

Chapter 12

A Kaleidoscope of Words and Senses to (Re)Think the Chagas Problem: Experiences in Argentina and Brazil



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12.1 Introduction

Chagas is a complex socio-environmental health problem with a direct and indirect impact on millions of people all over the world (Coura and Viñas 2010). The degree of advancement in scientific knowledge about the biological, medical, and

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epidemiological aspects of Chagas over the last 100 years has not translated into an equivalent increase in the welfare of people affected by Chagas (Sanmartino 2015). Thus, the complexity of the problem requires an innovative and interdisciplinary approach that recognizes the value of understanding the multiplicity of factors involved. In this sense, within the framework of the group “*What are we talking about when we talk about Chagas?*” (*¿De qué hablamos cuando hablamos de Chagas?*), we aim to make the topic visible in different educational and community contexts, critically reflecting with work team members and society to promote the exchange of knowledge and ways of thinking among the highest possible number and diversity of social actors. To accomplish this goal, we organized a variety of activities, including trainings and workshops, proposing a multidimensional approach to the topic where art, science, and other “sub-universes” (Good 1994) engage in dialogue to situate the Chagas problem beyond dichotomies and traditional approaches (Carrillo et al. 2018; Mordeglia et al. 2015; Sanmartino 2015). In this context, we share this chapter as a contribution to the collective fabric woven by speaking words about the Chagas problem in particular, health promotion in general, and art(s) as a tool and bridge to overcome barriers in the search for social transformation (Chap. 1, this volume).

12.2 What Are We Talking About When We Talk About Chagas?

As mentioned above, Chagas is much more than a disease; it represents a complex socio-environmental health issue in which elements of a different nature converge and interact with each other (Sanmartino 2015). However, the way in which the Chagas problem is generally addressed—in literature, prevention and control actions, awareness and education strategies, etc.—is focused on and limited to some specific aspects, particularly the biomedical perspectives. As a consequence of this partial and static understanding, as if it were a “monochromatic kaleidoscope” with few fixed pieces, the progress made in some disciplines has not had a proportional effect on the health and welfare of those affected by Chagas. For this reason, our group discusses and works on Chagas from an innovative and comprehensive perspective from at least four dimensions: *biomedical*, *epidemiological*, *socio-cultural*, and *political*. As we will highlight, each dimension offers and adds groups of unique pieces or “colored beads,” with their special shapes and peculiar colors that interact and complete the others in a “kaleidoscopic puzzle” (see Fig. 12.1). In a kaleidoscope, every little bead with its own shape, color and size, is essential to forming a diverse and enriching image: a dynamic image that results from a unique conjunction of all the parts (Carrillo et al. 2018). In fact, the kaleidoscopic model implies movement of its pieces!

As with all puzzles, all the pieces—in this case called *dimensions*—contribute the same weight to the image we want to assemble/observe, and if one of them is missing, we cannot access the whole figure. Similarly, in all kaleidoscopes, the

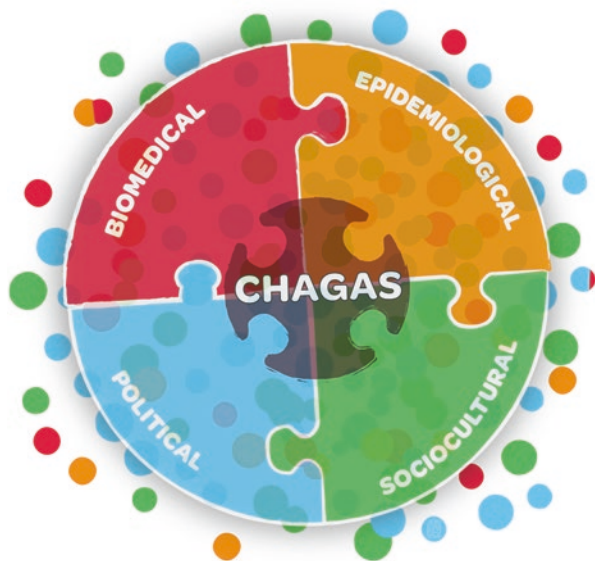


Fig. 12.1 Chagas problem represented as a “kaleidoscopic puzzle”. (Design: Ruth Oñó)

richness of the images we observe is made possible by the contribution of each and every one of the colored beads—in this case, every component of each dimension, every actor, and every bit of knowledge involved. For this reason, we believe that components of all four of the dimensions briefly described below are necessary when approaching the Chagas problem because they constitute the aforementioned “kaleidoscopic puzzle,” and they make sense if we analyze them as a whole from the dynamic interrelationships existing among them.

