



# A Social Approach to Chagas Disease: A First Step to Improve Access to Comprehensive Care

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## 4.1 Introduction

The increasing complexity of the problematic of Chagas,<sup>1</sup> product of the multiple realities where it is currently present, poses the need of recognizing that we are facing an intricate socio-environmental health problem related to both rural and urban environments in not only the Latin American context but also worldwide [1]. These current and diverse scenarios imply crucial challenges for health teams, researchers from multiple disciplines, and public policy makers because they evidence the existence and needs of populations usually disregarded. In this context, it is pertinent to ask ourselves “what are we talking about when we talk about Chagas?” For this question, relevant answers should be provided for each of the scenarios where Chagas exists. The committed and permanent search for these answers will lead inevitably to recognize the need of

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<sup>1</sup>We will use the *Chagas* or *problematic of Chagas* denominations to avoid circumscribing the subject to the biomedical aspects (Chagas disease) and therefore we recognize the multiple causality and the multiple implications for people in different territories, and social and institutional realities that address it.

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developing comprehensive approaches including the experiences and knowledge of all the actors involved in one way or another. When we talk about “all the actors involved,” we refer to those who provide academic knowledge from the diverse disciplines necessary to understand Chagas beyond the biomedical area, and those who are affected directly or indirectly by the disease. Furthermore, the search for answers to this question should involve all the actors who might provide knowledge from the areas of communication and education, widely and openly understood.

According to estimates from the World Health Organization, between six and seven millions of people are currently infected by *Trypanosoma cruzi* [2]. This figure evidences complexity not only because of the magnitude it represents but also because it is estimated that barely 10% out of these people are aware of the fact that they carry the parasite, and only 1% out of that population access to the available therapies [1]. The evidence speaks for itself and, in front of it, the words spoken by Carlos Chagas and Emmanuel Dias more than a 100 years ago retain their full validity: “besides the technical innovations, the definite overcoming of the human Chagas disease involves, above all, political willingness and social responsibility” [3]. We humbly add to the masters’ reflection that, besides biomedical and technological advances, the definite overcoming of the problematic of Chagas involves, above all, the incorporation of issues that have not been considered in the traditional approaches, such as respect to the peasant and indigenous’ knowledge, the particularities of migrant and traveling contexts in the current globalization framework, and the weight of stigmatization and, thereby, of social exclusion (a frequent experience, stronger and more tangible than the physical consequences of *T. cruzi* infecting an organism), among others. We agree, in this sense, with the paradox formulated by Ventura-Garcia et al.: “Although the importance of social and cultural factors is broadly acknowledged, current approaches to NTDs<sup>2</sup> almost always neglect aspects of the sociocultural—biological—environmental triad. This results in a narrower understanding of Chagas disease that hampers sustainable prevention and control” [4:1].

In this scenario and considering the complexity of Chagas, we consider crucial to address the actions of intervention, care, and research related to the topic from a new paradigm. To accomplish this, it is essential to return to some pending discussions and incorporate new theoretical frameworks to understand the problematic.

This chapter will allow from a perspective that considers and values the questioning to the classical epistemologies of health and illness, enhancing the hegemonic approach perspective by the incorporation of new actors and essential knowledge to embrace the diversity of the current scenarios. We question the “place” from where we talk and address the problematic of Chagas because it evidences not only underlying epistemological frameworks but also the ways of addressing the relationship with the Other and the mechanisms and practices from which we face health interventions and acknowledge power relationships and the knowledge at stake. From these considerations, we would like to propose reflections and alternative epistemological scenarios from which it is possible, from our perspective, to address the problematic of Chagas in a contextualized and comprehensive way.

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<sup>2</sup>NTDs: Neglected Tropical Diseases.

## 4.2 About the Social and Inclusive Approach

### 4.2.1 What Are We Talking About When We Talk About Chagas?

From a biomedical perspective, Chagas disease has been described as an illness caused by the parasite *Trypanosoma cruzi*, which is transmitted to human beings and other mammals by an insect (depending on the place, known as *vinchuca*, *barbeiro*, *kissing bug*, *chinche besucona* and *chinchorro*, among other names) or through other ways such as transplacental and oral transmissions, blood transfusions, organ transplantation, or, to a lesser extent, laboratory accidents.

