

Do not be afraid of us: Chagas disease as explained by people affected by it

Mariana Sanmartino^(a)

Andrea Avaria Saavedra^(b)

Jordi Gómez i Prat^(c)

Ma. Cristina Parada Barba^(d)

Pedro Albajar-Viñas^(e)

^(a) Grupo de Didáctica de las Ciencias, Instituto de Física de Líquidos y Sistemas Biológicos (Consejo Nacional de Investigaciones Científicas y Tecnológicas – Universidad Nacional de la Plata). Calle 55, n° 910, 1900. La Plata, Buenos Aires, Argentina. mariana.sanmartino@conicet.gov.ar

^(b) Escuela de Trabajo Social, Facultad de Ciencias Sociales y Humanidades, Universidad Autónoma de Chile. Santiago, Chile. andreaavaria@gmail.com

^(c) Unitat de Medicina Tropical i Salut Internacional Vall d'Hebron-Drassanes, Programa de Salut Internacional de l'ICS. Barcelona, España. j.gomez@vhebron.net

^(d) Secretaria General Asapechavae-ValenciaEspaña, Vicepresidencia de Findechagas, Delegación Oficial para Europa de Findechagas. Valencia, España. secretariageneral@asapechavae.org

^(e) Programa de Control de la Enfermedad de Chagas, Departamento de Control de Enfermedades Tropicales Desatendidas, Organización Mundial de la Salud. Ginebra, Suiza. albajarvinasp@who.int

This paper presents an international study that was conducted between October 2011 and January 2012, in which a video (spot) to boost awareness and raise the profile of Chagas disease issues was designed and developed. This study was of qualitative nature and analyzed information that was gathered from 38 questionnaires that had been answered by individuals affected by the disease and by specialists on this disease. The information from each group was classified according to factors that they associated with the word Chagas, along with the difficulties, adversities, challenges, objectives and achievements relating to the disease. The

responses, reports and anecdotes relating to each of these factors were analyzed. The conclusions emphasize the need to know and make known the difficulties that people affected by Chagas disease experience, bearing in mind that the realities are manifested differently depending on the context.

Keywords: Chagas disease. Qualitative study. Information. Education and communication. Representations.

Introduction

Chagas disease, also known as American trypanosomiasis, is a disease caused by the protozoan parasite *Trypanosoma cruzi*. The World Health Organization (WHO) estimates that at least 8 million people are infected, from the United States of America to Argentina and Chile, mainly in 21 Latin American countries, in the zone traditionally considered endemic. It is calculated that more than 10 000 people die of Chagas disease every year.^{1,2} *T. cruzi* infection is transmitted mainly by vectors, the bloodsucking triatomine insects variously known as *vinchucas*, *chinchas*, *barbeiros*, *chipos*, *kissing-bugs* or by other names depending on the geographical area. The disease can also be transmitted through blood transfusions or transplantations of certain organs of infected donors, or congenitally, during pregnancy or childbirth, or through the ingestion of food contaminated by infected triatomine faeces. Due to its extent and its consequences, Chagas disease is considered a significant public health problem in Latin America.³ Although more than half of all people with positive serology for Chagas present no symptoms, it is estimated that about one third will develop manifest forms of the disease, in the form of heart conditions, disorders of the digestive system (usually dilatation of the oesophagus and/or colon), neurological symptoms or combinations of these.

Increasing movements of population – a widespread phenomenon throughout the world encompassing urbanization, international migration, business travel, tourism

and adoption – has changed the traditional epidemiological profile of this and other diseases.⁴⁻⁷ Today, Chagas is a predominantly urban disease, given that more than two thirds of infected individuals live in cities, and the high proportion of undiagnosed cases represents a major challenge. Worldwide, it is estimated that less than 10% of people with Chagas disease are aware of their condition; many people, due to a lack of information and knowledge, do not seek appropriate health care.^{1,2,5} A positive Chagas disease diagnosis has a psychological impact on those affected. Recent studies indicate that people at risk of having being infected often prefer not to know whether they have Chagas disease, because they are afraid of it and the imagined consequences, owing to popular beliefs or experience of family or friends who did not respond to treatment and/or died.^{8,9} Accordingly, the diagnosis and treatment of people with Chagas disease requires a proactive and comprehensive approach, incorporating biomedical, psychological, social and cultural elements. It is important to avoid a situation in which the disease leads to exclusion and stigma, to work proactively to dispel the myths and fatalist ideas surrounding it, and to promote access to treatment and social inclusion.¹⁰⁻¹²