12.2.1 Biomedical Dimension

This point of view—one of the most common means of addressing the topic—focuses on Chagas as the parasitosis caused by the unicellular parasite *Trypanosoma cruzi* (*T. cruzi*). One of the main routes of transmission of *T. cruzi* is the so-called “vector route,” in which infected blood-sucking insects (triatomines, which in Argentina and other countries from the Southern Cone are known by their Quechuan name “vinchucas” and, in English, “kissing bugs”) transmit the parasite through their stool. However, it can also be transmitted during pregnancy or delivery (vertical or congenital transmission), through the transfusion of blood or the transplant of some organs of infected donors, through the consumption of foods or beverages containing the parasite, or by laboratory accidents of people working in health or scientific fields. Chagas disease has an acute stage, when the parasite enters the organism, which can either be characterized by symptoms like malaise, prolonged

fever, and vomiting or be asymptomatic. After approximately 1 month, the chronic stage starts. Although 70% of people with a chronic Chagas infection may not present any symptoms throughout their lives, 30% of them may develop heart, digestive, and—in very unusual cases—neurological problems 20 or 30 years after becoming infected. The available treatments are partially effective, and the sooner the diagnosis, the more effective the treatment. However, although there are good detection methods, it is estimated that only one out of ten people has been diagnosed (Coura and Viñas 2010), which directly affects both individual and public health. We usually approach both points of view, biological and medical, together as a unique kaleidoscopic puzzle piece: the “*biomedical dimension*” (Sanmartino et al. 2012), which has traditionally been the common and hegemonic approach to addressing this complex problem.

12.2.2 *Epidemiological Dimension*

This dimension considers that Chagas disease is endemic to Latin America and originally spread out from rural areas in the southern United States to Patagonia (Argentina and Chile). There are currently at least eight million people infected with *T. cruzi* in the world, mainly in Latin America (with at least 1.5 million people in Argentina, the authors’ home country) (WHO 2012). Nevertheless, the epidemiological picture has become more complex due to the migratory movements of the last few decades as well as the urbanization and globalization phenomena and climate change. As a result, Chagas disease is no longer exclusively a rural problem or only a Latin American reality (Briceño-León and Méndez Galván 2007). We are currently facing a problem that is present in both rural and urban contexts around the world.

Biomedical and epidemiological dimensions are undoubtedly important; however, they are not enough to represent all the complexity involved in the “kaleidoscopic problem” of Chagas. That is why we have added components (“colored beads”) from at least two more dimensions to this dynamic puzzle to better comprehend the Chagas complexity.

12.2.3 *Socio-cultural Dimension*

This aspect involves “cosmovisions” or worldviews and cultural practices of directly or indirectly implied actors; management of the environment; particularities of rural and urban contexts; social representations; stereotypes; prejudices; and social assessments (discrimination and stigmatization, among others).

12.2.4 Political Dimension

Lastly, we add this dimension that involves issues related to public management and health decision-making, education, and legislative topics at local, regional, and global levels. This dimension also includes public and private administrations, whose economic resources directly or indirectly affect this problem. Furthermore, this dimension encompasses personal, civil, and community points: the decisions that each one of us—as individuals or as a group, from our civil and professional roles (in research, teaching, communication, health care, etc.)—actively or passively assumes when we think (or not) about Chagas from a certain perspective.

12.3 Brief Thoughts on the Art-Chagas Problem Dialogue

We are convinced of the necessity of going beyond “preventing and curing the disease” to focus on the practice of health promotion to improve people’s quality of life. With this purpose in mind over more than 7 years of work, our multidisciplinary group has approached the Chagas problem from an integrated, innovative, and “kaleidoscopic” way in different educational and social contexts: schools, museums, fairs, universities, and social organizations. Our aim is to integrate multiple aspects, perspectives, and languages from the four dimensions (biomedical, epidemiological, socio-cultural, and political) into a collaborative work in permanent dialogue with different social actors to create and encourage various ways of looking at, understanding, and approaching the complexity of Chagas to ultimately produce positive synergy in outcomes (see Chap. 21, this volume, for further background on synergy in health promotion initiatives).