For decades, Chagas disease has been associated to the populations with scarce economic resources from rural and semirural areas of the American continent. However, today more than ever, we know that it is not an “exclusive” disease of certain human groups and geographical contexts. Currently, it is essential to recognize that we are facing an extremely complex problem that overcame the geographical, cultural, social, and disciplinary traditional borders a long time ago. The present challenge implies acknowledging that “Chagas disease requires an explicitly multi-dimensional approach in which prevention, control, and care strategies and programs are designed and implemented jointly, and in which the social and biomedical sciences, together with the experience of those affected, are incorporated and articulated” [4]. In other words, it is crucial to support the fact that, beyond the biomedical and epidemiological aspects traditionally (and almost exclusively) considered, in the current and past configurations of Chagas disease converge an intricate web of elements related to the social, cultural, economic, political, and environmental aspects, among others. Today, more than 100 years after its “discovery,” it is evident that the classical scenario in which it was described has changed and that, in a globalized context, we must overcome the biomedical dimension to improve people’s health conditions.

Therefore, to adopt a comprehensive approach, we define four large dimensions, whose dynamic combination of elements conveys the complexity of the problem. These dimensions are combined, metaphorically, in a *kaleidoscopic puzzle* [5], where the parts become meaningful when considered in mutual dependence and interrelationship within the whole and, in turn, depend on the analysis perspectives from which they are observed. The relationships established within and among the dimensions provoke that today, at a certain place in the world, the problematic of Chagas emerges with particular features, in contrast with some other regions and historical moments. Basically, these four proposed dimensions could be defined as follows:

- The biomedical dimension includes features ranging from the biology of the causal agent and vectors to medical issues regarding the disease manifestation, diagnosis, treatment, and transmission.
- The epidemiologic dimension concerns the aspects that characterize the situation from a population scale, using parameters such as prevalence and incidence, distribution, and infestation rates. The phenomenon of the growing

migration that influences the configurations of the problem is also considered in this dimension.

- The sociocultural dimension is related to cultural patterns and cosmovisions, home conditions, environmental management, the distinctive features of both rural and urban contexts, and social representations and prejudices that reproduce, for example, discrimination and stigmatization.
- The political-economic dimension involves, apart from the economic and macroeconomic conditions affecting the problem, the features related to public management and health, educational, legislative, and economic decisions at local, regional, and global levels. Furthermore, this dimension includes the position and decisions that we, as citizens and professionals, assume when thinking of Chagas disease in different environments (research, teaching, communication, health care, etc.).

When recognizing this multidimensionality of intervening elements and factors, it is evident the need of counting on the contributions from all the fields of knowledge and incorporating to the approach new and contextualized theoretical frameworks that might enlighten the comprehension of this problematic. In this sense, we are particularly interested in the contributions of the so-called Epistemologies of the South [6], which presents a way of proceeding that allows appraising, legitimating, and validating the knowledge born in the fight of social groups that have systematically suffered the exclusions, injustices, and discriminations caused by capitalism, colonialism, and patriarchy. Regarding those who live *systematically the exclusions, injustices, and discriminations caused by Chagas disease*, we find with (high) frequency the reproduction of characterizations that stigmatize and configure *an Other* affected by Chagas disease as *poor, silent, victim, patient*; this Other is generally a passive recipient of solutions designed from a great geographical, ideological, and cultural distance.

Because of this, it is time to revise critically the hegemonic discourses and recognize the obstacles they imply for the understanding of the topic. Identifying the resistance faced by people “affected by Chagas disease” and knowing and acknowledging those Others as active individuals, holders of knowledge and creative answers, is the point from where it will emerge uncountable learnings that must be considered for the collective search of comprehension and solutions.

The criticisms and foundations on which the Epistemologies of the South are built, as Boaventura de Sousa Santos himself claims [6], demand thinking about the unthinkable, assume the surprise as the constitutive act of the theoretical labor recognizing that, in the current context of social and political transformation, we do not need *cutting-edge theories*—which, by definition, do not allow themselves to be surprised—but *rearguard theories* instead. That is, we must accompany closely the transforming labor of the social movements to question and understand the possibilities in which collective implies creating articulations, translations, alliances among the diverse actors, their positions, and experiences. In other words, the Epistemologies of the South poses more the work of an implicated witness and less the one of a clairvoyant leadership; they require the development of

approximations to what is new for some people and old for some other people; they lead to open analytical spaces for *surprising* realities (because they are new or because, so far, they have been produced as nonexistent) where transforming emergencies and liberating alternatives might sprout. In particular, for the topic we are considering here, the Epistemologies of the South are one of the most fertile frameworks to incorporate new realities and analytical spaces to collect from there transforming and liberating scenarios that, within the context of health care and biomedical hegemonic approach of Chagas, have been forgotten or simply disregarded.

### 4.2.2 Current Context(s) of Chagas Disease: Diverse Scenarios, Diverse Challenges

The current scenario of the problematic of Chagas, considered as a global health problem, defies us at various levels. On the one hand, it requires the comprehension of the *territory*, the multiple geographical, social, political, institutional, personal, familiar, and communitarian contexts in which the disease and its consequences are (re)produced. It is essential to identify the mechanisms used to address the problematic, that is, intervention methodologies, epistemological frameworks, and paradigms from which Chagas is understood and approached. It is also crucial to consider the structures used and activated to deal with Chagas, identify the actors involved in these processes, and recognize the complexity and the challenges implied by the new scenarios, both for researchers and health teams and for the affected people, their families and communities, to act accordingly.

