



## The disease in its labyrinth: advances, challenges and paradoxes over 100 years of Chagas in Argentina

La enfermedad en su laberinto: avances, desafíos y paradojas de cien años del Chagas en Argentina

Zabala, Juan Pablo<sup>1</sup>

<sup>1</sup>PhD 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](mailto:jpzeta@unq.edu.ar)

**ABSTRACT** This article analyzes the century-long persistence of Chagas disease in Argentina, taking into account the different dimensions (the biological, the informational, the political, the professional and the technical) that take part in the disease's definition. Emphasis is placed on the identification and discussion of fundamental tensions that have marked the history of the disease, with the intention of discussing the concrete conditioning factors that have, on the one hand, permitted the continuity of Chagas as a subject of political consideration, but on the other have made it impossible to reach a situation of definitive control over the disease.

**KEY WORDS** Chagas Disease; Knowledge; History; Policies.

**RESUMEN** El artículo analiza la persistencia de la enfermedad de Chagas en la Argentina durante más de un siglo, prestando atención a las diferentes dimensiones (biológica, de conocimiento, política, profesional y técnica) que participan en su definición. Se pone el acento en la identificación y discusión de algunas de las tensiones fundamentales que han marcado la historia de la enfermedad, con la intención de discutir cuáles han sido los condicionamientos concretos que han marcado, por un lado, la continuidad de la enfermedad dentro de la consideración política pero, al mismo tiempo, la imposibilidad de alcanzar una situación de control definitivo.

**PALABRAS CLAVES** Enfermedad de Chagas; Conocimiento; Historia; Políticas.

## INTRODUCTION

Chagas disease, also referred to as American trypanosomiasis, celebrated a century of existence in 2009, from the day Carlos Chagas announced the discovery of *Trypanosoma cruzi* (the causative parasite), the insect vector (triatomine bug in English, called *barbeiro* in Brazil and *vinchuca* in Argentina) and a set of characteristic clinical symptoms. This announcement occurred in the Brazil of the early 20th century, a time when the control of infectious diseases appeared a sure ticket to order and progress (1,2).

Throughout the 20<sup>th</sup> century, Chagas disease became a symbol of the huge portion of the population of Latin America living in conditions of material poverty, especially in rural areas, with little information or access to basic health and sanitation services. This situation is currently reflected in official figures showing 8 million people infected with the parasite – who are susceptible to suffering from the chronic cardiac and digestive conditions characteristic of the disease – and 100 million people at risk of getting infected, as well as 56,000 new cases annually and 12,000 deaths per year (3).

For over half a century, Chagas has been recognized as a major public health problem, at least discursively, both in Argentina and the rest of Latin America, and several intervention programs have been developed in order to control the disease. These programs have included a variety of actions, such as the elimination of vectors, the promotion of research in different areas of knowledge, the regulation of blood transfusions, education campaigns, and housing improvement. Nevertheless, the antiparasitic treatments in use today are the same that have been available since the mid-1970s, and the other treatments used for cardiac or digestive symptoms are not specific to the afflictions derived from Chagas disease.

How can we understand the persistence of the disease throughout the decades, in a context in which technical resources are available for its control and the political initiative to allocate funds to fight this disease exists?

This article seeks to formulate a response to this question based on the idea that Chagas disease has been marked by a fundamental

tension between recognition and neglect that has influenced its history. On the one hand, we find the existence of actions that have emphasized the importance of Chagas as a social problem, placing it in the field of politics and in the collective consciousness as an issue requiring intervention. On the other, we observe actions that have tended to invisibilize the problem in political, medical and symbolic terms. The results of this tension are prolonged actions aimed at controlling the disease in different ways, but also the impossibility of definitively achieving this objective. In other words, Chagas disease has neither been so neglected as to disappear from the political agenda nor so present as to put a permanent end to its reproduction cycle.

