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Power and money in Chagas disease: a historical omission

Poder y dinero en la enfermedad de Chagas: una histórica omisión

***Storino**, Rubén*[1]

[1]PhD in Medicine. Professor of Medical Sciences. Assistant Professor of Public Health, Faculty of Medical Sciences, Universidad Nacional de La Plata, Argentina.
r_storino@yahoo.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.

In the article "The disease in its labyrinth: advances, challenges and paradoxes over 100 years of Chagas in Argentina," (1) Juan Pablo Zabala offers an interesting synthesis of different biological, political, sociological and technical aspects related to Chagas.

Nevertheless, he omits specifically mentioning two aspects that, to my way of thinking, are essential to understanding why Chagas disease remains an unresolved public health problem in Argentina, unlike in other neighboring countries such as Uruguay, Chile and Brazil, where the disease has been successfully controlled. These aspects are:

1. The power of a hegemonic group of professionals that, specifically with the support of the State, has been making decisions about Chagas and its control over the last 40 years in Argentina, decisions that reach from the fight against the vector to the granting of research subsidies.
2. The economic interests of a sector in close contact with that hegemonic group that has prioritized investment in and the allocation of money to two issues which, although important, are not the only issues relevant to Chagas: the development of serological reagents and insecticides.

In order to comprehend this analysis, it is necessary to recognize that the paradigm of Chagas disease as a problem exceeds a biopsychosocial framework, involving factors of political and economic power. Therefore, Chagas becomes not only a traditional disease of poverty but also a paradigm that uses concealment and exclusion as mechanisms of social and employment discrimination.

Many actors interact with this reality: the State, researchers, physicians, serological carriers of Chagas, individuals with chronic Chagas disease, society, the communications media, and the pharmaceutical industry.

All of these actors to some extent contribute to maintaining a certain indifference to the permanent resolution of the problem. In the predominant state of affairs, each sector attempts to prioritize its own interests, precluding joint community action in which knowledge and power are at the service of the indigent, the marginalized and the dispossessed who suffer from this disease.

These actors form the spectrum of this failure, representing factors that determine the persistence of the disease (2): the State, which minimizes the problem through its government officials; researchers that prioritize their grants and subsidies; physicians that neglect this disease affecting poor patients; serological carriers of Chagas that hide their condition due to their past experience of exclusion from employment; individuals with chronic Chagas disease that are unprotected by the social security system; the indifference of society; the absence of the communications media; and the pharmaceutical industry, which deserts research efforts into new drugs because they offer little opportunity for profits.

To understand these processes it is also necessary to carry out a historical analysis of the events that led to this current situation.

Salvador Mazza, who rediscovered Chagas disease, made the mistake of relocating the Argentine Regional Pathology Study Mission [*Misión de Estudios de Patología Regional Argentina*] from Jujuy to Buenos Aires, shortly before his sudden death in Mexico in 1946. Thus, Chagas disease lost the opportunity to have an internationally recognized research center of excellence on the ground, unlike the Oswaldo Cruz Institute in Brazil.

SALUD COLECTIVA, Buenos Aires, 8(Suppl 1):S23-S38, November, 2012

Therefore, there was no other option but to conduct Chagas disease research in Buenos Aires. This research was carried out lethargically until its rearousal in the 1960s and 1970s with the founding of the Dr. Mario Fatala Chabén National Institute of Parasitology and the creation of the National Chagas Program, with operational headquarters in the province of Córdoba. Within this context emerged a hegemonic group that took over Chagas policy almost in its entirety and, to a certain extent, has continued to do so over the last 40 years.

This group, supported by the State of Argentina irrespective of whether the government in power was de facto, Peronist or Radical, was made up of public officials, health science professionals, and basic and technical researchers, whose model of Chagas disease control consisted of prioritizing the development of serological reagents and insecticides. This was a vertical model not only in terms of power structure but also given the hegemonic direction exerted in Buenos Aires over the rest of the provinces. Thus, other paradigms were cast aside, such as the decentralization of power to provinces and even municipalities, comprehensive health care for patients, and the provision of cardiac medications to patients with Chagas cardiopathy, without getting into other more complex aspects like education, housing and the incorporation into the labor market of those with Chagas. Although the vertical model centralized in Buenos Aires, with its sights and funds set on the fight against the *vinchuca* [triatomine bug] and the detection of positive serology for Chagas, achieved some significant results, it still could not eradicate transmission of the disease in many provinces. Between 1962 and 1991, this model cost the government 500 million dollars, which was allocated to salaries, traveling expenses and supplies (3). After 1991 the budget for Chagas disease has been included with other endemic diseases, which prevents us from knowing the actual expenditure for Chagas disease in Argentina in the last decades.

