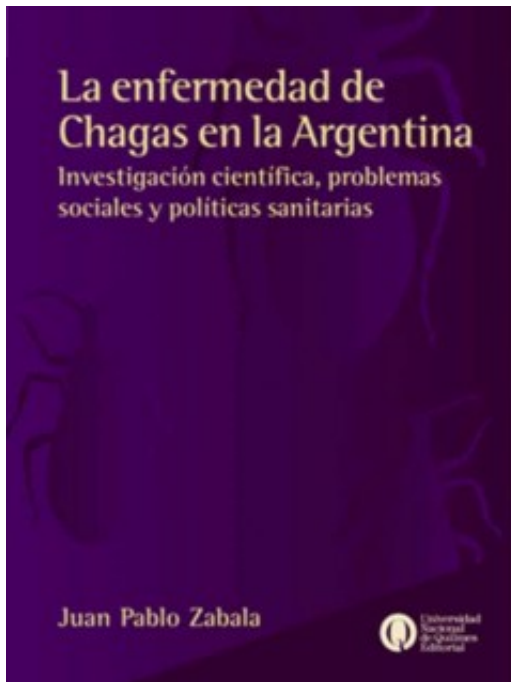


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## Zabala's Chagas Disease in Argentina

2014-07-28 12:04:47

By Gabriela Bortz



[La enfermedad de Chagas en Argentina. Investigación científica, problemas sociales y políticas sanitarias](#)

[Chagas disease in Argentina. Scientific research, social problems and health policies]

By [Juan Pablo Zabala](#)

Universidad Nacional de Quilmes, Argentina. 2010. 360 pages.

“Mal de Chagas” is a disease that affects 2.5 million people in Argentina and 8 million in Latin America. Caused by the parasite *Trypanosoma cruzi*, it generates heart, digestive and/or nervous system problems that may lead to death. The main vector of contagion is an insect (in Argentina, called “vinchuca”, in Brazil, “barbeiro”), which nests in the walls and roofs of dilapidated huts. Chagas disease is effectively a disease of poverty, as its transmission is associated with deficient housing, insufficient material conditions and sanitation facilities, malnutrition, and lack of access to

sanitary information.

Chagas is considered a “neglected disease”. This is due to: the lack of overt symptoms; the lack of information about the disease; the resignation concerning its existence and effects among populations where the disease is endemic; the tendency of infected people to hide their diseased status to avoid job discrimination; and lack of interest of private laboratories to develop new treatments due to the low purchasing power of the sick. Despite this relative neglect, research on Chagas in Argentina goes back to the early twentieth century and in the last thirty years the disease has received increasing attention from researchers in biomedical circles. These researchers have increased awareness of the disease in prestigious Argentinian academic circles. This has led to new research opportunities facilitated by the academic researchers’ working conditions, funding, research expertise, and international connections. Simultaneously, research agendas on Chagas have been displaced, from drug and vaccines development to basic research, with the discursive use of the first to assert the legitimacy of Chagas as an object of scientific research within the latter.

At a conceptual level we might ask: how was a set of scattered phenomena transformed into a scientific object – an ontological, observable and manipulable entity? At a socio-political level we might ask: how does the disease become ‘real’ as a social problem? What place does it take in the country’s political agenda and in the science and technology (S&T) policy agenda?

In his book, Juan Pablo Zabala studies the dynamics of inextricably intertwined social and conceptual worlds, examining how they define and redefine the landscape in which heterogeneous elements interact: research, physicians, scientists, research centers, state agencies, international networks, and policy makers. He shows how the trajectory of attention to Chagas disease was strongly shaped by factors including: the political and institutional agendas of the actors who promoted its construction as an “issue”; the scientific disciplines considered the main knowledge producers at different points in time (and intervention strategies with which they were associated); the broader political circumstances at the level of the state (government changes, *coups d’états* and political persecution); and international networks and research funding.

*Chagas disease in Argentina* provides a historical and sociological account in which three main levels of analysis are interwoven. These include analyses of:

(a) The formation of an epistemic object and the production of scientific knowledge: How were the object and research problems constructed?;

(b) The relationship between scientific knowledge and the development of public health interventions: How – and by whom – were the social and health problems constructed? What solutions were developed in response to the different understandings of the problems? How did the results of scientific research shape the intervention strategies on society?;

(c) How interactions between actors, groups and institutions led to the acceptance and stabilization of certain representations over others as well as the allocation of resources to certain forms of intervention rather than others.