It is necessary to explore this tension and analyze the way in which it is inscribed within the rationalities, beliefs and interests of the different actors involved in the definition of the disease – politicians, physicians, researchers, the infected and the ill – in order to avoid replicating the two approaches typically used to explain the “failure” to control Chagas. The first of these approaches, which is eminently scientific and technocratic, emphasizes the lack of development of adequate means of disease control, such as vaccines, more effective antiparasitic drugs or insecticides with greater residual action. From this standpoint, advances in science and technology are what will eventually enable us to put an end to the problem (a). The second explanation tends to take a political and commercialist perspective: the persistence of Chagas is related to lack of political interest because it is a disease that affects people who are poor – and who are thus subjects unable to generate earnings and profits. Therefore, the only way to solve the problem is to define political priorities with non-mercantile criteria.

When we take a closer look at the disease, we see that these simplistic approaches do not reflect its reality. Chagas is a complex entity conditioned by the biological processes involved as well as the professional, economic, political, cultural and institutional interests at stake in the definition of the disease and, above all, in the way to take action and intervene. As a result of this complexity, the trajectory of the disease contains a series of paradoxes that have marked its prolonged history:

- a. A milestone in the history of science, and yet an entity which tends to be invisible within current medical practice.
- b. A “neglected disease,” and yet a constant in the public policy agenda.
- c. The achievement of relative success in terms of fighting the vector, and yet the persistence of a reality that contributes to the vector’s development.
- d. The disease with the largest affected population, and yet the least visible social group in terms of identification and social organization.
- e. A rural disease, and yet an urban public health problem and a threat to developed countries.
- f. An important symbol of the scientific community’s commitment to social reality, and yet a sign of the scant concrete incidence of science in people’s living conditions.
- g. A field of knowledge with major advances, and yet with drugs approximately 40 years old and with limited effectiveness.

These paradoxes will be analyzed through three fundamental nodes in the definition of Chagas, which may enable us to understand, according to the particularities of the disease (5), the way in which the tension between visibility and invisibility has expressed itself historically, always as a result of a mutual conditioning among the different technical, biological, informational, professional and political dimensions. The first of these nodes refers to the definition of the disease according to its biomedical aspects, both in its characterization and in the administration of treatments. The second makes reference to the way in which the disease has become the object of different types of public policies, with the consequent implementation of different plans of intervention. The third refers to the disease as a structuring framework of identities and relations, which condition and preform the identities of the affected individuals.

## DISCOVERY, REDEFINITION AND DISAPPEARANCE OF THE DISEASE

Diseases differ from the rest of the social problems in that their definition uses as a frame

of reference one or many of the biological events which, through the expert views of scientific and professional knowledge, condition how the disease is conceived. This obligates us consider that the very definition of those events – objective in appearance – is also the result of social processes in which it is possible to find elements that condition how the disease is finally constituted as a social problem.

In the case of Chagas, the process by which the disease became a stable medical entity is particularly rich for exploring the tension between *visibility* and *invisibility*, as the profound changes it has undergone at the cognitive level throughout its history have made the demarcation of the problem unstable. Chagas disease made a striking appearance in the medical and scientific world at the beginning of the 20<sup>th</sup> century. Its appearance is recognized as an exceptional case in the history of traditional science and medicine, given that in a very short period of time a single person was able to discover all the components of a new infectious disease: the causal agent (*Trypanosoma cruzi*), the vector (*vinchucha*, *barbeiro* or triatomine bug) and the clinical profile of the disease.

The characterization of the disease first made by Chagas in his works stated that, in recent infections, the *acute* stage “almost always results in death [...], especially in the case of children under 6 months of age,” whereas in children “over 1 year of age, it does not always prove fatal; many infected individuals pass on to the chronic stage” (6 p.263). Undoubtedly, the *chronic* stage (b), related to the effects of the infection in the long term, was what aroused the greatest interest in the medical community and public health policymakers. In this stage of the disease, Chagas asserted, the parasite caused serious functional perturbations in the thyroid gland and nervous system, thus suggesting an explanation for the health situation of a region characterized by a high rate of goiter; a vast number of cases of profound anemia with great organic decline, causing developmental delays in children and infantilism in adults; notable deficiencies in the nervous system; and, associated with these deficiencies, speech and communication impairments along with a large number of cases of imbecility (7). Chagas further stated that “in some cases [...], especially in adults,

perturbations of the cardiac rhythm are very frequent" (6 p.265).

