bulges, not so much out of vigilance for potential parallels between card and arm, but curiosity. Curiosity for something that was rather alien.

For me, there was a disconnect with the card, even though TB had in some ways shaped my life.

That disconnect doesn't exist, cannot exist, for many, even today. According to the World Health Organization, in 2014 "9.6 million people fell ill with TB and 1.5 million people died from the disease" (WHO 2015b, ¶2 under "Key facts"; see also WHO 2015a, 8). Moreover, "an estimated 480,000 people developed multidrug-resistant TB (MDR-TB)" (WHO 2015b, ¶6 under "Key facts), nearly a tenth of whom have extensively drug-resistant TB (XDR-TB) (WHO 2015a, 2). By 2015, XDR-TB "had been reported by 105 countries" (WHO 2015a, 2).

Although TB occurs in every region in the world, some shoulder heavier burdens. The World Health Organization reports:

> In 2014, about 80% of reported TB cases occurred in 22 countries. The 6 countries that stand out as having the largest number of incident cases in 2014 were India, Indonesia, Nigeria, Pakistan, People's Republic of China and South Africa. Some countries are experiencing a major decline in cases, while in others the numbers are dropping very slowly (WHO 2015b, ¶2 under "Global impact of TB").

Thus, while great strides have been made in reducing the overall death rate from TB and saving lives, concerns remain. As Mario Raviglione, director of the Global TB Programme, writes in the preface to the 2015 *Global*

[2] That said, my parents always believed, and continue to do so, in education. At university, my father focused on psychology, my mother on learning disabilities. Both went on to earn master's degrees. And today, when we meet up on Sunday mornings for our weekly walk around a local lake, we speak primarily of health—in the World Health Organization sense of the word (WHO 1946)—and social justice, trying to understand, and find ways to ameliorate, the lack of will we humans can exhibit when it comes to others' suffering.

Tuberculosis Report, TB is "a classic example of a disease of poverty" (WHO 2015a, x). It was born in poverty and is sustained by poverty (see, e.g., Snewin, Cooper, and Hannan 2002). For example, the WHO reports that "[g]lobally an estimated 3.3% of new TB cases and 20% of previously treated cases have MDR-TB, a level that has changed little in recent years" (WHO 2015a, 2). And a "primary cause of MDR-TB," the WHO states elsewhere, "is inappropriate treatment. Inappropriate or incorrect use of anti-TB drugs, or use of poor quality medicines, can cause drug resistance" (WHO 2015b, ¶3 under "Multidrug-resistant TB").

Drug resistance, therefore, is "a human-made phenomenon" (Selgelid and Reichman 2011, S9), a combination of lack of access to medicines for many who need them, adherence issues among patients (e.g., rationing for economic reasons, discontinuation due to side effects), diagnostic and clinical errors, stigmatization, and continuing disincentives for change in health systems, politics, and industry.

But if it is "a human-made phenomenon," then, too, are the solutions.

The question remains, however, whether such solutions are possible within our current social contracts. In what has become a rather controversial op-ed piece, Peter Buffett, son of American entrepreneur and philanthropist Warren Buffett, wrote frankly in 2013 about what he and his wife have termed "Philanthropic Colonialism"—which not only involves attempts to "save the day" and solve local problems in other cultures with "very little knowledge of a particular place" (and sometimes succeeding only in creating "unintended consequences") but also "conscience laundering," or giving back in fractional ways in order to appease any moral distress sparked by a system that "creates vast amounts of wealth for the few" at the expense of all (Buffett 2013, ¶2, ¶3, and ¶7).[3]

Focusing on charity, then, "just keeps the existing structure of inequality in place," and Buffett instead calls for "a new operating system," one steeped in humanism (Buffett 2013, ¶8 and ¶13). The title to his piece, "The Charitable–Industrial Complex," references U.S. President Dwight D. Eisenhower's warning upon leaving office in 1961 to beware of a growing military–industrial complex, the intertwined and reinforcing relationships "between corporations and the armed forces" that seek to maximize their own interests regardless of any peril to democracy (Bacevich 2011, ¶1). History and international relations professor Andrew J. Bacevich, in examining several of Eisenhower's speeches related to the "economic, social, political, and moral" implications of "misappropriate[ing] … scarce resources" and diverting "social capital from productive to destructive purposes" (Bacevich 2011, ¶5–¶7), concludes that "the president contemplated a world permanently perched on the brink of war—'humanity hanging from a cross of iron'—and he appealed to Americans to assess the consequences likely to ensue" (Bacevich 2011, ¶4).

This "cross of iron" smacks of Thomas Hobbes' state of war, which, while "perfect freedom," can only be "solitary, poor, nasty, brutish, and short" (1886, 64).

