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Chagas disease: A brief analysis of some of the factors influencing the disease's persistence

Enfermedad de Chagas: breve análisis de algunos factores que influyen en su persistencia

Moretti, Edgardo¹

¹PhD in Biochemistry. Specialist in Immunology. Laboratory Head, National Chagas Service. Professor, Faculty of Medical Sciences, Universidad Nacional de Córdoba, Argentina. eram112@live.com.ar

Commentary on: Zabala JP. The disease in its labyrinth: advances, challenges and paradoxes over 100 years of Chagas in Argentina. *Salud Colectiva*. 2012;8(Suppl 1):S9-S21.

As Dr. Juan Pablo Zabala's excellent article (1) demonstrates, Chagas disease offers a clear example of the need to find points of connection between the biomedical and social sciences, which often travel in separate lanes. The complexity of this endemic disease requires the perspectives of different disciplines as well as the making of political decisions to which these different disciplines should contribute. In this way, social, bioethical, psychological, anthropological and philosophical aspects must be present in any discussion aimed at making the problem "visible" and contributing to its solution, considering the human being as the main objective. Foucault's (2) concepts of biopolitics and biopower and Badiou's (3) notion of spectacle bodies, enslaved bodies and bodies with ideas serve as examples of this.

I will discuss some aspects that I consider significant (although strictly speaking, Zabala's whole article is significant) from a biomedical perspective based in my professional training and

from a social perspective based in my personal inclinations.

I agree with Zabala's lucid way of addressing the problem using the tension of visibility-invisibility. I also consider central his questioning of the persistence of the disease for more than 100 years and his critique of the simplistic approaches adopted in an attempt to explain that persistence.

The multiple paradoxes accompanying Chagas disease start with the discovery of *Trypanosoma cruzi*, the etiological agent, and the disease caused by this parasite. Due to several circumstances – among them the famous "mistake of Carlos Chagas" in attempting to establish a cause-and-effect relationship between trypanosomiasis and goiter, two entities associated in time and space – this disease has always been the subject of discussion. Unfortunately, these discussions, rather than contributing to the solution of the problem, have pushed it into the background and subordinated it to irreconcilable personal positions, political ups and downs, excessive "medicalization," among other situations that have favored such descriptions as "forgotten disease," "silent and silenced endemic disease" or "hidden harm." Even the World Health Organization (WHO) includes it among the sadly labeled "neglected diseases," an adjective undoubtedly well applied to describe men and women whose "invisibility" marginalizes them (1), as stated by Zabala. Or, in the words of Dr. Ramón Carrillo: "Faced with the diseases caused by misery, faced with the people's sorrow, anguish and social misfortune, microbes, as causes of disease, are poor causes."

In the article under discussion, there is a quote from a WHO publication (4) according to which "official data" reveal that 8 million people are infected. If in Latin America just a few years ago the number of infected was estimated at 18 million people, it is difficult to understand how this last official data, "decreasing" year by year,

were reached. Was it due to errors in previous estimates? To the exaggerated “optimism” of official data? To the tendency to make the problem less “visible”? A disparity of 10 million people between these estimates is too high to permit a rational explanation of the disease’s “statistical disappearance.” Indeed, as Chagas disease is an indicator of poor quality of life, some governments of the endemic countries may be tempted to favor the “invisibility” mentioned by Dr. Zabala, in addition to the neglect of people who live in hyper-endemic areas, such as the *wichis*, *pilagás* and other ethnic groups from the geographical region of Gran Chaco. In a *wichi* community, a few years ago, we detected a prevalence of infection 10 times higher than the national average (5) – and unfortunately, taking Carrillo’s quote into account, Chagas disease may not be the main problem of these communities.

What other factors may be influencing this invisibility? Undoubtedly, university education is another important factor. In this regard, at the Training Sessions to Reinforce Chagas Disease Education in Health Sciences Degree Programs (6), held at the Universidad Nacional de Córdoba and attended by professors of Health Sciences from all over the country, the issues raised were the existing deficiencies in education and the pressing need to reinforce the teaching of Chagas disease and other diseases of regional impact. It was discussed that the focus should be placed on undergraduate degree programs, given that if students do not perceive the importance of the problem during their undergraduate training, their interest will be limited during graduate instruction, for reasons also explained by Dr. Zabala (1). These Sessions, which have been held three times in Córdoba since 2008 and, thanks to the support of the Pan American Health Organization (PAHO), also took place in Recife and Lima in 2009 and 2010, seek as a primary objective to denaturalize the idea that the diagnosis and treatment of Chagas disease only concerns “specialists in Chagas disease.” Instead, they propose that physicians of any specialty should be familiar with the basic concepts necessary for prevention, diagnosis and treatment; that biochemists should have the basic skills and knowledge to carry out and interpret parasitological and serological diagnoses; and so on in all of the health-related degree

programs. One effect of these Sessions was that they served as the base for the National Chagas Program to include for the first time education, in addition to information and communication, as a tool for controlling the endemic disease (7).

In this vein, Dr. Zabala’s article presents a topic offering an interesting motive for debate: Should cardiac diseases be treated by “Chagas specialists”? From our standpoint, based on the conclusions of the Sessions mentioned previously, pediatricians, neonatologists and infectologists should be trained to treat all infections, including acute, vectorial and congenital infections, and, similarly, clinicians, cardiologists or gastroenterologists should be able to provide medical or surgical treatment of chronic Chagas disease. To the contrary, the treatment of individuals infected with Chagas, prevention in the case of pregnant women or at-risk populations, prophylaxis and immunosuppressive treatment, to name certain concrete examples, is unfeasible.