The reverberations of Chagas's announcement lay not only in the scientific ability to identify a new species but also in the capacity of those assertions to propose a biologically-based explanation for a social situation of poverty, deprivation, and underdevelopment, via the identification of causes invisible to most people. With this demarcation, the experienced eyes of a scientist trained at the forefront of the protozoology of the time, with access to a scientific laboratory and with a prestige consolidated in previous successful public health campaigns (c), offered a new lens for understanding the decades-long misfortune of millions of people scattered across the immense region of Brazil set away from the coast. And, from this point of departure, the articulation of a political movement – led to a great extent by Chagas – that proposed the "sanitization of Brazil" through the eradication of certain agents hazardous to public health, with scientific research spearheading these measures (9,10).

Nevertheless, Chagas's description in the first years of the disease then became the subject of long-standing professional debates which questioned the seriousness of the disease and marked the transition from a first stage of wide recognition to another defined by uncertainty, controversies and, definitively, neglect. In particular, the difficulty of demonstrating cases that confirmed the magnitude of the disease (d) and the continued questioning of the relationship between the parasite and goiter radically rocked the foundations of what had constituted the disease as a public health problem (e).

Many years elapsed before reaching the current definition of the disease as characterized by cardiac and digestive conditions. From the early 1920s to the late 1930s, research regarding the disease focused on defining the true effects of the parasite, the way to identify infected individuals, and the possibility of distinguishing a specific clinical profile. This task took on special significance in the studies carried out by Salvador Mazza in the Study Mission on Regional Pathologies of the North [*Misión de Estudios de Patología Regional del Norte*] in the mid-1920s (13,14). At a time when it was believed that the disease did not exist in Argentina, Mazza explored the matter in the context of a program of study on regional pathologies in the north of Argentina,

promoting and articulating different studies that looked in to many of Chagas's initial concerns (f).

In that context, the disease increased in importance as the number of "acute cases" compiled grew. This growth was favored by the discovery of "Romaña's sign" – an inflammation of the eyelid caused by the bite of the *vinchuca* – which allowed the disease to be identified by non-expert physicians (2,9,16,17,18). By the late 1930s, the disease began to be considered a public health problem of great importance within the scientific-medical field, thanks to the accumulation of certified cases and the intensive activities of scientific communication carried out by Mazza and his collaborators.

Nevertheless, despite the resurgence of Chagas as a subject of professional interest, the definition of the clinical profile of the disease remained erratic. Goiter and nervous conditions lost importance in the definition of the clinical profile, while the cardiac form of the disease, starting in the 1930s, became the main interest of research studies, both in Argentina and Brazil. Chagas and his disciples maintained, within a small group, their interest in the issue in Brazil: "The cause-and-effect relationships, if indeed they exist, between goiter and infection by *Trypanosoma cruzi* are debatable. [...] It is an open question that merits further studies and insights" [*Discutíveis são as relações de causa e efeito, acaso existentes, entre o bócio e a infecção pelo Trypanosoma cruzi. [...] É uma questão aberta, a merecer estudo e perspicácia.*] (19 p.63). Not until the 1950s did Chagas cardiopathy become the object of systematic research for cardiologists, who defined within the framework of that specialty both the specific characteristics of Chagas in relation to other cardiac diseases and the diagnosis of "chronic Chagas cardiomyopathy" via electrocardiogram (g).

With this description of the cardiac profile, the disease broke the random barrier separating the infected from the ill: having Chagas disease would no longer mean simply testing positive in a biochemical test for *Trypanosoma cruzi* infection, but also developing a specific condition, identified by the instruments and knowledge of cardiology. Therefore, its importance as a public health problem was based on a specific number of individuals with a condition impairing their work

ability, which translated into the suffering of those with the condition and into measurable losses in the country's production capacity due to the reduction in the workforce.