These challenges imply the awareness of this complex problem as regards not only the global framework where it is currently manifested due to human mobility, but also the way in which Chagas affects the individuals and their families, transnational families, and individuals who travel because of their mobility projects and that, independently of their mobility, should be assisted in their needs to guarantee their rights [7]. The epidemiological change implies recognizing a territory that has widened; the disease localization becomes mobile through the traveling individuals. From this perspective, we have to observe the way in which Chagas is approached in these multiple scenarios, identify the institutions, and characterize the structures recognizing that the individuals come from diverse health and health care experiences and that they are in a different scenario. We should recognize that a located approach, limited to a context and to one way of intervention, is no longer possible. Instead, we should consider the complexity of intervening and identify the opportunities to be opened: we should go from national to transnational, from biomedical to multidimensional, from individual to familiar and collective, abandoning the idea of the Other as a *patient*, dependent, and recognize him/her as an agent, that is, as a subject able to identify his/her position in the structure, the properties of that position, and the politicization of his/her practices [8].

Transforming the paradigms through which we comprehend (and describe) Chagas and the *affected people* implies to transit the overcoming of positivist,

biomedical, and Eurocentric epistemologies that sustain the objectivity and the distance as related and comprehensive principles and withdraw from the individual's experiences and knowledge. As we mentioned, we should also approach to epistemologies that allow an emancipation process, that is, a transformation not only in the academic, institutional, and medical performances but also in the search for the transformation of the inequality structural conditions.

A change in the methodologies used to intervene in the problematic is crucial; the strictly biomedical approach fragments the understanding of the topic, reduces and inactivates the individual. Chagas should be faced from approaches that lay their foundations in the questioning to the colonialist practices through which knowledge and learnings concerning the topic are reproduced, as well as in the subordination, invisibility, and inequity practices that support the general health performance [9]. We should go forward, sharpen our vision, and enhance the listening and, therefore, our understanding.

In the current scenario of human mobility, diversity challenges health teams; it calls them to consider the cultural, social, and epidemiological diversity in the care ordinariness, which does not necessarily imply a questioning to the subordination or subalternity logic reproduced in the health care systems or to the ways of approaching the health issue. Within this framework, interculturality, as a relational strategy in these contexts, constitutes a proposal that emerges from the questioning to the epistemological frameworks through which individuals intervene in health to solve the implications of a disease that burst in new scenarios and health care teams and systems, which are not always trained or prepared to face the problem, and the tensions that imply the learnings and conceptions of health and illness. To open to the Other entails the recognition of our own and the Other's cosmovisions, an exercise that is only possible through empathy and dialogue [10]. Not recognizing the differences closes the systems and encapsulates them to reality constructions where the own system is reproduced. In general, the State opens to incorporate the differences, but neither from the recognition nor from the agency co-construction processes; on the contrary, diversity is approached from an opening that, in practice, incorporates the differences from assimilationist and domesticating practices [11]. On the other hand, the development of cultural competences is also an opportunity for the health teams because it allows them to open themselves and incorporate the Other through a dialogic process that resignifies and enriches the practice itself.

We should understand that biomedicine is a cultural construction, associated to cosmovisions, generally ethnocentric, and Eurocentric; it places the knowledge in the medical practitioner (generally, a man). Populations and cultures elaborate constructions of health and illness that emerge from their cosmovisions; this is the way in which the notions of care, health, and illness are built and the mechanisms intervening in this process are developed [12, 13]. In this context, assuming oneself as being ill from Chagas disease has characteristics related to the subjective construction of the disease and the context where it is experimented, elements that are intertwined with the gender, the institutionality, and the objective and subjective

conditions the individuals face because of, for example, migration or belonging to a transnational family [14, 15].

Recognizing the social, cultural, and gender components associated to health problems has allowed widening the approach perspective and acknowledging the inside of the problematic and the multiplicity of elements to be considered in the description and understanding of Chagas. In this sense, rurality stresses significantly the presence of the problematic. In this context, the housing issue constitutes a relevant tension for the people affected, not only because the house is associated to the presence of the insect vectors but also because in this scenario a series of aspects (such as local practices in housing building and use) coalesces with mechanisms through which the problematic is solved (fumigation, house or belonging burning, house relocation, etc.). Hence, from the intervention in health, we have activated health care practices that burst in the most intimate individuals' space, their homes, depriving, discrediting the people and families' efforts, and underestimating the value of ancestral practices. The action of the States through public policies, from fumigation to relocation of families and demolition/building or disposal of houses, entails the loss of intimacy and resolution capacity and agency of individuals and families. Thus, it has been observed that these practices of eradicating adobe brick and thatched roof houses do not necessarily translate, in fact, in a decrease of the risk of contracting Chagas disease through the vectorial way because the presence of insect vectors in a building is more related with structural issues than with the sort of material implied [5].