As to the influence exerted by the scientific research into Chagas disease, the following statement opens a debate that greatly exceeds the possibilities of this commentary: “the scant concrete incidence of science in people’s living conditions” (1 p. 11). I agree that research has frequently dealt with the *Trypanosoma cruzi*-host interaction as an interesting experimental model rather than to contribute to solving concrete problems, partly distorting the objectives of the national programs promoting Chagas disease research, which reached their peak in the 1970s and 1980s. It is to me beyond question that without basic research, advances in knowledge are unthinkable; indeed, that there are abundant examples of important medical applications which were the product of “basic research.” Nevertheless, in the case of Chagas disease, there has perhaps thus far been less applicability to the health field than would be expected.

It is however fair to mention, as does Dr. Zabala’s article, the numerous research studies into clinical medicine, epidemiology, vectors, reservoirs and many other aspects which led to “the rediscovery of Chagas disease” by the team headed by Salvador Mazza in the Argentine Regional Pathology Study Mission [*Misión de Estudios de Patología Regional Argentina*]. In my view, this was one of the most important periods

in the history of Argentine medicine, in which physicians in cities and towns of numerous provinces took up Mazza's call to study an unknown and controversial disease, apparently restricted to tropical regions but nonetheless found in provinces such as Mendoza and Neuquén, to name only the southernmost provinces (8-10). Simply amazing.

Since the 1960s there have also been many significant research findings regarding the clinical profile of the disease (11,12) and congenital transmission (13,14), among other aspects; such transmission has been responsible to a great extent for the urbanization and globalization of Chagas infection. Also important to mention are the notable advances in serological diagnosis and, possibly in the future, molecular biology methods still in the standardization stage (15), in addition to the demonstration of the efficacy of a vaccine for domestic animals – identified reservoirs of the disease – which could interrupt the epidemiological chain in active transmission sites (16,17). There are certainly more examples that the limited space of this commentary impedes me from mentioning, however I would like to reiterate that scientific research should show greater commitment to the practical applications of its studies.

In terms of the “visibility-invisibility” tension, heated controversies still exist regarding the following aspect addressed in the article: the “random barrier separating the infected from the ill” (1 p.13). Interesting questions about the chronic stage are raised: Who are only “infected”? Who are “sick”? Does it depend on the sensitivity of the study methods? Does it depend on the opinions of experts that may vary from one generation to the next? Technological advances undoubtedly fuel this controversy, which is not exclusive to Chagas. The concept of “proto-diseases” is surrounded by controversies connected to the pharmaceutical companies' interests.

The apparent paradigm by which 25% to 30% of infected individuals develop cardiac or digestive pathologies decades after infection is currently under discussion, to such an extent that the Argentine Federation of Cardiology [*Federación Argentina de Cardiología*] has recommended changing the denomination “undetermined stage” to “chronic stage without demonstrable pathology.” This is a matter of debate which, of

course, includes the question of what patients should be treated with antiparasitic drugs. For years infectologists and cardiologists have strongly disagreed with each other, and it seems that in the present the debate has been rekindled.

To conclude, I would like to make reference to one of Zabala's reflections, in which the author states that the persistence of Chagas disease may be “the predictable and logical result of the actions of the different social actors involved” (1 p.18). Such a statement poses a formidable challenge to government officials, politicians, researchers, professors, health care professionals, and other “social actors.” Perhaps the problem is not “Chagas disease,” but rather the infected, sick or at-risk individuals, primarily children, who hope to “make themselves visible” while immersed in living conditions that contribute to the persistence of endemic diseases and the emergence or reemergence of diseases we thought had been eradicated.

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Power and money, culture and knowledge. Response to the commentaries

Poder y dinero, cultura y conocimientos. Respuesta a comentarios

Zabala, Juan Pablo¹

¹PhD in Social Sciences, Facultad Latinoamericana de Ciencias Sociales. PhD in History of Science, Université Paris 1 Panthéon Sorbonne. Researcher of the Consejo Nacional de Investigaciones Científicas y Técnicas at the Institute of Science and Technology Studies, Universidad Nacional de Quilmes. Director, General Archive of the Nation (Argentina). jpzeta@unq.edu.ar

Response to the commentaries of: Storino R, Stagnaro AA, Freilij H, Auger S, Castro I, Moretti E. *Salud Colectiva*. 2012;8(Suppl 1):S23-S36.

The diversity of the commentaries made put into evidence some of the tensions mentioned throughout my article, enabling us to observe the concrete expression of the paradoxes. The commentators, not only experts in Chagas disease but also actors involved in day-to-day interventions, give examples of the implications and limitations they face every day in the control of the disease.

In this sense, and returning to the question of how to explain the persistence of the disease over 100 years after its discovery, there seems to be consensus around the idea that the primary cause is the lack of actions sustained over time. With slight differences, most commentators hold that Chagas disease control is a matter that depends on political willingness to allocate funds for control strategies that have already been applied in the last decades. "Much has been done," says Freilij (1 p.29), "but there is still much more to do." And the indicators described serve to support this position.