This new description implied a reconfiguration in the meaning of the disease, in that a specific medical specialty – cardiology – emerged as the area of legitimate knowledge and professional practice for defining sick individuals, the symptoms of the disease and the gravity of those symptoms. This also meant a relocation of the problem spatially, in that public health care centers in the city of Buenos Aires began to diagnose chronic cases of Chagas disease among their patients, rural migrants who moved to the city to work.

Broadly speaking, over the last decades, the visibility of the disease within the medical world has been maintained within this articulation of knowledge and practices. This persistence can also be observed in the professional world and in the heart of health institutions: the formation of a community of cardiologists specialized in Chagas disease and the creation of Chagas services in different hospitals are tangible indications that the issue has maintained certain relevance within the health field.

Nonetheless, this visibility is opposed by other tendencies that threaten the recognition of Chagas as an autonomous morbid entity. Indeed, it is possible to observe at least two phenomena in the last years that tend towards the invisibilization of the disease. Firstly, the advances in cardiology increasingly lead, on the part of the cardiologists themselves, to the treatment of the disease according to the patients' coronary symptoms, disregarding that such deficiencies are caused by a parasitic infection. Whether through drugs, pacemakers or micro-defibrillators, Chagas cardiomyopathy receives specific treatments that tend to reverse those symptoms, in the same way as with any other cardiac condition. In other words, it is not necessary to be a specialist in a particular area in order to treat Chagas disease.

This phenomenon has its impact in the organization of the health profession. Whether due to the lack of intellectual and professional challenges or the scant economic possibilities it offers, Chagas does not appear an attractive option within the professional specialties. The communities of experts maintain their same

senior members but have little generational turnover. Therefore, although it may be recognized within public health discourses as an important health problem, Chagas disease tends to be invisibilized within current professional medical practice, and is diluted within procedures that are not specific to its etiology.

Only in the last years have initiatives been implemented to reinforce the importance of treating the parasitic etiology of the Chagas-originated cardiac conditions, suggesting the administration of antiparasitic treatment to the chronically ill. This approach has not escaped controversy (20) as at least two opposing views exist without there being conclusive evidence on the subject. On the one hand are those who argue that once the parasitic infection has persisted over a certain number of years, the antiparasitic treatment is ineffective and its administration is no longer justified, as it provides no benefit to patients and exposes them to the harmful side effects of the drugs prescribed. However, others argue that the treatment is beneficial even for the chronically ill, although the negativization of the infection can only be demonstrated in serological analyses after several years. The second perspective has gained ground in recent years and treatment is now officially recommended in children and adolescents. Regardless of how the controversy is finally resolved, it is interesting to note that behind the scientific debate lie two different ways of delineating the disease from a medical standpoint: one that considers only those with cardiac or gastrointestinal conditions (who make up only 30% of all those infected) through general treatments used for similar conditions of different origins, and another that recovers the specificity of the disease by attacking its etiology and suggesting intervention in the totality of those infected.

### **CHAGAS AS THE OBJECT OF POLICY: BETWEEN NEGLECT AND RECOGNITION**

Chagas is one of the so-called "neglected" diseases. This term has been applied to a group of widespread endemic diseases, which mainly affect populations of little resources in Latin America, Africa and Asia, and cause great losses



in terms of mortality and morbidity. In particular, this term is applied to those diseases that do not represent an economic interest to the pharmaceutical industry that would justify the development of new drugs. The consequence of this lack of interest is that there is little dynamism in the development of modern and more effective treatments, as in the case of Chagas.

This neglect can also be perceived in other dimensions such as in the lack of initiatives for disease treatment, control or eradication, even if the necessary means of preventing or curing those diseases exist, frequently at a low cost. However, the image transmitted by the term “neglected” should be somewhat attenuated, at least for Argentina. Chagas disease has remained an important issue both in the public health agenda and in the collective conscious at least since the 1950s, and is still the object of specific health campaigns carried out by the government and NGOs, including vector control, housing improvement, and actions to educate and raise awareness in the populations in which the disease is still endemic, among other measures.

