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Chagas disease in non-endemic countries: ‘sick immigrant’ phobia or a public health concern?

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In recent years, the literature on neglected tropical diseases (NTDs) has advanced in significant ways: there is a renewed sense of urgency in World Health Organization reports, new specialized journals have been launched, and advocacy groups are leveraging social media to gain attention to the burden of NTDs around the world. But as the literature in this field develops, there is a danger of an important split between work that recognizes the profound geopolitical patterning of NTDs, and focuses accordingly on structural factors that lead NTDs to thrive in some areas of the world and not in others; and, alternatively, work that ‘securitizes’ global health and thereby focuses on the ‘risk’ posed by NTDs to populations in non-endemic countries. This article examines this schism through the example of Chagas disease.

Keywords: neglected diseases; Chagas disease; immigration; globalization; inequality

Introduction

Neglected tropical diseases (NTDs) are a heterogeneous group of parasitic and bacterial diseases that afflict the poorest of the world’s poor (Mathers, Ezzati, and Lopez 2007; Hotez 2008). They are thought to affect a total of one billion people worldwide, with most cases occurring in sub-Saharan Africa (WHO 2010). They also continue to exert a heavy toll in parts of Latin America and the Caribbean (Hotez et al. 2008). NTDs differ in their etiology, biological mechanisms, and clinical symptoms, but they share a series of social features; above all, they are bound together by poverty. It is poverty that exposes people to the parasites and bacteria that cause the major NTDs, and it is poverty, along with a lack of global political will, that keeps NTDs under-diagnosed, under-researched, and under-treated.

Indeed, NTDs are a proxy for poverty and disadvantage (Hotez and Ferris 2006); NTDs are prevalent only in settings of poverty and they thrive in zones of military or paramilitary conflict (Beyrer et al. 2007). It is clear that NTDs form a part of a vicious circle: poverty nurtures the risk of contracting an NTD, and NTDs, in turn, severely diminish the economic capacity of individuals and communities, thereby nurturing poverty and inequality. Importantly, this is recognized at the highest levels of global health governance. For example, the WHO proclaims that NTDs ‘constitute a serious

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obstacle to socioeconomic development and quality of life' (2010, 5). Yet, despite this burden, few international resources have been devoted to research on NTD treatment, control, and prevention.

There are signs, however, that NTDs are beginning to receive more attention from global health researchers. The WHO has reenergized this field with several landmark reports in the past few years (WHO 2010, 2012), and advocacy organizations such as 'END7,' which focuses on eliminating ascariasis, hookworm, lymphatic filariasis, onchocerciasis, schistosomiasis, trachoma, and trichuriasis, have gained traction in social media campaigns. Social science engagement with NTDs in English-language journals has also shown promising signs of development in recent years (Spiegel et al. 2010), though much remains to be done. Little has been written from a critical perspective in the social science literature about NTDs, and what exists has not advanced an adequate theorization of the links between global inequities, poverty, structural violence, and NTDs (De Maio *forthcoming*; Mantilla 2011).

It is important to note that the reference to NTDs as 'neglected' does not imply that they are of secondary importance behind other infectious diseases such as HIV/AIDS, tuberculosis, and malaria – diseases which have gained attention in the Millennium Development Goals. Global health researchers have established that the combined burden of NTDs ranks as high as those of other better-known afflictions in many places, even if their death toll is lower. Rather, *'their neglect reflects their epidemiology'*: they are prevalent among the poorest and most marginalized of the world's population' (Manderson et al. 2009, 1; *emphasis added*). NTDs are burdens of what Beyrer et al. refer to as 'forgotten populations,' emphasizing that because NTDs do not generally affect so-called developed countries, they have been 'largely ignored by medical science' (2007, 619). For Hotez, NTDs are the 'forgotten diseases afflicting forgotten people' (2008, 6). But while forgotten, they are very much real in their impact.

NTDs are estimated to cause more than 500,000 deaths annually – that is, every year NTDs kill as many people as were killed in the 2004 Christmas tsunami (Hotez et al. 2006), but they do not make the news, as their victims are almost entirely confined to the poorest classes in poor countries. NTDs have been largely ignored by the pharmaceutical industry, and until recently, NTDs have also been ignored by social scientists. Recently, however, NTDs have gained more attention from researchers in social science, though funding bias may continue to prohibit the social sciences from playing anything but a marginal role in interdisciplinary teams (Allotey, Reidpath, and Pokhrel 2010; Mantilla 2011; Pokhrel, Reidpath, and Allotey 2011; Reidpath, Allotey, and Pokhrel 2011).