In the last few years a number of innovative approaches have been pioneered, both individually and collectively, to improve treatment of people directly or indirectly affected by Chagas disease, by combining biomedical, psychological, social and anthropological elements and seeking to overcome stigma and barriers.^{6,13,14} 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 people affected and for society as a whole.^{15,16} Mention 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. These have been crucial in terms of raising awareness, promoting access to diagnosis and care, and giving a boost to the development of applied research.¹⁷ 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), which currently brings together 20 associations in the Americas, Europe and the Western Pacific.^(f)

Accordingly, with a view to raise awareness of the realities facing people affected by Chagas (whether as asymptomatic carriers of the parasite, disease sufferers, friends or family members), and in an attempt to influence public opinion in general and specific social groups in particular, the Chagas Disease Awareness and Profile-raising Project (PROSEVICHA) was launched in 2011. An international and intersectorial working group was formed to devise and implement the project, which decided by consensus – as a first step – to make visible the reality facing people affected by Chagas disease in different contexts. In this paper, we give an account of the qualitative results of the first international study of social representations^(g) of Chagas, conducted among people affected by Chagas and specialists in different countries in the Americas and Europe. It is crucially important to explore aspects that, subjectively speaking, determine and govern the behaviours and conduct that influence people’s treatment, perception and health. The information we gathered enabled us to construct a general model of the everyday representations and personal experiences that colour interpersonal relations and give rise to the social processes of exclusion or inclusion of people affected by Chagas. We wanted to explore certain information that would serve as a basis for developing the script of a short video to promote wider knowledge and raise awareness of Chagas disease-related issues.^(h)

#####

^(f) The following countries are represented by the associations that are currently members of FINDECHAGAS: Argentina, Australia, Bolivia, Brazil, Colombia, Spain, the United States of America, Italy, Mexico and Venezuela.

^(g) Generally speaking, the concept of a *social representation* includes the cognitive, affective and symbolic components that guide people’s behaviour in their everyday life, and the forms of organization, interaction and communication in relations between individuals and between and within groups as part of the process of cohesion.^{18,19} Representations are described in theoretical terms in social psychology (Moscovici); Jodelet classifies these theoretical constructs, related to those of Schutz, and Berger and Luckmann, to account for the mechanisms we use to reproduce reality as a given.^{18–20} Representations are a tool for understanding the other, for knowing how to conduct ourselves in relation to the other and even to assign the other a place in society.²⁰ We therefore believe that current representations of Chagas are also complex sources of stereotypes, value judgements and attitudes towards the disease, the persons affected by it, its modes of transmission, its causes, consequences and the contexts in which it exists.¹⁵

^(h) In this work, *awareness-raising* is understood to mean the need to generate, on the widest possible scale, influence and awareness of Chagas-related issues to foster social recognition of the importance of Chagas disease at local, regional and even global level. We use awareness-raising in the sense developed by the World Health Organization, which seeks to develop strategies to promote health.²¹

Accordingly, we thought that linking our initiative with the qualitative research in a dialogue-based process would be an original and evidence-based contribution. The script of the video would be developed on the basis of the representations identified and the messages that emerged from the research.

Methodology

To develop a short video to raise awareness of Chagas disease-related issues among the general public, we approached FINDECHAGAS directly. The Federation brings together people affected by Chagas disease who form associations in all parts of the world; it also includes health specialists and social scientists, and people involved in the treatment, monitoring and investigation of different aspects of the disease. The organizations that comprise the Federation and its associated working groups reflect the wide diversity of contexts and experiences of people affected by Chagas disease in terms of sex, age, occupation, place of residence, ethnic, social and cultural origin, among other characteristics.