On the other hand, in the context of people's growing spatial mobility the individuals themselves and their bodies become currently the mobile depositaries of *the disease*. People face the lack of knowledge as well as the lack of opportunities of solving health problems, especially in the scenarios in which the professional and institutional capacities do not approach or consider Chagas disease. Through people's mobility, the fragility of the guaranteed health rights is evidenced in both the countries of origin and destination as well as in the social and institutional issues. In this scenario, the formation structures of the health care personnel, the resolution capacities of unknown problematics and, mainly, the capacity of dialogue and recognition of the Other and the legitimate knowledge he/she has as regards his/her body are confronted. Understanding the problematic of Chagas as a public health problem at a global level challenges countries and health care systems to interact and develop strategies that altogether allow guaranteeing rights, accessibility, and elimination of stigmatization associated to it. Chagas disease is an opportunity to open ourselves to emancipating learnings and practices.

### 4.2.3 Present and Absent Actors: Toward the Inclusion of Experiences

As we have been pointing out, considering the person affected by Chagas as an *actor* (and not as a *patient* or *passive recipient* of interventions designed from institutional and ideological distances) allows recognizing and promoting opportunities for these

people's participation in initiatives to solve the complex social-environmental problematic that Chagas constitutes.

How an actor becomes an actor? Thanks to the agency, the ability to act, the ability to transform. According to Pierre Bourdieu, among other constructivist thinkers, the agency is the power of influencing in the structures, despite the historical traction through which these structures condition, the actions and their scope possibilities [16].

Probably, it is impossible to draw an exhaustive map of the actors involved in the complex web of Chagas; moreover, when this map and the lines through which we could analyze the influence of ones over the others vary according to the context. Anyway, thinking about the parts involved in any complex problem from the theory of social action [16] might promote that the problem could be understood and critically observed. After this analysis, it could be faced with inclusive initiatives.

We could ask ourselves, for example: which actors have had the true agency in the intervention planning proposed so far against Chagas disease? Those who have not had and/or do not have this agency? Furthermore, it should be necessary to stimulate asking these questions for the concrete case in each initiative (prevention, research, political incidence, etc.). To question ourselves is an exercise that, from the Epistemologies of the South viewpoint [6], allows us to widen and deepen the initiative scope and demand engagements, as it will be seen later.

The experience of rural communities related to their coexistence with the vector insect might be regarded or disregarded at the time of designing contemporary monitoring and control programs in the so-called *endemic areas*. The same can be decided after confirming the influence ability of certain actors from Latin American populations, for example in Europe, at the time of activating the demand of care and treatment strategies of Chagas disease considering their contacts in social networks and their relatives in origin and destination places. To ignore or add those actors to the understanding or transforming table is, as we have indicated, the first one of the decisions that might support (or not) a change of paradigm in the approach of the problematic of Chagas.

Bourdieu's reflections have never been purely theoretical; on the contrary, they have been built after diverse research in the field. If one could imagine the author trying to understand the problem of Chagas disease, probably he would have proposed to start with a conversation with the first affected ones, as actors. Maybe, he would have relied upon the "spontaneous sociology" of the social actors, which is something more complex than discarding the scholar knowledge and retaining the ordinary one [16]. He would agree with de Sousa Santos in affirming that, from the "sociology of absences," before working with experts one should work with all the experiences, especially with the ones that have been excluded or actively produced as nonexistent, that is, as unbelievable alternatives to what exists [6].

Understanding the affected people's multiple experiences and learnings is one of the ways that urges to be explored to comprehend the problematic and evidence the anxieties and the diverse learnings. Hence, knowing the experiences of the teams of chemical control against the vector, the primary health care physicians, the specialists, the local authorities, the decision makers, etc., would allow a more global and



comprehensive understanding of the problematic. To interpret all the actors, Bordieu would say, it is not necessary to comprehend them from our own conceptualizations but to figure out the “logic of practice,” that is, the logic explained from the performance of acts displayed in their respective times [17].