The official recognition of Chagas as a public health problem dates back to the late 1930s. As a sign of this interest – recent at that time – on the part of the State, Alfredo Sordelli, Director of the Carlos G. Malbrán Microbiology Institute highlighted the following at the 10<sup>th</sup> Pan American Sanitary Conference in 1938:

The infestation is spread all over the Argentine territory [...] Recently there has been such a recrudescence that the number of cases reaches at least 300. We therefore consider the problem worthy of great attention (16 p.450) [Own translation].

It was not until the end of the 1940s that this recognition assumed greater importance, owing to the convergence of three independent processes: a) the redefinition of the disease in medical and epidemiological terms as a chronic and mainly cardiac condition affecting approximately 1,000,000 people in the country (the number of people presumably infected with the parasite); b) the availability of Gammexane as the primary means of fighting the insect vector; and c) a context of public health policies favorable to

the recognition of and fight against epidemics, embodied principally by the figure of Ramón Carrillo, Minister of Health under Peron’s government. Therefore, Chagas disease came to be categorized as a “national problem” (21) and around it an institutional apparatus was developed which included programs for fighting the vector as well as the planning of activities for diagnosis, research, and development of alternative treatments.

The main Chagas intervention policies were oriented towards interrupting infection by the vector, that is, infection through the bite of the *vinchuca*. These policies manifested themselves in different ways throughout the 20<sup>th</sup> century. They were first implemented by the Executive Committee for Chagas Disease Research and Prophylaxis [*Comité Directivo de Investigaciones y Profilaxis de la Enfermedad de Chagas*], created in 1950 as the first institution officially responsible for fighting the disease, which reported to the recently created National Ministry of Health. This Committee saw the beginning in Argentina of what its director Cecilio Romaña, former colleague of Salvador Mazza, called “the era of residual insecticides and [of] the ‘new awareness’ awakened by preventive medicine” (22 p.215).

Throughout the years, this institution underwent several transformations. In 1952 it became the National Service for the Prophylaxis and Fight against Chagas Disease [*Servicio Nacional de Profilaxis y Lucha contra la Enfermedad de Chagas*], also headed by Romaña, “in charge of the implementation, enforcement and surveillance of the programs created for such purposes” (Executive Order 2177 on July 8, 1952). It was in this context that the first Chagas disease control measures took place, following the technical considerations that emerged from Romaña’s experimental studies. The first insecticide-spraying campaigns (with Gammexane) were conducted systematically in the provinces of Chaco, La Rioja and Catamarca, though these campaigns were of an experimental character and the number of houses sprayed was quite limited in scope (23).

In the period succeeding Peron’s government, both institutional transformations and medical care for Chagas were constants. The consolidation of Chagas disease as a major social problem was accompanied by the creation of a series of institutions aimed at identifying and

measuring the disease and controlling its transmission, not only through the *vinchuca* but also through the establishment of compulsory tests for Chagas disease in blood banks and hemotherapy services (starting in the early 1960s), and subsequently in organ donations. Thus, from the mid-1950s onward, the National Service for the Prophylaxis and Fight against Chagas Disease, created by Health Minister Ramón Carrillo, continued to develop and transform until becoming the current Fátala Chabén National Institute of Parasitology, dedicated almost exclusively to the diagnosis of Chagas disease. It is also important to mention the creation, in the early 1960s, of the National Chagas Program, a nationwide structure responsible for the fumigation of rural houses that has been conducting campaigns to fight the vector for decades.

All of these measures have experienced the ups and downs of Argentina's history, and the systematicity of their implementation has varied according to the interest aroused in the provincial authorities of each historical period. Nevertheless, it is possible to observe a general decrease in the tendency of the transmission of the disease in the different modes of transmission. Thus, while in 1964-1969 10% of the total 18-year-old population presented the infection, by the early 1980s this percentage had decreased to 5.8% and in 1993 to 1.9% (24 p.61). Official statistics currently show figures similar to these last ones and suggest that the average prevalence of infection with *Trypanosoma Cruzi* in children under 14 years old is approximately 1.5% (25).

However, these general figures do not account for the disparity among the different regions. In the case of Argentina, while some provinces have certified the interruption of vector-borne transmissions, others still show a high risk of transmission.