As this field of research develops, it grapples with an important 'framing' debate: do NTDs matter in and of themselves, because they exist, burden poor populations, and could be averted? Or do they matter because they are a threat, can cross national borders and affect non-endemic countries? There is danger of a divide between two kinds of work: one that recognizes the profound geopolitical patterning of NTDs, and focuses accordingly on structural factors that lead NTDs to thrive in some areas of the world. Alternatively, there is work that 'securitizes' global health (Price-Smith 2002; Labonté 2008; Labonté and Gagnon 2010) and thereby narrowly focuses on the 'risk' posed by NTDs to populations in non-endemic countries.

The securitization of global health invokes a state's need to defend itself from external threats (Peterson 2002; Bashford 2006; Aldis 2008). It frames disease as a threat, much like a foreign enemy that must be defeated. In this light, 'global battles' against disease are waged to protect advanced industrialized states from contagion

(Owen and Roberts 2005; Elbe 2010). According to Davies, ‘... powerful actors still only see a health crisis as worth responding to when it threatens them. Massive national expenditure on disease control can only be justified when governments can draw a link between the threat, infectious disease, and national security’ (2010, 22). The problem in all of this, of course, is that a ‘securitized’ discourse on global health, where disease is primarily seen as a threat to otherwise healthy populations in non-endemic countries, leaves the social conditions wherein disease flourishes intact.

Davies (2010) describes this ‘securitized’ perspective as the *statist* position (see also Fidler 2005; Maclean 2008; Price-Smith 2009). It has played a fundamental role in global efforts to prevent and control the spread of HIV (Elbe 2006), bringing greater political visibility and funding. Yet as Feldbaum, Lee, and Patel (2006) argue, ‘global health works to improve the health of all people within and across states, while the national security field works to protect the people, property, and interests of only one state.’ The statist position, based on the notion of securitization, may bring some benefits in terms of disease awareness and research funding, but it comes at a great cost – diverting our attention to the worries of the powerful over the needs of the poor (O’Manique 2006; Brown 2011).

Opposing the statist position, Davies (2010) defines the globalist tradition. This perspective is more strongly tied to the global discourse on human rights and social justice. From this position, disease is seen from the perspective of individuals and marginalized populations, and it need not threaten non-endemic countries to be deemed a political priority. The HIV/AIDS literature is clear that securitization of disease is a nuanced and complex process, bringing benefits and limitations. How this framing process will unfold with NTDs is uncertain – though as examined below, recent attention devoted to the ‘globalization’ of Chagas to non-endemic countries indicates that the statist perspective may be growing in importance.

Chagas disease

Chagas disease is Latin America’s most important parasitic disease (WHO 2010; Llovet, Dinardi, and De Maio 2011). It is spread primarily by a ‘kissing bug’; these blood-sucking *triatomine* insects live in crevices of the walls and roofs of very poor homes; they thrive in the crooks and gaps left in mud-thatch construction and in walls made of precarious building materials. When they bite they defecate into the bite wound, and in doing so can transmit a parasite (*Trypanosoma cruzi*; *T. cruzi*) into its victim, leading to Chagas disease. Chagas infection is followed by two phases: acute and chronic. The acute phase can last from 4–8 weeks, and is characterized by fever, swollen lymph glands, and often, inflammation at the biting site. Up to 40% of infected people develop chronic Chagas disease (Reithinger et al. 2009), which is characterized by cardiac and gastrointestinal complications. If left untreated, these can be fatal. In disease endemic areas like Bolivia, Paraguay, and northern Argentina, Chagas is the leading factor in cardiovascular deaths (Reithinger et al. 2009). There is concern in the literature; however, over how difficult it is to isolate the cardiovascular effects of *T. cruzi* seropositivity from the pathogenic effects of poverty (Linnetzky et al., 2012). Almost a third of patients are estimated to develop Chagas-related heart damage, and 10% to develop damage to the oesophagus, colon, or nervous system (or a combination of these), typically in the late chronic phase of the disease (WHO 2010).

It is a quintessential disease of poverty – one that poor peasants are at most risk of contracting, one that is largely undiagnosed, and one that has never been a priority for

for-profit pharmaceutical research (only two pharmacological interventions for Chagas exist, and both are over 30 years old, with limited effectiveness, toxic side effects, and complicated dosing regimens). This reflects a true ‘market failure,’ whereby the lives of the poor are deemed to be of little value; the development of new vaccines or treatments failing contemporary judgments of ‘cost-effectiveness’ (Trouiller et al. 2002). Unique to the Americas, Chagas generates an estimated burden of 426,000 DALYs every year (WHO 2010). It is almost entirely associated with poor quality housing in rural settings.