In this sense, as proposed by Ros (2004), art is a language—among multiple languages—that expresses and communicates the ideology, subjectivity, and vision of people’s reality. In addition, art is a specific way of knowing, analyzing, and interpreting our environment through different symbolic languages (body, sound, visual, dramatic, and literary). For this reason, we believe that different artistic expressions summon, communicate, and sensitize people differently, providing sensitivity and depth in the interpretation and analysis of complex topics such as Chagas (Sanmartino and Ale 2011). In agreement with Aranda Zamudio, we are convinced that science and technology offer us the possibility of understanding and transforming the world, showing us its limits, whereas art allows us to break these limits and go beyond them, challenging reality and ourselves (Aranda Zamudio 2011).

In this way, along our path, the artistic languages explicitly nourished the collective fabric around the Chagas problem in all the possible dimensions. In our experience, we have created and encouraged the deliberate promotion of spaces, instances, and productions where different expressions of visual arts, music, audiovisual arts, literature, and performing arts take on special importance (Mordegia et al. 2015). Many of these productions emerged from learning spaces (such as the one presented

in this chapter) and, at the same time, became resources to promote discussions, reflections, critical viewpoints, and even new artistic expressions.

In this chapter, we aim to advance the systematization process of the art-Chagas axis that crosses practically all the proposals we have developed (and continue to develop) in the group “*What are we talking about when we talk about Chagas?*” We focus on the analysis of the literary productions elaborated by different actors (teachers, degree and/or postgraduate students, and professionals, among others) after having participated in multiple training opportunities (courses, meetings, workshops) between the years 2012 and 2018 in Argentina and Brazil. In this analysis, we evaluated the different dimensions of the Chagas problem that were included in these texts and also characterized the actors, identifying the characters’ roles and the strategies posed to approach the topic in each case.

12.4 “Brushstrokes” About the Theoretical Context That Guides and Inspires Our Work

Throughout these years of work, we progressively recognized the potential of systematizing our experiences, both to learn from our practices and to advance findings in a way that allows us to share our learnings with others (Sanmartino et al. 2014). The “systematization of experiences” is a process of reflection and critical interpretation about and from the practice, performed from the reconstruction and structuring of the objective and subjective factors that are part of an experience to extract learnings and be able to share them (Jara 2012). Thus, as Torres and Cendales (2006) propose, we assumed systematization as a research practice with its own identity, and not as a moment or stage in research; it is not an assessment, because its intention is not to evaluate the accomplishment or the impact of a planned objective, but instead to recover the knowledge and meanings of the experience to make it stronger. As a qualitative-critical investigation in which the processes of reconstruction, interpretation, and transformation of the experience are simultaneously developed, “systemization of experiences” implies an engaged participation of their constituents at the same time as it contributes to their formation (Torres Carrillo 1996).

We are also interested in incorporating into our readings and interpretations certain contributions from the so-called *Epistemologies of the South*, which propose approaches for the construction and validation of knowledge developed by social groups as part of their struggles and resistance against the injustices and oppressions generated by capitalism, colonialism, and patriarchy (De Sousa Santos 2014). Particularly for the purposes that underlie these pages, we worked using the *Ecology of Knowledge* as an organizing framework. This perspective assumes that all the practices of relationships 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 are made visible through the plural epistemologies of the scientific practices and, on the other

hand, of promoting the interdependency between scientific and non-scientific knowledge (De Sousa Santos 2014). In other words, it is an ecology based on the recognition of the plurality of heterogeneous knowledges (where modern science is one of them) and on the continuous and dynamic interconnections among these kinds of knowledge without compromising their autonomy. Hence, as opposed to a rooted monocultural perspective, the *Ecology of Knowledge* understands knowledge as an intervention in reality more than as a hierarchy of occidental knowledge over other ways of knowing. That is, this perspective does not consider knowledge in abstraction but rather as practices of knowledge that allow or prevent certain interventions in the real world.

In this frame, we believe that promoting a kaleidoscopic approach of the Chagas problem implies putting into practice the *Ecology of Knowledge*, which would allow us to reach a *Cognitive Justice* (De Sousa Santos 2014). De Sousa Santos states that from the conquest and the beginning of modern colonialism, there has been a kind of injustice that founds and contaminates all the other kinds of injustices we have acknowledged in modernity; whether they are socio-economic, sexual, racial, historical, or generational injustices, it is all about cognitive injustice. In this sense, it is evidenced throughout the work that among the different kinds of injustices related to the Chagas problem (political, economic, social, cultural, sanitary), there is a transverse injustice directly related to knowledge because, as we mentioned earlier, the biomedical/epidemiological knowledge is recognized almost exclusively as the only valid one.