Furthermore, the stories heard during the specialized care in Chagas disease in contexts characterized as *nonendemic* in Europe approximate us to the actors from experiences that are even more invisible than the ones experienced in the traditional rural and Latin American scenarios. Their narrations talk about the past time (the childhood in the rural community of origin, the migrant trajectories, etc.) and reveal, in the same way, the coexistence with the vector and the lack of information about the real risks they faced or, even worse, the lack of ability to change the material conditions associated to the disease. Far from their birthplace, these people identify a change that might be linked with the elimination of the disease. However, the presence of Chagas disease at the *endemic areas*, and at *nonendemic areas*, on the one hand, indicates that certain conditions are perpetuated and, on the other hand, evidences that a lot has been achieved from one generation to the next one as regards the vector control and the access to diagnosis and medication. Several of these transformations are related to a change in the population’s welfare conditions, housing modifications, access to treatment, etc. These and other actions allow cutting—socially and within families—the *T. cruzi* transmission.

Thus, we can claim that there is agency conquest in those who, through multiple processes of social mobility, have accessed to better conditions and structural opportunities. The associativity and the social mobility also contribute in the conquest of rights. We can see that phenomenon in those who decide to generate a change in their communities through the participation in peasant organizations that fights for violated rights in rural areas or in those who take part in associations of people affected by Chagas disease that proposes to activate, in *endemic* and *nonendemic* contexts, the access to diagnosis and treatment or propose to look for the customs release of second-hand cardiac pacemakers coming from abroad.

The scenarios are diverse, the people’s actions and reactions are multiple, as diverse as their learnings and experiences. Within the framework of these diversities, we can comprehend that the working conditions limit the access to health care. We need to identify the stigmas associated to the disease, and understand the complexity of each social scenario, for example, for people in the European context and people in the current Latin American rural context. At the same time, this positioning implies to understand that—close or far from the *endemic zones*—people try to move away from those constructions that impoverish them or represent them as *ill people*, which produce them as *nonexistent* in terms of the *sociology of absences* proposed by de Sousa Santos [6].

It should be stressed that the study of perceptions and social representations of Chagas disease should not be approached only toward the knowledge and representations of the affected people, because the way in which the other actors see and understand the problem also reproduces the features of the topic complexity. We should recognize in all the actors the presence of stereotypes, assessments, attitudes toward the problematic and the people affected, the modes of transmission and the

contexts in which the disease is spread (or not), and its causes and consequences [18]. In this sense, we agree with some other authors that approach the need of incorporating and unveiling the complexities in the perceptions and social representations about Chagas [5, 18, 19]. We understand that it is key to deepen the learnings and experiences of all the actors involved in the complexity of Chagas (health teams, researchers, communicators, educators, decision makers, etc.), considering besides that all of them are stained with reality constructions produced in each context. As we shall explain below, these studies constitute a concrete proposal so that the interventions in Chagas disease lay their foundations in a contextualized and inclusive beginning, tending to equity among the parties involved.

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### 4.3 About the Comprehensive Care

#### 4.3.1 What Are We Talking About When We Talk About “Comprehensive Care”?

As we have stated along these pages, we agree with Ventura-Garcia et al. when they propose that Chagas disease is embedded in a web of relationships marked by biological, sociocultural, political, economical, historical, and environmental circumstances that shape its incidence and prevalence, as well as the population’s response [4]. In the complexity and multidimensionality of this *web of relationships* the need of approaches that meet expectations is evidenced, whether from research and care, or from other instances. Because of this fact, the development of the so-called (and sometimes overused) *comprehensive care* leads us to challenges that cannot be underestimated.

Beyond some worthy exceptions, we generally observe that one of the main failures of the implemented strategies lies in the predominance of a fragmented and biased viewpoint. This viewpoint is oriented toward Chagas as a disease, ignoring that it constitutes a complex problematic characterized by factors of different nature, which make sense when they are considered in mutual dependence and relationship [5]. In this sense, when exploring, for example, the social representations about the problematic of Chagas in members of the health care team, a restrictive viewpoint on the biomedical aspects is evidenced; moreover, that viewpoint is biased by stereotypes (poverty disease, silent disease, rural disease, a disease associated to housing precariousness, etc.) [18, 19] that hinder the development of the pursued *comprehensive approach*. The reproduction of prejudices leads to stick to attitudes of blaming and stigmatization toward the people affected by Chagas disease themselves, preventing in turn to enquire about the underlying causes that bring together in the problem persistence, whereas the association between rurality and poverty, established by most of the biomedical professionals, reflects the prejudices associated to the nonurban way of life. This viewpoint ignores, and usually disregards, the value of traditions, habits, and practices of certain groups affected by the problematic so that the *experts* become the only ones trained to provide solutions to improve the affected people’s lives [18, 20].

Therefore, at the moment of thinking about the spaces where *comprehensive care* should be displayed, it is inevitable to consider the existence of diverse scenarios provided that, as it has been already mentioned, the migrant and urbanization phenomena allow locating Chagas also in urban contexts and worldwide. Due to these reasons, we understand the urgent need of putting into practice strategies promoting health that consider the topic as a public health issue not only at regional and national scales but also at international level.