The analysis of these figures allows us to highlight that too much has been invested and too little has been provided as a base for sustained actions. This raises the question: Why was no investment made in the training and empowerment of the 200 communities that are still at risk of vertical transmission so that they could carry out actions against Chagas disease? A possible answer is: So that the same group could continue controlling the power and the money in a vertical and centralized way.

Nor was action taken to economically develop those towns in endemic areas with vector transmission, where progress has not yet arrived.

For years, the independent professional teams working with Chagas disease that have felt marginalized by the hegemonic power have used the phrase: "*There are more people making a living off of Chagas than people cured of Chagas*."

If we analyze the political and economic decisions and the power networks made up of a stable group of officials of the National Government, along with a number of health care professionals and basic researchers, regarding the funding of not only measures of control but also the development of diagnostic techniques, biosensors for detecting the *vinchuca* and research into the supposed biological markers of cardiac damage, we may assert that too much money has been squandered. This has been further aggravated by criminal charges of corruption, although these were finally dismissed, as is often the case in Argentina.

The major problem is that those funds have not reached those with Chagas disease in order to modify the multidimensional nature of this disease, as they continue to struggle through a life of poverty with shacks as their only stable housing, with no education and in the worst of labor conditions.

Advances in the knowledge regarding the multiple aspects of Chagas disease have resulted in the fragmentation of that knowledge with clear benefits for basic researchers, who were able to obtain substantial subsidies, unlike the patients involved in the studies, who only received a "thank you" for providing their blood samples and for posing for photographs.

Historically, those suffering from Chagas disease have been reduced to testimonial images, unable to exercise any influence in the initiatives, decisions or expenditures regarding Chagas disease.

The solution to this historical injustice lies in a paradigm shift, in the style of the scientific revolution suggested by Kuhn (4).

This requires that two substantial modifications be made:

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SALUD COLECTIVA, Buenos Aires, 8(Suppl 1):S23-S38, November, 2012

1. That the current paradigm of vertical hegemonic power exercised by the state and allied professionals and researchers be replaced with the empowerment of Chagas patients, especially those living in neglected communities within endemic areas, adopting the Ecosystem Model of Health with full participation in political and economic decisions (5).
2. That the current linear paradigm, whose most adopted models are serological diagnosis and the use of insecticides, be replaced with the paradigm of complexity described by Morin (6), which recognizes multicausality and multidimensionality such as that in the problem of Chagas disease.

Therefore, a joint task must be carried out, in which actions are translated into concrete measures that strengthen the development and participation of the community, involving other sciences like anthropology, sociology, ecology, psychology, politics and economics, covering all levels of prevention, focusing on the comprehensive medical care of Chagas disease patients, and establishing centers for the study and control of Chagas disease in all its aspects, especially in the incorporation into the labor market. We must modify the situation of marginalization and neglect faced by millions of patients with Chagas, victims of a disease of poverty which is worsened by its concealment and by the power relationships and economic interests in which few individuals without Chagas disease benefit at the expense of millions who do have Chagas.

BIBLIOGRAPHIC REFERENCES

1. Zabala JP. La enfermedad en su laberinto: avances, desafíos y paradojas de cien años del Chagas en Argentina. Salud Colectiva. 2012; 8(Suppl 1):S9-S21.

2. Storino R. La cara oculta de la enfermedad de Chagas. Revista de la Federación Argentina de Cardiología. 2000;29(1):31-44.

3. Segura E. El control de la enfermedad de Chagas en la República Argentina. In: El control de la enfermedad de Chagas en los países del Cono Sur de América. [Internet]. OPS; 2002 [cited 25 Sep 2012]. Available from: http://www.paho.org/Spanish/AD/DPC/CD/dch-historia-incosur.htm.

4. Kuhn T. La estructura de las revoluciones científicas. México DF: Fondo de Cultura Económica; 1980.

5. Possas CA. Social ecosystem health: confronting the complexity and emergence of infectious diseases. Cadernos de Saúde Pública. 2001;17(1):31-41.

6. Morin E. Introducción al pensamiento complejo. Madrid: Gedisa; 2003.

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Social and political reverberations in the social study of a disease

Resonancias sociales y políticas del estudio social de una enfermedad

***Stagnaro**, Adriana Alejandrina*[1]

[1]PhD student in Social Anthropology, Researcher, Institute of Anthropological Sciences. Assistant Professor, Faculty of Philosophy and Letters, Universidad de Buenos Aires, Argentina. astagnaro@uolsinectis.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.

Through a multifaceted approach to Chagas disease and its spread in Argentina for something over a century, Juan Pablo Zabala (1) makes heuristic contributions to the reflection on the approaches by which the definition of the disease has traditionally been delineated.

His discussion of the tensions operating in the configuration of the disease and its historical evolution nourishes an intense dialogue involving important questions, such as the paradoxical political and institutional focus on the social relevance of