So too, perhaps, with the charitable–industrial complex, although Buffett's editorial looks to John Rawls instead of Hobbes, asking us (in so many words) to return to an "original position," to go behind a "veil of ignorance," and to build "from the ground up" a "[n]ew code" (Buffett 2013, ¶13)—one that maximizes the minimum and secures not only basic equal liberties for all but also "effective freedom," where genuine access to resources is a reality that enables individuals and communities to develop and grow and pursue their educational, entrepreneurial, and other dreams (Rawls 2003). We must also, then, take cues not merely from Rawls but Charles W. Mills (1997), whose examination of *The Racial Contract* requires that we acknowledge—and dismantle—the malign normative system within social contract theory that has been blind to the historical and enduring "whiteness" of liberalism, to the embedded biases rooted in colonialism about who "counts" as equal, free, rational persons (Mills 1997). Instead, we must create genuinely inclusive social contracts.

"What we have is a crisis of imagination," Buffett urges. "Albert Einstein said that you cannot solve a problem with the same mind-set that created it" (Buffett 2013, ¶14), and thus we cannot address the global issue of TB (and so many other diseases) without addressing the underlying socioeconomic system in which it thrives. Without addressing the poverty that created it and the poverty created from it.

TB is not something alien, not a disease of an "other." It is my disease. It is our disease. This issue of the *Journal of Bioethical Inquiry*, with a symposium on tuberculosis edited by Paul H. Mason and Chris Degeling and in honour of World TB Day 2016, underscores this. It examines the intersections of narratives of TB from multiple

[3] I thank Susan Arshack, grants director at Armstrong State University, for sharing her perspectives and Buffett's article with me during a recent grant-writing workshop.

disciplines and diverse perspectives. It emphasizes the "deeply personal story" that is TB, even as the global disease burden and efforts at eradication continue to seem daunting (Mason and Degeling 2016, under "Abstract").[4]

So many years ago, when I unconsciously played with the card that accompanied the tuberculin skin test, I was asking the question of "Why me?" Not in the usual way we pose this query, when we are stricken with illness and want to know from our maker, from society, from those in our lives why we find ourselves diagnosed with a given disease at a particular time. Rather, unbeknownst to me, I was asking "Why me?" in the sense of "Why am I not vulnerable?"

It is a question that must be asked more.

And one that demands response.

We have the duty—just perhaps not yet the Kantian good will—to do more than merely "keep the pot from boiling over" (Buffett 2013, ¶8), to do more than merely perpetuate a system where, as Rawls would put it, the "inequalities … are not to the benefit of all" (Rawls 2003, 54). George Merck reputedly once said that if his pharmaceutical company "discovered a cure for cancer, he'd not patent it. … How can you keep it away from people? How can you charge a lot of money? What's the excuse? You can't do that" (recounted by chemist Max Tishler, cited in Werth 1994, 127).

What is our excuse?

In various permutations, we are all born of disease. Even Rawls' *A Theory of Justice* was born of disease.[5]

We are, as poet Charles Bukowski phrased it, "born like this / into this"[6]:

we are
born like this
into this
into these carefully mad wars
into the sight of broken factory windows of emptiness
into bars where people no longer speak to each other
into fist fights that end as shootings and knifings

born into this
into hospitals which are so expensive that it's cheaper to die
into lawyers who charge so much it's cheaper to plead guilty
into a country where the jails are full and the madhouses closed
into a place where the masses elevate fools into rich heroes

"Dinosauria, we," Bukowski deems us, and should we wilfully fail to heed this forecast, soon we may just be

the last few survivors … overtaken by new and hideous diseases …
and there will be the most beautiful silence never heard
born out of that.

Can we prove him wrong?
Will we?

[4] The issue also includes several responses to a TB-related "In That Case" column. The case study and four of the replies can be located via the *JBI* website at http://bioethicalinquiry.com/.

[5] In Thomas Pogge's biography of John "Jack" Rawls, he notes that the "most important events in Jack's childhood were the loss of two younger brothers, who died of diseases contracted from Jack"—one from diphtheria, one from pneumonia (Pogge 2007, 5). Pogge also emphasizes that Rawls' "sense of justice" was heavily influenced by "his mother's work for the rights of women" and "his own reflections on race and class" in his hometown of Baltimore, Maryland (Pogge 2007, 6). Likewise, I, too, must thank my mother, who, through her ceaseless philanthropic work—while working full-time, co-raising children and now grandchildren, and caring for parents and other friends and relatives—has always been and continues to be a role model for me. Still working full-time, she recently co-founded a community garden that has, with collaborative partners, helped to create free, healthy meals for thousands of local schoolchildren. I also am shaped by and often share with my students my father's mantra: that no one should be hungry, homeless, or without healthcare.

[6] This and the following Bukowski lines are from the poem "Dinosauria, we" (see Bukowski 2002, 319–321).

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