Chagas has become a paradigmatic example of the challenges that the current territorial changes and globalization pose for health research and public health care. In this sense, it is crucial to aim at the development of an integral, updated, and contextualized approach, oriented not only to preventing the disease but also to promoting health as a means of improving people's lives.

Understood this way, comprehensive care includes both the necessary diversity of health professionals to *treat* properly the requirements of each case and the implementation of multidisciplinary and multisectorial devices to guarantee the approach of the violated human rights, the cultural, social, labor, and legal aspects, and the materialization of true knowledge exchange nourished by the involved actors' experiences and knowledge. In particular, we consider that a worthy contribution in this sense is constituted by the proposal of the *Ecology of knowledge* provided by the Epistemologies of the South [6], which begins by assuming that all the relationship practices among human beings, as well as between human beings and nature, imply more than one way of knowledge and, thus, of ignorance. It consists, on the one hand, of exploring alternative scientific practices that have become visible through the plural epistemologies of scientific practices and, on the other hand, of promoting the interdependence of scientific and nonscientific knowledge. In other words, it involves an ecology based in the "recognition of the plurality of heterogeneous knowledge (being one of them modern science) and the continuous and dynamic interconnections among them without compromising its autonomy" [6:10]. Hence, against a rooted monocultural conception of knowledge, the *Ecology of knowledge* does not consider knowledge abstractly, but as learning practices that allow or prevent certain interventions in the real world.

### **4.3.2 Difficulties and Tensions as Regard Access: Objective and Subjective Barriers**

The processes involved in the population's health care entail the interaction among health care teams, professionals, and people and their families. Usually, this relationship takes place in an institutional context of hegemonic knowledge considered, in general, legitimate. In addition to this, the individuals in the interaction put into dialogue or confrontation their own cosmovisions, that is, the way through which people and systems understand health and illness and, consequently, construct care modes and mechanisms used to elaborate resolution strategies for health problems. In these spaces, there is an interaction of care, health, and illness models

that must be evidenced, especially when we approach Chagas disease from hegemonic models [21].

At the same time, these interactions are constructed within sociopolitical frameworks where health is a right, as well as it is people's mobility in most of the countries around the world. In order to understand health and illness in the context of Chagas, it becomes essential to territorialize the problematic firstly, which involves the comprehension of the environment, its changes and adaptations as well as the scenarios (institutional, sociopolitical, local, etc.) associated to the transformations in the individuals' life conditions. These changes are related to the neoliberal exploitation methods and consumption; within this framework, the individuals interact among them through the means because they construct transnational families, and they organized themselves according to international organization structures.

In local contexts, human mobility has shown the fragility of the universal health care systems and, paradoxically, the acceptance of diversity. The current social scenarios reveal the social tensions based on xenophobia and racism as well as the gender inequalities. In which way Chagas disease, as a health problem, is perceived in these contexts? Within the framework of the health system, Chagas disease allows, for example, being aware of the women's position in care practices against health problems, and the responsibility attributed to them as regards health care of the family in general and the children in particular. The way in which women assume the responsibility in the transmission of Chagas places them as high vulnerability individuals because of stigmatization, social rejection, gender violence, etc. In this background, women must be guaranteed health conditions for themselves, such as preconception controls to diminish the chances of infection of Chagas through pregnancy and, at the same time, improve their health conditions and quality of life [15]. However, we should take care about the mechanisms used to approach them, preventing the reproduction of prejudices and discriminatory behavior and being aware of the social exclusion processes due to the relationship between gender and the disease transmission mechanisms.

Physical conditions, ethnicity, social class, and religion account for the need of constructing an approach that implies the revision of relationship strategies [19]. Thus, for instance, in migrant population contexts, both in research and in the development of care and detection policies of Chagas disease, it is essential to revise the strategies carefully to sensitize, educate, and implement interventions with native and foreign populations. On the other hand, as we stated in the previous section, the learnings and experiences of the affected people should be considered to promote the dialogue among the health care team members and the other involved social actors. We also stated that this dialogue will lead to the development of strategies oriented toward guaranteeing the right to health disregarding people's origin and context.

Health should be acknowledged as a fundamental right for all people in the diverse global scenarios. This means that States should guarantee the care, treatment, and monitoring of Chagas disease in *endemic* and *nonendemic* contexts as well as in the current context where this problematic constitutes a global health

problem and the population has not been considered yet the leading and main actor to whom all the actions related to the disease approach should be addressed.

Currently, the access barriers experimented by the population affected by Chagas reflect relationships with objective elements that condition the access to both health care and work due to presence of positive serology. On the other hand, these barriers imply that the individuals, although being holders of universal rights, face situations of discrimination and social exclusion, product of their national, ethnical, and gender. Both in the societies where the people affected by Chagas disease are *traditionally* located and in the *new contexts* where the disease is present, people face social exclusion constructions associated to discriminatory practices based on a diversity of prejudices and stigmas that constitute barriers of structural and subjective or symbolic inequality.