Through his focus on this particular case and the interweaving of these three levels of analysis – with attention to historical particularities – Zabala calls for reflection on the social utility of science and the orientation of S&T policies in developing countries.

The book is structured chronologically. Within the socio-conceptual trajectory, we first encounter a period of the construction and definition of the disease in which the main actors were a small group of scientists, with training in protozoology and tropical medicine, interested in identifying the links between the pathogenic agent and a set of clinical symptoms. In a second phase, during the 1920s and under the microbiology paradigm, the characterization of the disease became stabilized by the representation of its acute stage. The eye inflammation associated with this acute stage of infection, a clinical sign that could be identified by non-specialists as easily as by specialists, allowed for a widespread redefinition of the disease and facilitated its recognition by the country's medical community and secured its place in the public health agenda.

Between 1940 and 1960 Chagas became recognized as an important sanitary and social problem. This reconceptualization involved a new set of actors, sanitary physicians and policy makers, leading to another new conception of the disease, specifically as the cause of a chronic heart condition of great epidemic proportions – rural at first and urban thereafter, due to internal migrations. New public health interventions and practices were introduced, focusing on epidemiological diagnosis, measurement, and prophylaxis.

Finally, beginning in the 1970s, in a fourth stage, intervention policies were stabilized and the disease was taken up by new actors: biomedical researchers from the fields of biochemistry, immunology and molecular biology. At first, research was oriented toward the development of therapeutics and vaccines. However, with increasing academic interest in and incentives for basic research on molecular explanations of the disease (namely, funding availability, insertion within international research networks, possibilities for academic career promotion), the objective of

developing therapeutics and vaccines was displaced. Concurrently, in the late 1970s, the importance of the disease within national health policies declined and state agencies that were devoted to their implementation entered into a process of institutional weakening.

As Shapin and Schaffer (1985) argue, “solutions to the problem of knowledge are embedded within practical solutions to the problem of social order, and that different practical solutions to the problem of social order encapsulate contrasting practical solutions to the problem of knowledge”. On this level of analysis, Zabala traces the process of co-construction of knowledge about social and health problems (i.e. different ways of constructing the problem and object of research) and solutions for these problems (i.e. diverse intervention practices). In this sense, while different ways of framing knowledge prefigured diverse solutions in the form of health policy measures, the political stances that prevailed at each historical period tended, in turn, to promote certain knowledge production practices that fostered those measures. The measures, at the same time, stabilized the political positions of the different stances over time, both at the level of national politics and within expert communities.

The author frames his research within a tradition of sociology and history of science and technology, returning in his analysis to heuristic tools from both the constructivist and the neo-institutional approaches to the sociology of science. From a constructivist perspective, Zabala delineates a journey through the meanings that different social groups attributed to Chagas disease as a conceptual and social problem and the interventions that were accordingly carried out. The analysis recounts the negotiation of meanings between actors in the construction of Chagas as a morbid entity, as an object for public health and a research object, and the respective ways of representing the disease: its symptoms, diagnosis, the actors that were involved, privileged spaces for knowledge production and ways of considering and intervening on the infected population.

Using a neo-institutional matrix, the book examines how disciplinary frameworks shaped knowledge production (enabling some research paths while constraining others) and the different “scientific subcultures” that predominated across the different historical periods: parasitology, microbiology, entomology, immunology, biochemistry, molecular biology. Analyzing disciplinary framings of the disease along with the institutional conditions under which scientific activities took place (i.e. research practices, ways of posing questions, institutional constraints and incentives, international networks involved, possibilities for participating in policy decision making), permits Zabala to identify how the relations between knowledge production and social-sanitary interventions were shaped.

From the resulting conceptual framework, Zabala – through a thorough historical account – captures the complexity of Chagas disease’s “biography” as an “epistemic thing” (Rheinberger, 1997), as a social problem and as an object of intervention.

But what lessons can be learned from the case of Chagas? From a policy perspective, who is included and who is excluded via diagnostic practices, agenda setting, policy design and implementation? Whose views are taken into account? How are S&T and health policy agendas interwoven? And how does this research encourage us to reflect on national scientific and technological policies in Latin American countries? Along the journey delineated by Zabala, three elements remain stable: the consideration of the disease as a “social problem” at the policy level, the participation of scientists in the definition of these processes, and endemic poverty of people infected by the parasite. Regarding this last point, while a multitude of heterogeneous actors have been involved in ascribing meaning to the disease and shaping its representations, one group has been conspicuously absent: the sick.