### Chagas and the promotion of research

Apart from the control of vector-borne and transfusion-based transmission, Chagas has received considerable attention in policies of scientific research promotion and has thus become the object of research for many groups from different scientific disciplines.

This interest on the part of the scientific community starting in the late 1960s must be understood taking into account a number of factors. These include the interest of certain research teams in giving social relevance to scientific research; the sustained funding provided by the Argentine national government for researching the issue; the creation of a World Health Organization Committee oriented towards the promotion of research on Chagas disease, which served as an international source of resources starting in the late 1970s; and, as a result of all of these elements, the development of a social space articulated around the disease, which included the participation of several researchers specialized in Chagas disease from many Latin American countries, especially Brazil and Argentina.

Thus, scientific research became a legitimate intervention strategy for the different actors involved in the promotion, production, circulation and dissemination of knowledge. This process covered a wide range of topics, as the proliferation of Chagas-related scientific activity reached all relevant research specialties, from entomology to medicine to chemistry; however, the main focus was on facilitating the diagnosis of the disease and eventually developing a vaccine or appropriate antiparasitic drugs. This meant research studies primarily concentrated on two issues: the human immune response to parasitic infection, in order to create a vaccine; and the physiological and metabolic characteristics of the parasite, as well as its reactions to different drugs.

These studies promoted the creation of new knowledge about different aspects of the disease and permitted major advances in some fields, particularly in the adaptation and development of new diagnostic methods. Nevertheless, the political hope underlying the initial support of these research studies never came to fruition, as the research did not lead to significant changes in treatment methods. In fact, at present the only available drug for antiparasitic treatment is benznidazole, which was approved in 1970. Indeed, benznidazole (along with nifurtimox, developed in 1966) has received considerable attention due to its alleged ineffectiveness in the chronic stage of the disease and the presence of marked side effects in patients.

## PEOPLE WITH CHAGAS: SICK, INFECTED, OR INVISIBLE?

In terms of social practices, a disease is the result of a set of actions that arise from the recognition of its specificity. In the case of Chagas, this process involves specific actors – the individuals with Chagas themselves, the physicians who treat them, government officials, and even the rest of society that reacts in different ways to the public manifestation of the problem – who associate the idea of the disease with knowledge that serves as a parameter for their actions. Thus, every disease plays a social role fundamental in the lives of the subjects implicated. From the diagnosis of the disease to the taking on of a specific role connected with that disease, the everyday actions of the individuals implicated will be affected, one way or another, by the expectations and shared meanings of what this diagnosis implies.

In Chagas this aspect generates a rather paradoxical situation, which reflects the tension between visibility and invisibility constantly at play in its definition as a social problem. On the one hand, the statistics show that a large number of people are affected, to the extent that Chagas disease is considered the greatest endemic disease in the continent in epidemiological terms; in Argentina alone it is estimated that there are 1,600,000 individuals infected with the parasite. On the other hand, the individuals directly affected by Chagas have not, throughout the history of the disease, constituted themselves into a significant collective actor capable of demanding recognition or rights or making specific claims, as has been the case in other diseases such as HIV/AIDS (h).

From a formal point of view, recognition of the affected individuals – whether in terms of “victims,” patients, or subjects of rights – has been a historic demand of the medical community and has been implicit in every affirmation made about the importance of the disease as a public health problem, from the incorporation of the disease in specialized conferences and its inclusion as a disease of obligatory denunciation to the incorporation of research in routine health controls.

In more concrete terms, Law 22360 was enacted at the beginning of the 1980s, stating that preventing and fighting Chagas disease was of “national interest,” in order to “favor the control

and eradication of this endemic disease in the country” (26 Art.1). The primary objectives of the law were, on the one hand, “to elaborate technical norms [...] for the development, execution, evaluation and control of programs in the fight against Chagas,” and, on the other hand, “the registration, orientation and treatment of the sick” (26 Art.2). The first purpose was connected to structures already in existence, with the law stipulating the need for collaboration among the public health authorities of the different districts. Regarding the second purpose, however, the law introduced some significant changes in the norms, establishing compulsory Chagas testing in five key areas: upon entry into military service; in blood banks and hemotherapy services (both already under regulation since the early 1960s); upon entry into primary school; in routine health exams for pregnant women; and in pre-employment medical examinations.