An estimated 7–8 million people are thought to be infected in the region of the Americas (with some estimates more in the 10–20 million range – there is a lot of imprecision in these estimates), with most of these cases being asymptomatic and undiagnosed (Reithinger et al. 2009). Endemic areas exist in 21 countries of Latin America (Dias 2009). Argentina, Brazil, and Mexico are thought to have the largest number of cases of *T. cruzi* infection, at more than one million cases in each country (Franco-Paredes, Bottazzi, and Hotez 2009; WHO 2010). But Bolivia has the highest rate of *T. cruzi* infection in the world, with an estimated 6% of the overall population infected (WHO 2010). Some surveys of pregnant women and blood donors in hyper-endemic communities reach prevalence rates of 30–40% in that country (Breniere et al. 2002; Pirard et al. 2005). Despite these high figures, few NGOs work explicitly with Chagas patients, and the END7 campaign – which has gained traction in social media to generate public awareness of NTDs – does not include Chagas in its focus.

Vector transmission is the most important way of spreading Chagas disease – but it can also be spread through transfusions with infected blood and it can also be passed from mother to fetus through the placenta (Barona-Vilar et al. 2012; Carlier et al. 2011). Improved blood donation screening mechanisms in Latin America have diminished disease transmission as a result of transfusion (WHO 2010). Whereas in 1990, only Argentina, Honduras, Uruguay, and Venezuela performed serological screening of all blood donors for *T. cruzi*, the list of countries which screen all donors has now risen to 8, including Brazil, the most populous country in the region. Four other countries now screen 99% of blood donors (Schmunis 2007). However, that is not to say that this has resulted in diminished attention to the prospect of *T. cruzi* transmission through blood transfusion and/or organ transplantation. A new wave of articles and WHO reports raise the spectre of a ‘globalised Chagas,’ emphasizing the global risk of Chagas in non-endemic countries.

The spectre of a ‘Globalized’ chagas

Chagas disease has been detected in non-endemic countries where vector transmission does not exist (due either to climate and/or housing infrastructure which is unsuitable for triatomine insects). There, migrants have brought *T. cruzi* infection with them and pose a danger of transmitting the parasite into the blood supply, and congenital transmission is also a possibility among migrants groups. Increased recognition of this epidemiological patterning may lead to improved resources for affected groups – but it may also lead to a further stigmatization of NTDs like Chagas and a backlash reminiscent of the ‘sick immigrant’ paradigm (Beiser 2005; De Maio 2010).

Schmunis’ (2007) analysis of Chagas spreading along immigration routes is an important article in this area. He plotted legal and undocumented migration flows from Latin America to the global north to estimate the global epidemiology of Chagas in non-endemic countries. Schmunis gathered information on the number of immigrants,

both documented and undocumented, from national statistical agencies in receiving countries; he then took into account the prevalence of infection in the country of origin, and estimated the size of the population in each country that may be expected to have *T. cruzi* in their blood. He estimates that the number of infected migrants is in the thousands for Australia, Canada, and Spain, and in the tens or even hundreds of thousands in the USA. Some work now cites that up to a million people may carry Chagas in the USA (Hotez et al. 2012), although these are only estimates; no population registers of Chagas-infected people exist or are technically/ethically viable. Supporting Schmunis' argument, a new wave of empirical studies has examined Chagas seropositivity among immigrants. For example, a study of blood donors in New York City found a 'persistent and possibly increasing population of patients with Chagas infection,' associating this prevalence with foreign born people, mainly Salvadorian and Mexican (Zaniello et al. 2012). Another study at a health center in Barcelona found an even larger prevalence than in the New York study, mainly affecting Bolivian born people (Roca et al. 2011). These studies support Schmunis' affirmation: 'there is ample evidence that non endemic countries harbor a population of individuals infected with *T. cruzi*, and that, sooner or later, nations should have to confront the prevention of transfusion or organ-acquired infection, as well as secondary prevention of congenital infection' (2007, 79). At the same time, Schmunis thoughtfully raises a warning of possible unintended consequence of this line of analysis, urging that legislation be developed to protect immigrants from discrimination over their *potential* infection.