The exploratory study presented here was completed between October 2011 and January 2012. The information was collected through e-mail exchanges with the Federation and its affiliated or associated organizations and specialists in different countries. The main objective was to identify representations of Chagas disease contained in the answers and experience reports of the respondents. The principal areas explored were representations of Chagas disease; the problems, challenges, objectives and achievements recounted by persons with positive results to *T. cruzi* serological tests who are either members of or associated with FINDECHAGAS organizations (“persons affected by the disease” or “members”), and the investigation of these topics with subject-area specialists from the biomedical and social sciences, in Europe and the Americas. Contact was established through local organizations/institutions or associations forming part of the global network of FINDECHAGAS contacts. The respondents replied directly by e-mail (each organization

provided assistance to individuals who had difficulties writing and sending their replies).

A structured self-directed questionnaire ⁽ⁱ⁾ consisting of 6 open-ended questions was sent to a purposive sample of 30 people affected by Chagas disease and 30 specialists involved with some particular aspect of the disease. The survey asked for general information such as age, sex, country of birth, country of residence, membership of an association and connection with Chagas disease. A thematic analysis was conducted of all the questionnaires received (19 from each group) on the basis of the following categories: representation of Chagas disease, the problems or obstacles encountered, the challenges and objectives arising from experiences of being diagnosed and living with Chagas disease, and any achievements in overcoming problems. Taken together, these categories cover all aspects of how Chagas disease is understood, represented and experienced. The results of this analysis were used as “raw material” for the team tasked with developing the script of the first short video ⁽ⁱ⁾ to raise awareness of Chagas.

Results and discussion

A total of 38 survey questionnaires were received, analysed and grouped as follows:

- 19 questionnaires from persons affected by Chagas disease (13 women and six men), from Bolivia, Brazil or Colombia; living either in the Americas or Europe; with the occupation of household employee (five), public official (four in post, one retired), farmer (three), shop assistant (two), physician (one), biochemist (one), dressmaker (one) and caretaker (one); and ages between 25 and 76.
- 19 questionnaires from Chagas disease specialists (nine women and ten men); from Argentina, Bolivia, Brazil, Colombia, Venezuela, the United States of America, Belgium, Spain or Switzerland; with the occupation of physician (nine),

#####

⁽ⁱ⁾ The questionnaire was cross-checked by the specialists carrying out the research, without any pretesting.

⁽ⁱ⁾ Available at http://youtu.be/i_22d7qaVks#

biologist (two), social worker (two), systems analyst (one), chemistry graduate (one), public health specialist (one), biochemist (one), nurse (one) and parasitologist (one); and ages between 23 and 73.

The findings are presented separately, first of all those from members of organizations of people affected by the disease, followed by the ones from the specialists. The information was organized in accordance with the themes/categories identified in the thematic analysis of the responses and incorporated the accounts and narratives that illustrate the categories outlined above.

Representations of people affected / members of organizations]

On hearing the word “Chagas”, the **first things** mentioned by the respondents were their experiences or fears about the disease and the possibility of death. They also expressed their bewilderment on receiving the diagnosis. Most of the respondents are from endemic countries, but they were not necessarily diagnosed in their respective countries of origin.

One of the first emerging categories relates to the manifest experience of the disease developing as a physical process. The respondents experience fear associated with the possibility of dying; their fears are also fuelled by memories of close friends and family members who have died from Chagas disease.

“At first I didn’t know about the disease, so I was very frightened, because I had heard that many of my friends had died of it. One friend dropped down dead while he was playing football, I knew he had the disease because he wanted to donate blood but they wouldn’t let him”. (farmer, 36 years old, Bolivian living in Spain)

The fear, uncertainty, ignorance and loneliness associated with the disease are expressed in the form of resistance to diagnosis. People prefer not to be told they are Chagas disease–positive, since they receive the confirmation as a death sentence.^{22, 23}

“I didn’t want to have the tests because I didn’t want to know, I didn’t want to worry, thinking I was going to die..., but my friends joined the Chagas campaign and I tagged along to keep them company and to my surprise they found I was positive. I felt really depressed, afraid and worried, but fortunately at the appointment with the doctor and in the association they calmed me down and now I tell my friends to get tested”. (farmer, 36 years old, Bolivian living in Spain)