Strikingly, the population affected by Chagas disease has not been engaged directly in the struggle against the disease; their needs have always been represented by other, more powerful, actors (Kreimer and Zabala, 2006). This leads us to pose the challenging question: how can Chagasic patients become activists for promoting R&D and policy interventions? While there are many diseases for which patient activism and expertise has played a significant role (AIDS is a prime example, Epstein, 1995), in the case of Chagas disease, conditions of structural poverty, lack of access to information, and general neglect has prevented “chagasics” from becoming acknowledged actors within discourses about the disease. Their empowerment as a group, and the possibility of their inclusion into the Chagas debate, is thus a structural challenge: it needs to go far beyond aiming at a specific solution to a specific problem, but instead to seek a systemic socially inclusive process.

*Chagas disease in Argentina* also allows us to critically analyze the reasons why finding solutions for neglected diseases – Chagas is a paradigmatic case – have not yet become scientific and technological priorities even within countries where these diseases are prevalent and where there are sufficient R&D capacities to take up the challenge. In addition, the book raises questions about the kind of R&D solutions that are sought (and funded): do national and international funding agencies promote and pursue basic or applied research? In case of the latter, do they look for new high-tech diagnostic kits (for a disease that already has a diagnostic gold standard) or do they fund R&D for prevention and treatment? Are the R&D solutions that are sought articulated with the actual needs of the health system?

Lastly, the book identifies a dilemma that is integral to research strategies and norms of academic evaluation: if career promotion and funding assignment is related to publishing in international high impact journals (most of which focus on basic science), what are the possibilities for developing R&D institutional agendas oriented towards solving local social problems? And what are the possibilities for engaging in research that may be less fruitful in terms of publication but may result in interesting technological developments for addressing social needs?

Zabala's *Chagas disease in Argentina* presents an interesting study of a disease that is emblematic to Latin America and a fruitful analysis of the socio-conceptual trajectory of a research object which is perpetual being reconstructed. The analysis presented in the book is not only relevant to rethinking other neglected diseases prevalent in the region (tuberculosis, dengue, leishmaniasis), but also, and in a broader sense, to promoting wider research-based discussion – and stakeholder engagement – on how S&T policies are oriented (or not) towards addressing local problems and needs.

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#### **Works cited:**

Epstein, S. (1995) The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. *Science, Technology, & Human Values*, Vol. 20 (4), Special Issue: Constructivist

Perspectives on Medical Work: Medical Practices and Science and Technology Studies, 408-437.

Kreimer, P. and Zabala, J. P. (2006). ¿Qué conocimiento y para quién? Problemas sociales, producción y uso social de conocimientos científicos sobre la enfermedad de Chagas en Argentina, *Revista Redes*, 23, 49-77.

Rheinberger, H-J. (1997). *Toward a History of Epistemic Things: Synthesizing Proteins in a Test Tube*. Stanford, California: Stanford University Press.

Shapin, S. and Schaffer. S. (1985). *Leviathan and the Air-Pump: Hobbes, Boyle, and the Experimental Life*. Princeton: Princeton University Press.

Zabala, J. P. (2010). *La enfermedad de Chagas en Argentina. Investigación científica, problemas sociales y políticas sanitarias*, Bernal, Universidad Nacional de Quilmes.

#### **AMA citation**

Bortz G. Zabala's Chagas Disease in Argentina. *Somatosphere*. 2014. Available at: <http://somatosphere.net/?p=8694>. Accessed July 28, 2014.

#### **APA citation**

Bortz, Gabriela. (2014). *Zabala's Chagas Disease in Argentina*. Retrieved July 28, 2014, from Somatosphere Web site: <http://somatosphere.net/?p=8694>

#### **Chicago citation**

Bortz, Gabriela. 2014. Zabala's Chagas Disease in Argentina. Somatosphere. <http://somatosphere.net/?p=8694> (accessed July 28, 2014).

#### **Harvard citation**

Bortz, G 2014, *Zabala's Chagas Disease in Argentina*, Somatosphere. Retrieved July 28, 2014, from <<http://somatosphere.net/?p=8694>>

#### **MLA citation**

Bortz, Gabriela. "Zabala's Chagas Disease in Argentina." 28 Jul. 2014. *Somatosphere*. Accessed 28 Jul. 2014. <<http://somatosphere.net/?p=8694>>