12.5 Presentation of the Case Example—Where Did These Texts Come from?

The literary texts analyzed here were produced, as we have already mentioned, in diverse courses, workshops, and/or meetings held between 2012 and 2018 in different locations in Argentina and Brazil. The first time we performed the literary writing exercise about Chagas was in August 2012 within the framework of the first “Month of Chagas” that we organized in the Museum of La Plata (Buenos Aires Province, Argentina). There, we delivered a teacher training course consisting of seven meetings (21 hours in total) for ten kindergarten teachers. At the closure of the course, the participants were asked to write a story about the Chagas problem in first person, inspired by an image provided by the course coordinators that showed a group of people of different ages, as a family group, but without giving details about relationships between them, about rural or urban context, or about their social or economic position. The ten texts resulted in such beautiful literary expressions that we decided to gather them in a publication. To give the texts some color, at the end of the same year we organized a “Meeting of Illustrators” in the Municipal Ecological Park of La Plata. Numerous artists (professional and amateur) from the area were invited to be inspired by and to illustrate the teachers’ texts. The literary

and visual beauty obtained through these activities about the Chagas problem was condensed in the book “*We talk about Chagas: stories and strokes to think of a complex problem*” (Sanmartino et al. 2013; free at <https://hablamosdechagas.org.ar/recursos-libros/>); the book, beyond its value as a cultural object, resulted in an inspiring tool to approach the topic in new contexts or with new actors. From that first and pleasant experience onward, we decided to replicate the literary text production exercise in other scenarios, given the potential of the activity and the excellent reception of the participants turned into “authors.”

The other texts analyzed here corresponded to the following six contexts:

1. Workshop: “*Art and Chagas: expressions to think of a complex problem*” (4 hours work) within the framework of the I Brazilian Symposium of Cultural Entomology, May 2013, Feira de Santana, Brazil. Recipients: students of natural sciences and professionals devoted to the study of insects and their link with diverse aspects of culture (four texts).
2. Talk-Workshop: “*A kaleidoscopic proposal to think of Chagas today*” (5 hours work) within the framework of the seminar “Chagas disease: conscience and sensitization” (Iniciar for Global Action Foundation), June 2014, University of Buenos Aires, Argentina. Recipients: Research professionals and people interested in the Chagas topic in general (six texts).
3. Teacher Training Course: “*What are we talking about when we talk about Chagas?*” (15 hours work) within the framework of the Month of Chagas, September 2014, Museum of La Plata, Argentina. Recipients: teachers from all educational levels and university students (Degree Complementary Activity—National University of La Plata) (ten texts). The texts are published in the Appendix of the book “*We talk about Chagas: Contributions to (re)think the problem with a comprehensive view*” (Sanmartino 2015).
4. Workshop: “*(Re)Thinking the Chagas problem from a kaleidoscopic perspective*” (3 hours work) within the framework of the Annual Meeting of the Research Platform in Chagas Disease, Drugs for Neglected Diseases Initiative—Latin America (DNDi), August 2015, Buenos Aires, Argentina. Recipients: specialists from diverse disciplines, mainly biomedical ones, professionally related to the Chagas problem (seven texts).
5. Postgraduate Course: “*Educating in health from a comprehensive perspective: The multidimensionality of problems such as Chagas and illnesses transmitted by mosquitoes*” (Chagas block: 4 hours work), National University of Río Cuarto, June 2017, Río Cuarto, Córdoba, Argentina. Recipients: university teachers, postgraduate students, and students from other educational levels in courses related to education and health (four texts).
6. Postgraduate Course: “*Tools to understand and approach the multidimensionality of regional health problems*” (Chagas block: 4 hours work), National University of El Litoral, June 2018, Santa Fe, Argentina. Recipients: postgraduate students, teachers, researchers, and professionals related to health (four texts).

For all cases, the following instruction was provided to inspire the literary productions about Chagas:

With a family image as a trigger, in groups (of no more than six members), write a text (story, poem, letter, news story, etc.) in first person from the role assigned by the workshop coordinator (according to the features of the context where the activity is being developed, the roles might be: kissing bug, children, mother, father, neighbor, teacher, doctor, ruler, employer, journalist), considering the peculiarity that one of the family members in the image has Chagas disease (it does not matter who, but it is worth mentioning that the text must report that information in some way).

The 45 analyzed productions—with no directions about format or style (there were stories, letters, news stories, interviews, speeches, dialogues between different characters, play scripts, monologues, songs, and poems)—were written by 216 people of whom 80% were women, 17% were men, and 3% were an undeclared gender. With regard to their professional or academic activities, 49% were teachers from different educational levels, 32% were professionals and/or researchers, and the remaining 19% were degree and postgraduate students.