As in the other scenarios^{12,24}, the responses of the persons affected indicate their acceptance of, and resignation to, the situation in which they find themselves. In contexts where there are problems with access to treatment and medical care, this is connected with the lack of resources or meaningful opportunities to confront the diagnosis in a proactive way, with specific backup from the health system. On the other hand, in non-endemic areas for Chagas disease, people seeking health advice find themselves in a kind of vacuum, without any possibility of addressing their concerns or obtaining satisfactory answers in their quest for diagnosis and medical treatment.^{9,23}

As to **problems**, two types of reply can be distinguished: on the one hand, patients who resign themselves to their diagnosis without dwelling on specific problems, and others who mention social barriers and exclusion:

– In some responses, although the health impact of the disease is acknowledged, the person is resigned to the positive result of the diagnosis; given the impossibility of changing this reality, the problems occur when the disease and its consequences become manifest. The problems become more apparent as they encroach on health, social activities and employment, etc.

“I feel fine because I have no outward sign of the disease, but waiting for symptoms to appear makes me very nervous”. (household employee, 28 years old, Bolivian in Spain)

– Some respondents reported problems in various spheres, referring to “social barriers” or social exclusion in their everyday life. These situations arise when news of the positive diagnosis is communicated to their friends and family, and especially in the workplace.

The problems fall into three categories:

– employment and social environment: discrimination, stigma, marginalization, ignorance.

“When she was looking for a job, the fact she had Chagas disease meant she had problems getting work (...) She sensed that people had prejudices when she told them she had Chagas disease, judging by the reactions of certain family members, friends and work colleagues”. (public official, 73 years old, Brazil)

– access to medical treatment and care: when health services do not account with the specialist or specific expertise to respond to the patient’s needs appropriately, depending on the stage of development of the disease. This situation occurs both in endemic and non-endemic contexts.

“Finding a doctor who is well informed about the disease, how to go about getting treatment and follow-up care”. (physician, 42 years old, Bolivian living in the United States)

– problems associated with the disease progression, for example the concrete experience of specific abnormalities or generalized symptoms such as fatigue, headache, heart and other organ damage.

The **challenges** refer to the need to live with the disease, undergo medical tests and confront one’s fears (fear of losing one’s employment, of finding out that other family members have the disease, or can face adverse effects of treatment). The challenges in “society” refer to the need to confront prejudices, understand the problem, fight discrimination, and get involved at different levels (people affected or not by the disease). The challenge is to transform themselves into active actors: to gain awareness, communicate and organize themselves.

“If the person with Chagas disease is in employment, his or her colleagues or superiors need to understand that Chagas is not a contagious disease. Bosses need to be aware of this, and also that Chagas is not a disease that prevents people from doing their job. It is important to act against discrimination – after all, most people have the microorganism in their blood. People with

symptoms need treatment. Non carriers should help, out of common humanity, and it's important that people who are unfamiliar with the disease become aware of it. It is important to have more communication, to get involved in an association and take part in the struggle...". (public official, 64 years old, Brazil)

The need to stress that Chagas is not a disabling disease, and that it constitutes no danger to others, was identified. Associations and organized bodies are crucial in the social and political process of protecting the rights and interests of persons affected by the disease.^{12,17,23}

Interaction with the health system, specifically lack of appropriate treatment, poses a challenge. Health workers in endemic and non-endemic countries stress the need to develop strategies for appropriate specialized care adapted to the wide range of social, employment and geographical contexts in which people affected by the disease find themselves.⁶

The **objectives** include improving conditions of access to diagnosis, care and treatment, with emphasis on the development of new drugs.

Social organization is singled out as a vehicle for channelling strategies to address the needs of Chagas-affected people, with recognition of the Federation as an important body that focuses on fighting for universal access to treatment and follow-up.¹⁷

Other objectives have to do with the need to raise awareness and disseminate information about Chagas disease, fight discrimination and improve training for health workers (all repeatedly mentioned). The accounts stress the importance of countering the trivialization of the disease and social exclusion.