This government initiative could at first seem to favor greater recognition of the disease. Nevertheless, in reality, it has clashed with other factors that have tended to “invisibilize” the disease in the social arena. One of these factors is the tendency of infected individuals to hide their condition, especially when looking for employment, due to the discrimination they may face. As the disease may imply a disability impairing physical activity, those infected with the parasite (even if they have not developed any symptoms of the disease) may find themselves in less favorable conditions for obtaining employment than those who are not infected (27 p.553). Paradoxically, this 1980s law requiring pre-employment serological testing as a means of providing greater visibility to the disease, and thereby of facilitating its control, has not become a useful tool for the incorporation of the disease in the everyday life of the affected population. Instead, the law has turned into a new obstacle individuals must overcome to avoid disadvantages, not related to the physical grievances themselves, but rather to the marks that their rural past has left in their immune systems.

The consequences of Law 22360 were so paradoxical that in 2007, Law 26281 on Chagas Prevention and Control (28) reconsidered this unfavorable situation. This new law includes the previous statement on the prevention of and fight against Chagas disease as an issue of national



interest, but focuses on pregnant women, blood or organ donors, children, and newborns. Article 5 of this new law prohibits testing for Chagas disease in pre-employment medical examinations, deeming them discriminatory. Moreover, such has been the stigmatization of the infected individuals – 70% of whom do not develop any illness – that those who most advocate developing the awareness and involvement of different social actors in the fight suggest not making reference to “Chagas disease” but rather simply to “Chagas,” thus describing the infection as a particular situation but removing part of the negative connotation implied by disease (29).

There are other elements leading to the invisibility of Chagas related to the perception of affected individuals that the disease is not serious (30). According to Mariana Sanmartino, this occurs due to cultural factors, given the commonness of the disease, as well as biological factors, given the long-term evolution of the disease – in the cases in which it does indeed develop – and lack of symptoms. It is also worth adding the lack of implementation of specific protocols by health care professionals.

## FINAL REFLECTIONS

Throughout this article I have tried to analyze some tensions that lie within the definition of Chagas as a public health problem, in its biomedical formulation, in the policies aimed at controlling it, and in the definition of professional specialties and social roles associated with the disease. This strategy of analysis has a dual purpose. The first is to show the complexity of the disease as a biological, social, political and cultural entity, considering the specific actors that have defined it as such throughout history. The second is to specifically analyze the way in which the very process of defining how the disease is understood, how its incidence is measured, and what policies are adopted to fight against it establishes the limits of what actions are considered possible.

Therefore, irregardless of unfavorable political situations or periods of neglect, the persistence of Chagas can no longer be seen as the mere result of failures, lack of interest or the technical ineffectiveness of the available strategies, but the

predictable and logical result of the actions of the different social actors involved.

In this sense, from the perspective of political planning and resource management, it is necessary to separate the interest and reaction the disease has provoked in the State into different sectoral policies that promote specific initiatives within the State’s area of incumbence. While at a discursive level the eradication or control of the disease still seems a distant horizon, this goal must be translated into concrete actions, as policies should be designed for and oriented towards accomplishing concrete medium-term goals in a demarcated area of action, such as fumigation, control of blood donations or the promotion of scientific knowledge.

In some cases, the translation of that distant horizon of eradication into concrete actions developed as a result of this political interest comes up against structural limitations that go beyond the will of the actors involved. This is clearly seen in the case of scientific research, which does not aim to eradicate Chagas but rather to promote knowledge associated with it. Therefore, policies may show partially successful results, even if afterward no further processes are carried out by which the knowledge produced can contribute to the ultimate goal of definitive control (processes such as the development of new drugs by laboratories or the fine-tuning of new techniques to be administered en masse).