One of the risks faced by health teams is to attribute themselves the Others' *voice* when recognizing situations of exploitation, undermining, and social exclusion, among others, suffered by the people affected by Chagas. Although this assertion states the need of contributing in the restitution of the individuals' rights (because health teams, as State representatives, have the duty of guaranteeing the population's right to health), it is crucial to remember that this contribution should take place acknowledging the individuals' agency. Thus, professionals may support organization processes in which the individuals themselves might be represented and acknowledge individual agencies that favor intercultural interchange processes, but it is not acceptable for them to arrogate *the voice* of those who live Chagas disease as an everyday life reality. Men, women, and children, who within the framework of the problematic have been displaced or excluded, must be listened; but they themselves should articulate and develop mechanisms of social representation.

Furthermore, the presence of active individuals is key, those who, on the basis of their own experiences, might contribute to the development of culturally pertinent interventions and actions of intercultural character that imply an input to the improvement of the conditions of the violation of rights. We refer, for example, to interventions such as the programs "Expert patient" [22] or "Spread the voice" [23] that, somehow, acknowledge the individuals' agency within the framework of the problematic of Chagas. Agency that articulates with the medical performance provides not only a better understanding of the problem from the affected individuals' viewpoint and experiences but also a privileged learning space for the involved health teams.

### 4.3.3 Initiatives Designed in an Inclusive Relationship

Research findings and concrete intervention experiences performed in different places of the world present eloquent results about the importance of considering diverse actors as authentic partners to generate transformations inside the complex problem of Chagas. In the last few years, several innovative approaches have pioneered, both individually and collectively, the treatment improvement of individuals directly or indirectly affected by Chagas by combining biomedical, psychological,

social, and anthropological elements and seeking to overcome stigma and barriers [7, 22–25]. At the same time, information, education, and communication initiatives have been developed in a similar spirit, including strategies and resources designed to address the issue holistically and incorporate constructive and innovative perspectives, both for the benefit of the individuals affected and for society [5, 24]. Although the initiatives are still not numerous, they set a precedent to be considered and allow enlightening adaptations in broader areas (at local, rural, urban, cosmopolitan, and transnational contexts).

Analyzing all the implications of the previously cited experiences exceeds the aim of these pages. However, it is possible to recognize common ground to point out that, beyond the particularities of each case, in all the situations some transversal elements are highlighted, such as the acknowledgement of the agency or the potentiality of agency of all the actors, the integration (to a greater or lesser extent) of the diverse actors at the moment of designing the initiative, the perspective of rights, the consideration of the multiplicity of voices and aspects of the individuals' everyday life (beyond the *disease*), and the consciousness about costs and engagements of this kind of approach.

However, it should be clarified that an inclusive and dialogic beginning does not guarantee in itself the intervention success but, maybe, it allows delineating scenarios in which the eventual conflict due to the disagreement of conceptions and expectations of the diverse actors might be known in time, and the tensions might be channeled toward understanding and mutual cooperation. We might draw away from, for example, the “mismatch between the experience of those affected and the medical classifications of Chagas disease” indicated by Ventura-Garcia et al. [4]. The dialogue between the health systems and the individuals, and the opportunities displayed with the aim of understanding the diversity of conceptions of health and illness would improve the scenarios and the practices of the medical systems, not only because they allow a better agreement and approach to the affected population, but also because in the relativization of their own conceptions of health and the world, new possibilities are open to perform in health and health care [19]. Then, almost as a first measure, we suggest to reinforce research about the social representations of Chagas disease influencing the behavior, the agency, of both the affected individuals and the other involved actors [5, 18]. Hence, it will be possible to obtain practical and contextualized recommendations to co-design the best interventions as more information becomes available about the different experiences and the diversity of knowledge related to the problematic of Chagas and all the elements emerging at the moment of asking oneself *What are we talking about when we talk about Chagas?* in each particular context.

As we have already stated, from the possibilities opened when we recognize the affected individuals' experience and acknowledge their agency, cultural and intercultural pertinent interventions such as the “Expert Patient” [22] or “Spread the voice” [23] have been generated. Another type of agency whose potentialities have been evidenced is the one of the migrant people in the so-called *transnational social spaces*, that is, those spaces emancipated from the national borders. The transnational practices—those ones regularly held, with systematization and strong

adherence between the origin and destination migrant communities—explain that in the transnational spaces flow not only economic remittances but also social remittances, understood as “the normative structures (ideas, values, and beliefs), the practice systems, and the social capital flowing from the resident families into the host society toward its origin society” [26]. In this transnational context, data are already collected about changes in the searching paths of solutions of the affected individuals by Chagas disease in *endemic* areas that might be explained from the appropriation of ideas and practices influenced by their relatives living abroad [27]. These opportunities broaden and become complex if we consider that the mobility of several families can be ascribed in circular or cyclic mobility tradition from which the actors demand the health team’s capacity of adaptation, maybe toward the offering of a transnational care in Chagas disease, although that type of intervention could have been held only in structures financed by specific cooperation projects [27].