"People need to know that we aren't infected with plague, that Chagas isn't like leprosy or tuberculosis, there is no need to be afraid of us, and that although there is no cure, we have medical check-ups to make sure that our heart or other organs are not affected". (farmer, 36 years old, Bolivian living in Spain)

People in non-endemic areas need to see trained health professionals who can monitor them in the light of each context where Chagas disease occurs. Early

treatment in pregnancy is flagged as particularly important, owing to the implications of diagnosis, as is the importance of developing treatment protocols for pregnant women and their children.^(k)

“I went to the doctor for a pregnancy check-up and the obstetrician supervising my antenatal care didn’t know what I was talking about when I told him I wanted a Chagas test. Basically I thought it was a foreign-language communication problem, but then it occurred to me that he really didn’t know anything about Chagas disease. I came to the conclusion that, in this country, people know very little about the disease and there is no real information about the prevalence of Chagas among Hispanics”. (physician, 42 years old, Bolivian living in the United States)

Among **achievements** in the field of Chagas disease, respondents described various personal experiences (obtaining information, care and treatment) and other, wider issues (recognition and wider dissemination of the realities facing people with Chagas disease, wider participation in shared spaces, scientific progress). The role of associations in strengthening and raising the profile of people affected by Chagas disease was repeatedly mentioned.

“Establishment of the Federation, pooling of strengths and resources, dissemination and raising awareness of the issue”. (public official, 47 years old, Brazil)

Significant emphasis was placed on the positive image and importance of particular associations and of the Federation as grass-roots structures that have emerged (in a short space of time) as real alternatives for people affected by Chagas disease, offering them help and support in dealing with the disease and its effects.

“The truth is that I’ve had the courage to make this journey, and I’m still standing with support from my family, and I’m also standing side by side with the association of people affected by Chagas”. (caretaker, 55 years old, Bolivian living in Spain)

#####

^(k) This requires very specific awareness-raising, and at the time of writing the authors were involved in another audiovisual project to address the issue of congenital Chagas disease. This second short video has already been produced and can be viewed at www.youtube.com/watch?v=TVWg5pgHj2c

#

Associations fulfil the role of dissemination, education, and awareness-raising. They also have a political dimension that mobilize calls for appropriate healthcare and protection of social rights.

Representations of specialists

On hearing the word “Chagas”, the **first thing** mentioned by specialists was the idea of a disease (defined in most cases as silent, serious, neglected, poorly understood, having a big impact) that affects people described as poor, marginalized, Latin American, or migrant.

“A disease that has a big impact worldwide, that especially affects poor and marginalized populations”. (physician, 37 years old, Spain)

As in the rest of the literature,^{9,25,26} it can be seen that health professionals reproduce the idea of Chagas as synonymous with “poverty” and thus reinforce preconceptions about the disease as having to do with neglect and resignation.

The responses reveal no differences between the reactions of specialists working in disease endemic and non-endemic areas. The authors of the study wondered whether the views of the medical profession in endemic areas are communicated and disseminated to other regions where people affected by Chagas disease are found.²⁶

In the current context of human mobility, vector control and urbanization of the population, the circumstances and presence of the disease relate to certain “deficiencies”, such as lack of access to diagnosis and treatment, or stigma and social exclusion, even in contexts that would never be associated with “poverty.” Conversely, one specialist recounts that the triatomine bug was associated with “wealth”.

“In one community they wouldn’t allow us to carry out vector control with a spray because they said that triatomines brought richness or were synonymous with wealth, so people slept outside their bedrooms to leave the bugs in peace. This reaction was extremely bizarre and bewildering. We invested enormous efforts in persuading them to change their mind, and eventually succeeded. Now it’s very gratifying to see newborn babies getting medical treatment, and when they are found to have negative results of diagnostic tests after treatment, as well as the possibility to complete the treatment knowing that we can improve the quality of life of the disease carriers”. (physician, 40 years old, Bolivia)

It is essential to understand the basic meanings attaching to the complex web of issues around Chagas disease; from this starting point, we need to improve our approaches to understanding and addressing the circumstances in which the disease occurs. Here, qualitative research plays a crucial role in grasping the social and cultural aspects of Chagas disease because it enables us to optimize strategies to improve the conditions and quality of life of the people affected.^{6,24,27} We need new discourses and viewpoints that transcend conventional wisdom, according to which the disease is rooted in “poverty”, and we must overcome the stereotype that the problem is restricted to rural areas in Latin America, and that it is exclusively biomedical in nature and approach.¹⁵

Some specialists refer to social commitment or the necessary importance of social organization in connection with Chagas disease. They believe that a community-based approach that enhances these aspects at the health level is an essential tool for people affected by Chagas disease in terms of communication, access to healthcare and organization, and as a strategy for promoting relevant social and political action.^{22,}

26

The specialists mentioned the following perceived **problems**:

– in the employment and social sphere (discrimination, stigma, marginalization, ignorance) there are problems associated with social exclusion, difficulties finding and keeping a job, and issues with access to health system.