By disassembling “the fight against the disease” into concrete actions, we may also see how the political rationality of managing limited resources on some occasions makes it logical to give up the initiatives before the ultimate goal has been achieved. In the case of fumigation, for instance, the goal of definitive control implies maintaining action standards that are difficult to meet in the most endemic areas. In that way, the decrease in the rates of infection in the last decades and the relative success this implies also serves to limit these initiatives; the less important the problem is, the more likely it is that the actions will not be sustained. Consequently, it may seem more logical to allocate funds to other more urgent problems.

The final aspects that this article attempts to explore are the cultural dimensions that operate in the definition of the disease, both on the part of those who identify and discuss the disease

and those who suffer from it. Thus, even while acknowledging the social importance of the disease, due to its geographical spread and the type of populations it affects, in the use of these categories of analysis we must not overlook the reductionist exercise of the dominant urban medical discourse that subsumes a complex situation of living conditions, cultural diversity and profound material deprivation to a single symptom: carrying the parasite. The shortage of clean water, the precarious state of housing constructions, the limited access to basic health and education services, the lack of employment and food, the continued clash between indigenous cultures and the ways of life of western capitalism, the lack of recognition of civil rights and undocumented migrations, among other factors, are disguised behind a medical diagnosis. Indeed, we could call this a social synecdoche: representing the whole through a part, so

that Chagas becomes a way to name these populations, either to show solidarity with them or to identify them as a population that needs only to be cured.

This exercise may be done in a more or less critical way, emphasizing the imposition of a bourgeois and urban medical discourse on a strange rural reality, or proposing a strategy for relating to diverse social sectors so as to help those sectors develop tools that will eventually enable them to carry out strategies of protection and control of adverse situations. In any event, this article aims to recover both the complexity of the disease and the diverse rationalities existing within the perspectives of the actors involved, as a means of understanding the depth of the problem of Chagas as it is configured, concretely, in the society in which it is immersed.

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## ENDNOTES

a. Both in its optimistic and fatalistic variants (according to the hopes placed in the development of this new knowledge), this is the perspective underlying, in general, the news related to scientific or medical events that celebrate new knowledge as an "advance" against the disease, be this new development the identification of a protein or the genome of a vector, even if it is not the primary vector in the country. An example of this can be seen in the article "Gran avance contra el Chagas: logran decodificar el genoma de la vinchuca" [Great advance in the fight against Chagas: the genome of the triatomine bug has been decoded](4).

b. The chronic stage was first divided by Chagas into 4 types: the pseudo-myxedematous, myxedematous, cardiac and nervous types (6). The relationship between the parasite and thyroid dysfunction was reflected in the first name given to the disease: "Parasitic Thyroiditis."

c. A few years before the discovery of Chagas disease, the Manguinhos Institute, led by Oswaldo Cruz, had carried out the campaigns to eradicate yellow fever in Rio de Janeiro, thus gaining academic and political recognition as well as the recognition of civil society (8).

d. By 1935, the cases in which the presence of the parasite in humans had been demonstrated

microscopically did not reach 50. See Yorke (11), cited by Kropf (9 p.246).

e. The relationship between the parasite and goiterism was first called into question by the studies of Rudolph Kraus in the Institute of Bacteriology of Argentina's National Department of Hygiene (12).

f. Mazza's works included the identification of the first cases in the mid-1920s, the demonstration of the existence of the parasite in the region and the existence of vectors, the analysis of the natural reservoirs of the parasite, the identification of acute and chronic cases, the description of the characteristics of each stage, the analysis of diagnostic methods and, finally, trials of different treatments (without success) (15).

g. The works of Laranja and Nóbrega, from the Bambuí Research Center in Brazil, and of Rosenbaum and Álvarez, from the Ramos Mejía Hospital in Argentina, were essential in the definition of "chronic Chagas cardiomyopathy" (13).

h. In situations of drug shortages, or even given the threat of such shortages, the differences between these two groups are significant. While those with HIV/AIDS have held protests to demand the public provision of drugs be guaranteed, those with Chagas have not become a major actor in the public arena when faced with the news of the unavailability of the drug.

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