12.6 Some Methodological Considerations

Within our main goal of approaching the Chagas problem in a “kaleidoscopic” way by considering the arts as tools and bridges to go beyond the limits of typical approaches to addressing scientific questions, this work was centered on two particular objectives about the aforementioned literary texts: (1) to visualize and describe the conceptual representation of the different dimensions of Chagas, and (2) to characterize the actors, their roles, and their strategies to approach the problem depicted in the texts. We chose a qualitative methodology, since it allowed us to approach the social experience of the subjects and their links with “others” and with different ways of knowledge/power (Vasilachis de Gialdino 2007). Thus, on our first approach to the compiled texts, we made an individual reading prior to the formal analysis, acknowledging the appearance of the proposed characters and of other ones who were incorporated spontaneously as well as of the four-dimensional fabric that we proposed as the model to approach the Chagas problem. Then, we addressed our two objectives with specific methodologies.

12.6.1 *Objective One: Conceptual Representations*

For the objective related to analyzing the different dimensions of the Chagas problem, we used the *systemic network technique* proposed by Bliss et al. (1983) and the *word cloud/tag cloud generation technique* (McNaught and Lam 2010).

12.6.1.1 Systemic Network Technique

Systemic networks allow for structuring qualitative data according to a categorization previously determined or elaborated from the obtained words in the texts to be studied (Bliss et al. 1983). As a whole, the networks collect all the meanings to be analyzed and represent them in the form of an ordinary graphic language. For the network structuring, we pre-established, as primary categories, each of the four dimensions we proposed for the Chagas problem approach (biomedical, epidemiological, socio-cultural, and political). Then we started the readings and, according to their appearance, we defined the subcategories of conceptual organization included in each dimension. The level of subcategories emerged naturally, in accordance with the depth reached in the texts for each dimension. Hence, we considered that the appearance of different subcategories or deepness levels accounts for the dependence or independence among ideas, feelings, and values expressed in the texts. In this sense, every built structure or network is one among many possible others, related to the analyst's interpretation (Sanmartí 1993).

12.6.1.2 Word Cloud

The concepts systematized in each dimension of the systemic network were represented according to their frequency of appearance through a word cloud or tag cloud (excluding those that appeared only once or twice). The word cloud is a graphical representation of text data that assigns to each included word a size relative to its prominence in terms of frequency of appearance, obtaining a “quick and visually rich” shape (McNaught and Lam 2010). The platform used for the elaboration of the word cloud was WordArt (2009).

12.6.2 *Objective Two: Actors Characterization*

With the particular aim of characterizing the actors, their roles and their strategies, and the frequency of appearance of each them in the texts, we applied Content Analysis (CA) (Bardin 1977). The process started with a first “floating reading” (i.e., a reading that focuses on structures rather than deeply on the content) to identify the main analysis variables (Cea D’Ancona 1996)—for example, “type of character” or “role in the text” and their correspondent self-built categories system (see Table 12.1). Next, during the step of “material utilization,” we assigned codes to each variable and each defined category to load them into the IBM SPSS Statistics 23 program. This process permitted us to generate simple characteristics of the text samples—i.e., to count frequency of appearance for each variable and each category (for example, times in which “mother” was presented as the main character in “type of character”).

Table 12.1 Coding variables and their categories system

Variable	Description of variables with their categories system
Type of character	In all cases, the main character was provided by the exercise instructions; then, the authors decided freely whether to introduce (or not) more characters. The characters mentioned in the texts were: doctor, member of a family (aunt or uncle, daughter or son, niece or nephew, cousin, grandparent, children, mother, father), kissing bug, teacher, employer, mayor, journalist, neighbor, scientist (biologist), and people in general (men and women)
Role in the text	We classified characters into active or passive. Active characters were those in charge of decision-making and situation-solving; passive characters performed the activities the others had decided on (without questioning)
Attitude toward the problem presented by active characters	According to the situations posed in the texts, we identified the following attitudes: to provide biomedical information as well as diagnosis and treatment of the disease, to look for biomedical information, to advocate for more involvement of the state (via resources and/or campaigns), to deliver informative talks at school, to generate discrimination situations (especially in work environments), and to report discrimination situations in the media
Focus of the problem for active characters	We identified the following categories as the focus of the problem for active characters: lack of biomedical information, desire for better access to certain resources, little involvement of the government in providing budget and resources, and lack of information about legal rights
Recipients of the problem-solving strategies for active characters	We found the recipients of problem-solving strategies for active characters to be the following: people without information, patients, the community in general, doctors, interdisciplinary teams (doctors, social workers, field technicians, psychologists, and lawyers, among others), people infected in general, people infected who are not apt for work, media, and people who are not aware of their legal rights
Focus of the problem for passive characters	We identified the following categories as the focus of the problem for passive characters: lack of biomedical information, little presence of the state, lack of medical knowledge, little presence of the school, discrimination at work, people in general and their prejudices, knowledge within the family, and specialized Chagas-trained field technicians
Recipients of the problem-solving strategies for passive characters	We found the recipients of problem-solving strategies for passive characters to be the following: doctors, teachers, politicians, the community in general, and employers
Position in the strategy posed by passive characters	We identified the positions in the strategy posed by passive characters to be the following: waiting for answers and action plans posed by others (if there is a solution, the character accepts it); waiting for answers and action plans posed by others but, in certain cases, showing a certain degree of initiative at the time of asking for information and the necessary help; and the victim's position