“Marginalization. Not just as someone with Chagas disease, but because of poverty in general”.
(chemistry graduate, 68 years old, Argentina)

– at a personal level, discouragement and despair. The responses reveal an element of self-criticism that is at variance with official medical discourse, specifically regarding the immediate effects on Chagas disease patients.

“Health workers stick a label saying “disease” on people, which in many cases casts a dark cloud over the infected person’s life, and insist too much on the fact that they are ill”. (biologist, 31 years old, Colombia)

– regarding access to healthcare or treatment, some of the problems cited by specialists were lack of money and prevailing ignorance among the consulting population. They also highlighted limited knowledge about Chagas disease among health personnel and cited cultural obstacles resulting in lack of recognition and receptiveness that inhibits communication and understanding between health professionals and Chagas disease patients. The side effects of treatment were also cited as a problem.

The **challenges** referred to by the specialists have to do with the task of persuading patients to take responsibility for their health, in contexts in which the possibility of treatment or follow-up is problematic or non-existent.

“Regaining hope, learning to live with a chronic disease that could have a fatal outcome. Reclaiming dignity. The need to make up lost time after so many years of silence. Demanding concrete solutions (access to treatment, diagnosis, better living conditions)”. (physician, 37 years old, Spain)

The importance of health systems strengthening was stressed, in order to enhance knowledge, treatment and care of the disease.

“Ensuring access to and quality of services, especially at primary health-care level; mapping of carriers, guaranteed medication, strengthening of civil society organizations such as associations, democratic relations in organizations; strengthening of the international federation with leadership training in its active social role”. (social worker, 58 years old, Brazil)

In speaking of the challenges for “society,” respondents stressed the situation of people affected by Chagas disease and noted the need to end discriminatory practices in various spheres (personal, social, in employment and at school, among others): for this reason, it is essential to gain understanding of the issue and involve the whole of society.

“Listen to the silence of people living with Chagas disease to detect real needs and raise the awareness of people who do not have the disease, in order to provide assistance. Encourage forums for dialogue between them”. (nurse, 35 years old, Spain)

The responses of the specialists and people affected by the disease coincided with regard to the **challenges**; once again, emphasis was placed on improving access to diagnosis, treatment and care (with special mention of research into new drugs). The two groups also concurred on the need to develop awareness-raising and dissemination strategies to publicize the problem and end widespread discrimination and stigma. Respondents emphasized the importance of addressing the topic of Chagas disease through education, understood in the widest sense in various contexts and at various levels.

It is important to focus both on specialized treatment for people affected by Chagas disease, and also the need to flesh out the political commitment of the various stakeholders involved, taking account of specific situations and social circumstances.

“Confront the stigma associated with the disease due to a lack of information; discrimination in the workplace; consider people with Chagas disease as victims rather than actors; (...) lack of access to high-quality health services (...); need of continuous learning by health professionals; availability of drugs indicated for treatment of Chagas disease; provision of social welfare protection in the absence of working conditions, incorporating the human and social dimension into medical expertise (...)”. (social worker, 58 years old, Brazil)

The specialists referred to various scientific, social and political **achievements**, for example the wider dissemination and greater prominence of Chagas disease issues,

the partnerships between stakeholders in different contexts and from different disciplines, and the importance of social organization.

Advances are linked to the detection and expansion of information in relation to Chagas disease, framing these actions into the recognition of the rights of those affected.