The spectre of a globalized Chagas has also been raised in other studies. For example Perez De Ayala et al. (2009) document cases of chagasic cardiomyopathy in immigrants from Latin America in Spain and Jackson et al. (2009) describe congenital transmission of Chagas among Latin American immigrants in Switzerland. Studies like this appropriately signal the need for public health efforts against Chagas disease in non-endemic countries; this could be aimed at raising awareness among physicians about the disease, for example. And new procedures could be implemented to ensure that *T. cruzi*-infected blood is not accepted by blood banks. Along these lines, the US Food and Drug Administration recently issued guidance to blood banks in the USA for screening of Chagas (Ribeiro et al. 2009).

Most recently, Hotez et al. received widespread media coverage for their editorial dubbing Chagas the 'new' HIV/AIDS of the Americas (see Hotez et al. 2012), and popular media reports of the editorial emphasized the 'new' threat posed by the disease to the US population (for e.g. see Jauregui 2012; Mcneil 2012). These reports noted the burden of Chagas disease in Latin America, but overwhelmingly focused on the alarmist threat that the disease was something that would spread to the USA. The way in which the media sensationalized the Hotez et al. editorial is indicative of securitization, with Chagas coming to matter only when it was re-branded as a threat to populations in industrialized countries. At a time when the USA is experiencing profound battles over access to health care services, the notion that large numbers of immigrants bring an additional health burden to the native-born population may generate increased xenophobia and discrimination.

A focus on Chagas disease in non-endemic countries may also take our attention away from the more important picture, shifting our focus from the poor of the global south to the 'worried well' of the global north. Chagas disease in non-endemic countries is part of 'global health,' certainly – but the shift in emphasis and gaze distracts us from the real victims of NTDs, the poorest of the poor, and harkens back to images of the 'sick immigrant' paradigm, where immigrants are to be feared and immigration to

be controlled if disease is not to run rampant in otherwise ‘clean’ places (Beiser 2005; De Maio 2010).

From the globalist perspective, Chagas disease is not important just because it may spread to non-endemic countries, tainting their blood supplies and requiring specialized costly treatments for those affected, but because it continues to burden poor populations in the global south, causing unnecessary morbidity and premature mortality. From this perspective, NTDs need not threaten the industrialized countries to be deemed a priority. One of the challenges in contemporary global health research is to strengthen the globalist position on NTDs; to make it – rather than the statist perspective – the normative lens. Overcoming the reactionary and defensive characteristics of statist thinking in global health is a tremendous challenge, but one that can be met, as evidenced by the work of non-government organizations such as Partners in Health and *Médecins sans Frontières*.

At the same time, advancing the globalist perspective in NTD research will necessitate a critical reappraisal of possible solutions. Chagas disease offers a particularly strong rebuke to claims that pharmaceutical or biochemical solutions are sufficient. Vector control through insecticide spraying – while effective in the short term – raises long-term questions, beginning with the health effects of exposing populations and the environment to toxins, as well as the very real threat of vectors developing insecticide resistance, signs of which have already been documented (Dias, Prata, and Correia 2008). Instead of relying on vector control through the spraying of insecticides, a structural approach to reducing the burden of Chagas disease in the Americas would focus on improving the housing stock of poor populations, recognizing that the bug vectors thrive in the building materials use by rural peasants throughout the region (WHO 2012). A shift from biomedical to structural solutions may very well challenge contemporary funding arrangements, based on the priorities and interests of major global philanthropic organizations as well as national funders like the Canadian Institutes for Health Research and the US National Institutes of Health. However, such a shift could signal a much needed return to the progressive history of public health – a profession which at its best engages with and challenges structural arrangements that cause harm to populations (Navarro 2008; Raphael 2011; White 2012).

Conclusion

Chagas disease is unique among the NTDs for its ability to be framed as a threat under a ‘securitized’ global health paradigm. Other NTDs, including schistosomiasis and lymphatic filariasis, have far more limited geographic scope, and to the extent that global health research is guided by issues of securitization, these and other NTDs will continue to afflict the poorest of the poor without ever becoming a priority. They will remain the forgotten diseases of forgotten people. Alternatively, social scientists may yet contribute to the NTD literature by examining the structural roots of NTD epidemiology. NTDs thrive on poverty, on political marginalization and neglect, on unmet basic needs. Global health researchers have done much to map out the distribution of NTDs, and we now know more than ever before about their prevalence and incidence. And effective policies – rooted, above all, in the improvements of living conditions for the poorest of the poor – may yet be developed. It is our challenge to raise awareness of NTDs such as Chagas while at the same time supporting a globalist position on health; diseases like Chagas matter, not just when they become a threat to populations in industrialized countries, but rather, because they are an avoidable, unnecessary, and unfair component of global health inequality.

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