Focusing on the epidemiological dimension (orange words in Fig. 12.2), although it was not present in all of the texts, it was the second most important dimension according to the frequency of appearance and level of detail. Its components were condensed into four subcategories: *geographical distribution* of the disease in certain provinces in the north of Argentina, *epidemiological indicators*, *population* (or *migratory*) *movements*, and *prevention* and *vector control*, in agreement with the relevance assigned to the vectorial transmission in the biomedical dimension.

The socio-cultural dimension (green words in Fig. 12.2) appeared to be next in importance, represented by five concepts: *housing* (type and condition), *social representations* (for example, the roles of doctor and teacher), *discrimination* (both at work and among social classes and strongly linked to the concept of stigmatization), *person* or *migrant group*, and *quality of life*. In all cases, it was evident that the strong symbolic value assigned to certain social actors reflected the existence of hegemonic and stereotypical roles.

Lastly, the political dimension (light blue words in Fig. 12.2) included the common concepts of *public health*, *information/disinformation*, *citizen role*, and *education content*, and, to a lesser extent, the *legal framework* in Argentina (Ley 26.281, 2007). These concepts are centered in the role of the public policy—present or absent—and the state as the only ones responsible for it, whereas the appropriation of the personal political responsibility as citizens was barely represented by a tangential acknowledgment of the degree of disinformation of certain actors, even when it was a specific topic discussed in the courses.

As a general observation, we found that the conceptual structure of biomedical and epidemiological dimensions is hierarchically organized and is condensed in technical terms of high repetition (for example, the term *disease* represented, in turn, by the subordinate categories *acute disease*, *chronic disease*, *neglected disease*). In contrast, socio-cultural and political dimensions do not present a defined conceptual structure, being represented by a great diversity of concepts mentioned few times without hierarchical organization among them. We think that word diversity without hierarchy reveals the absence of a previous conceptual structure about the socio-cultural and political dimensions in the participants, because these points of analysis are not familiar to people who do not work in topics related to Chagas and social or political sciences.

12.7.2 *About the Characters Present in These Texts*

Considering the types of actors represented in the texts, in 60% of the cases main or secondary characters were embodied by members of the *family*, and in 40% of the texts the *doctor* figure was also included (in only one case, it was a female doctor). The *teacher* (female in all of the cases) appeared in 20% of the texts, the same as the *vinchuca*—considered as a main character with the ability to express itself. Finally, the characters of *employer* (male), *mayor* (male), *journalist* (male), *neighbor* (male), *member of the family*, and *scientist/biologist* (male) appeared in at least 10% of texts.

In most of the cases, active roles were embodied either by characters with professions recognized as “holders of knowledge”—*doctor* (35%), *teacher* (14%), *journalist* (6%), and *biologist* (2%)—or by characters with a favorable position within an asymmetric power relationship, namely *employer* (8%) and *mayor* (8%). Characters without an explicit stamp of power (either of authority or of knowledge), such as *neighbor* (8%), had an active role in only a few cases; on the contrary, all the passive roles were held by these actors’ profiles, frequently described as family members (*mother, father, child*). These findings suggest that perhaps these passive but familiar characters might be viewed as lacking the pertinent knowledge/power necessary for action.

12.7.2.1 Active Characters

Regarding the analysis of active characters, we focused on four axes: (1) attitude toward the problem, (2) problem focus, (3) role in their strategy, and (4) recipients of the strategies.