Mentions should also be made of forms of social mobilization spearheaded by associations of people affected by Chagas disease, medical workers, and researchers all over the world. They have been crucial in terms of raising awareness, promoting access to diagnosis and care, and boosting the development of applied research [28]. One extremely important initiative in this area was the creation in 2009 of the International Federation of Associations of People Affected by Chagas Disease (FINDECHAGAS),<sup>3</sup> which currently brings together more than 20 associations in the Americas, Europe, and the Western Pacific. This instance collects the experience and needs of women and men affected by Chagas disease worldwide.

Considering another type of actors, it is worthy to highlight the existence of initiatives such as the “Global Coalition of Chagas Disease”<sup>4</sup> that gathers researchers, public health professionals, and private donors who articulate with affected people and some other members of the civil society. Among their principal challenges, the Coalition leads efforts to approach aspects different from the biomedical dimension of Chagas such as the incidence and the access to diagnosis and treatment.

Finally, from the World Health Organization (WHO) as a possible scenario of confluence and spreading of validated initiatives, we underline the recent creation of the Technical Group No. 6 on Information, Education, and Communication (TG6 IEC)<sup>5</sup> of the WHO Control Program of Chagas Disease. This instance is presented as a key opportunity for a group of professionals—specialists from different areas without conflicts of interest—to counsel the WHO from multidimensional viewpoints to promote, on a larger scale, the change of approach necessary to account for the challenges posed in the new epidemiologic scenarios and the essential epistemological changes we have been stating.

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<sup>3</sup><http://findechagas.org/>

<sup>4</sup><http://www.coalicionchagas.org/>

<sup>5</sup>[www.beatchagas.org/](http://www.beatchagas.org/)

#### 4.4 An Overview: Some Keys to Facilitate the Desired Access

As a corollary of the words shared in these pages, we come back to the reflection leading us to think about the numerous elements that should be incorporated systematically and rigorously to the search for answers to understand the current problematic of Chagas and reach contextualized and long-lasting solutions. In this sense, we agree on that the new paradigm we referred to at the beginning of these chapter must consider the fundamental and unavoidable importance of subjectivity as it is stated by de Sousa Santos [6], who considers that objectivity depends on the quality of its subjective dimension and the development and consolidation of social transformation collective actions.

Therefore, it is necessary to systematize and assess the interventions from integrative perspectives as well as to develop research tools to expand the focus of these activities incorporating the sociocultural aspects of health. “Furthermore, both research focused on incorporating people’s experience and needs into policies and interventions in endemic and non-endemic countries and the development of preventive and/or control actions conducted with attention to affected individuals beyond medical spaces are crucial” [4:6]. However, we have to be cautious because the call is not only to add these perspectives, as we have already stated; on the contrary, it is about articulating dialogic relationships that favor supporting acknowledgement processes of the distances of knowledge and power from which we face Chagas. These distances translate into barriers for the access to an adequate and prompt health care and the stigmatization and violation of the affected people’s rights. Thereby, the revision of processes that in practice exclude, assimilate, and undermine is imperative to promote, from that revision, a dialogue introducing new social and institutional learnings and practices.

The epistemological transformation will allow enhancing the delimitation of the problematic of Chagas and, at the same time, will favor processes to acknowledge emergent actors and practices in order to incorporate diversities as regard gender, age, ethnicity, and class and to include other actors such as social, national, and international organizations, the media, etc. From research, its practices and the diverse ways of constructing knowledge, it must be evidenced the need of incorporating from the considerations of the Epistemologies of the South [4] the dialogic articulation required today in the understanding of Chagas disease. In other words, from these new perspectives, we might be alert to the changes and transformations raised from the individuals who consult (or not) and to the modifications from the health care systems manifested in those new relationships, to go beyond the current unequal framework of relationships and transform society. There we will find the signals to overcome the dichotomies accounting for practices of disqualification and *nonexistence*, in the end, of social exclusion: healthy/ill, ignorant/expert, poor/not poor, endemic/nonendemic, patient/agent, with a voice/without a voice, etc. By being aware of these dichotomies, we evidence the ideological frameworks through which we approach health and illness in general and Chagas disease in particular. With these evidences on the table, we will begin to walk with steady steps the collective way toward the development of true comprehensive approaches.



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