In the first axis, most (90%) of the attitudes toward the problem were constructive or “positive”; that is, they posed a concrete and specific solution for it. In this sense, doctors were identified as those in charge of providing biomedical information and diagnosing and treating those who needed it. Teachers were also acknowledged as providers of biomedical information at schools. We understand that these evaluations respond to a stereotypical view regarding the competencies of these professions. On the contrary, “negative” attitudes, such as discrimination toward an affected person by an employer and/or neighbor, appeared in a small proportion of texts (10%). Characters aimed at individual and personalized solutions did not consider, for example, the option of organizing themselves and/or contacting the existing organizations related to the problem. As an exception, there was one text—out of 45—where Chagas was recognized as a social problem (referred as “Chagas involves all of us” and “it is a problem for everyone”), although in this case there was not a manifested reference to a collective search for responses.

In the second axis, the focus of the problem for these characters was primarily centered (89%) in people’s lack of biomedical information. In only a small percentage (4%) was it mentioned that the role of the state was as a central actor, the one that must administer budgets and/or organize prevention campaigns.

Similarly, in the third axis of analysis, the strategies adopted by the active characters to face the problem were, on the one hand, those of sources of biomedical knowledge (44%) and, on the other hand, those of sources of power (41%) in charge of performing, managing, and/or organizing the posed strategies.

In the last axis of analysis, the recipients of the strategies were mostly individuals (89%) who, as we have already mentioned, lacked knowledge and power. In only a small proportion (11%) were the recipients doctors, media, and/or interdisciplinary work teams. Can we infer then that biomedical knowledge (of active characters present in the texts) constitutes a unidirectional, categorical, and non-dialogic knowledge that must be transmitted only by certain specialized actors? Are

“ordinary” people “mere receptors” of that knowledge in this uneven knowledge relationship, with no valid knowledge of their own to contribute to the understanding of the problem? (Sanmartino 2015).

12.7.2.2 Passive Characters

Regarding the analysis of passive characters, we focused on three axes: (1) focus of the problem, (2) position in the proposed solving strategy, and (3) recipients of the strategies.

In the first axis, we found that the focus of the problem for these characters was related to individual actions, centered frequently (67%) in the lack of biomedical information. On the other hand, 30% of these characters mentioned the state, doctors, school, and workspaces as places where there should be a search for solutions to the problem.

With respect to passive characters, we found that they were frequently (65%) in the position of waiting for responses or action plans elaborated by “others,” generally recognized as active characters. Only one-third of passive characters, although waiting for responses from active characters, showed initiative to ask for solutions and be in charge of accomplishing them. For example, we frequently found that some characters consulted a doctor about their possible positive Chagas disease diagnosis because they had been looking for information and knew about the existence of treatment. In these cases, although they had the initiative of looking for information and undergoing the existing treatments, they needed a doctor to confirm and decide the treatment. Among these passive characters, people carrying the infection were characterized by fear, uncertainty, and/or worry, persisting in their characterizations a certain degree of stereotyped and/or prejudiced assumptions toward them. It should be noted that a minority (3%) of these characters positioned themselves as “motionless victims” who neither accepted a solution nor performed actions to change “their fate.”

Finally, the responses of both active and passive characters complemented each other regarding who was identified as a recipient of problem-solving strategies. As we have already mentioned, active characters identified “ordinary” people as the main recipients; conversely, passive characters pointed out mostly *doctors* (75%), *teachers* (11%), *politicians* (8%), and *employers* (7%) as the recipients of such strategies. This result complements the analysis previously performed that represented active characters as not only the sources of knowledge and power, but also as the main (and only) responsible parties for permanent training, researching, informing, and assigning resources to and about the topic. The analysis positioned passive characters as “non-actors” in the Chagas puzzle, because they were not recognized by others or by themselves as holders of valuable knowledge or facilitators of concrete actions (of their own and others) to face the Chagas problem.

12.8 Final Words: What This Kaleidoscope of Words and Senses Left Us With

During the process of kaleidoscopic analysis of these diverse literary productions, we faced some difficulties that are worthwhile to consider for future experiences.

The first challenge pertains to dimensions. The conceptualization and categorization into one or another dimension was a difficult task in terms of simplifying into four categories a complex multidimensional matrix, whose dynamic and diffuse boundaries—depending on the subject and the situation—in many cases are blurred in the analysis. Furthermore, because of the literary nature of the texts, we found that there were not only explicit but also implicit or metaphorical aspects to be included. On the other hand, in the task of classifying complex concepts, we found in many cases an additional difficulty based on the abstract descriptions of the scenarios and/or the characters' situations. For example, several times there were references to provinces in the north of Argentina—made by authors who do not live in that region—as vaguely defined scenarios, without distinction between urban and rural realities and that put forward assumptions based on lack of knowledge and/or prejudice. In these cases, we assumed that when referring to a “place in the north” or a “north province” the authors were considering a rural setting typically related to Chagas distribution.

Another difficulty we faced was related to the characters and their strategies. We discussed both the level of detail that analysis categories should have as well as the possibility of losing the text richness when “reducing” its interpretation to predetermined categories. Because of this challenge, we left the categories open so that they could be revised, enriched, and/or redefined if necessary. We also debated quantifying certain aspects in this qualitative analysis process, eventually deciding to have a quantitative review first (by examining descriptive statistics) that later would allow us to develop more complex results. Certainly, we did not want to forget that this categorization was the product of a constant process of qualitative construction aimed at responding to work objectives and that we should be careful not to make broader generalizations. In this sense, as we have focused on some specific words, we are aware that part of the richness of the analyzed texts – in terms of their literary and/or artistic character – were left out to focus on the categorizations and descriptions that we present in this chapter.

According to Alderoqui and Pedersoli (2011), “the mirrors inside kaleidoscopes let us see the colored and multi-shaped beads contained within them multiplied, thus forming different images every time we rotate them. In this sense, building kaleidoscope views are to favor the observation of the same, integrating different viewpoints so that the overlapping of different partial images allows us to build a more complex and richer image than the one we isolatedly had about the topic.” In particular, a kaleidoscope view about the Chagas problem invites us to acknowledge the relevance of adopting different approaches for its complex analysis. At the same time, it is essential to recognize the dynamism of the built images because they emerge from the interaction among the considered components that, in turn, depend

both on the viewpoint of the different actors involved and in the great number and variety of conditioning related to the characteristics of the context (Sanmartino 2015).

Throughout these years working on this complex problem, different arts, sciences, and popular knowledge have been combined to create a kaleidoscope with beads of multiple shapes and colors whose objective is to overcome the dichotomies such as “sick/healthy,” “rich/poor,” and “rural/urban.” We are sure that both arts and education, in a broad and inclusive sense, are key elements to shorten the distance between formal and non-formal knowledge and build alternatives that impact and transform reality. For this reason, we promote joint work among researchers, teachers, students, and the community in general at all educational levels (school as well as technical and professional training levels) and in all possible contexts (rural/urban, formal/informal, where there are/are not vector insects, etc.) with the purpose of engaging a greater number and diversity of voices talking about Chagas (Carrillo et al. 2018). We also aim to make our work a source of inspiration to approach other complex issues that affect different communities by encouraging critical and inclusive reflections of diverse voices and looks.

Beyond the results shared here (and its limitations), we recovered the value of the words woven by the authors of the 45 analyzed texts as multicolored beads that contribute to this collective kaleidoscope. We agree with Saavedra Rey, who claims that the construction of a narrative transcends a mere writing exercise. This process is linked to the human experience, which gives the words new meaning by adding to the human condition novel interpretations that can be expressed and shared by diverse people as an aesthetic experience and, as such, a vital experience (Saavedra Rey 2011). Although the literary text produces a world alternative to the “real” one, it also reproduces logics of knowledge and power and makes visible (even between the lines) the history and its fights for consolidating a sense of the hegemonic world. It is undoubtable, then, that in every text analyzed there was intentionality, because the one who writes assumes a particular position and builds knowledge about reality from his/her own perspective. Because of these factors, we value the potentiality of the literary production, not only on what those words say and do not say about Chagas.

Finally, we are convinced that for the complex topic we are considering here, the *Epistemologies of the South* (De Sousa Santos 2014) are one of the most fertile frameworks to incorporate new realities and analytical spaces to collect from the transforming and liberating scenarios that, within the context of health care and the biomedical hegemonic approach of Chagas, have been forgotten or simply disregarded. In this sense, although various aspects of the conventional social imagination (centered in rural issues, poverty, vectorial transmission, and ignorance, among others) that emerge from the aforementioned *cognitive injustice* had a strong presence in the analyzed texts, we believe that the work of symbolic deconstruction and resignification of the value of political and socio-cultural dimensions proposed in the courses and workshops allowed the emergence of concepts usually infrequently noticed. Enabling and/or making visible other voices—in particular ordinary, local, and non-specialized knowledge—brings us closer to the conceptual richness offered by the *Ecology of Knowledge*, necessary for an effective and kaleidoscopic approach toward the Chagas problem.

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