“When reflecting on and discussing all these issues, and certainly after 23 years of working with carriers of Chagas disease, certain names stand out, such as Mr Alcino, Ms Terezinha, Mr Manoel, and Cristina (who had a pacemaker fitted recently): they represent perseverance, resistance, and struggle against the serious form of the disease and, most of all, resilience (...) and all the members of the associations in this network: the members themselves, the health professionals, as well as friends and family members. I hope that, through these names, everyone will feel represented, recognized and loved in this community that is fighting for change and for an inclusive society”. (social worker, 58 years old, Brazil)

Conclusions

Within its exploratory and applied scope (the development of a short video to raise awareness), this study highlights the most “superficial” aspects that emerge – upon initial investigation – from the representations expressed in the experiences of people affected by Chagas disease and specialists working in the field of that disease. We certainly do not believe that this study exhausts the topic or delves more deeply into the various aspects of the problem. The importance of this research consists in making a survey of information with a view to developing a short video based on material gathered directly from respondents, thereby enhancing the effectiveness of the message conveyed. This is the principal contribution of the proposal, because, as we have observed in other papers, many of the communications initiatives in the field of Chagas disease fail to address various aspects of the issue in a comprehensive way,²⁸ whereas in this case we have attempted to develop an explicitly multidimensional approach that incorporates the experiences and voices of the different stakeholders involved. In addition, the work indirectly corroborates the findings of previous research^{6,8,9,12-15,22-27} and reveals new convergence and challenges

in the field under study. In the course of our work, we observed how qualitative research can make a contribution to the understanding of social phenomena, and as such should be used to support communication and health promotion strategies, given that the views of people can enrich preventive health interventions.²⁹ This is particularly important in the case of conditions like Chagas disease, which are highly stigmatizing and therefore necessitate a change in the way that the disease is constructed and represented, both socially and professionally.

Our findings indicate certain recurrent themes: obstacles to appropriate and timely treatment; ignorance (on the part of all stakeholders, at different levels and with different consequences); fear of, discrimination against and stigma attaching to the people affected; the importance of communication and the existence of various forums for dialogue; and the need for targeted awareness-raising to dispel false or stigmatizing ideas and to raise the profile of people affected by the disease. We noted that the representations of Chagas disease expressed by members of organizations affiliated with FINDECHAGAS and specialists alike are strongly associated with death. According to the experiences recounted, this way of representing the disease might be due, among other factors, to problems encountered in gaining access to treatment and health care.

We have stressed the need to develop awareness of the role of health services: it is absolutely essential to identify shortcomings and to ensure that health teams discuss the part they play in processes of social exclusion associated with the lack of access to health care and employment of those affected by Chagas disease. We recognize that, customarily, Chagas disease entails a stigma that has social implications for the affected population.^{9,12}

To sum up, the following points should be noted:

- The findings of the study reveal a situation that continues to be characterized by stigma, neglect and exclusion for people affected by Chagas disease. The picture is the same either in disease endemic or non-endemic contexts. Whence the need to launch and sustain an effective public information

campaign worldwide, and to strengthen and multiply targeted communication and educational initiatives for all the stakeholders and sectors involved.

- FINDECHAGAS has a crucial contribution to make in the area of changing the way people relate and respond to the disease in the various contexts in which Chagas disease sufferers are. The federation promotes the idea that people affected by Chagas disease should be appropriately treated and monitored, and ensures that this actually happens.
- The need to think of research as a tool for generating communication and educational resources from a more critically aware perspective, especially if we consider that, through the result of our work and the dissemination of tools arising from it, we are contributing to the construction of meanings and representations around Chagas disease and all the related issues (in which we are all involved).
- The research effort, understood as the work to underpin and support the production of a short video to raise awareness and enhance the profile of Chagas disease-related issues, has underscored the need to bear in mind that the development of audiovisual material (or indeed material of any type²⁸⁻³⁰) in itself constitutes a form to define the problem and refer the people affected. The difficulty of developing a resource that addresses the aspects of the issue detailed in this article cannot be overstated; it is a challenge that validates the process as a methodological approach, and also reveals the need to develop new Chagas disease information resources (of an audiovisual or other nature) intended for general consumption. It is likewise important to acknowledge that qualitative research has its limitations in terms of broad and in-depth analysis, leaving open the challenge of making wider use of this work.

As a corollary, let us quote the closing words of the first short video developed on the basis of the survey of representations and stories that gave rise to this study: “It’s time to win the battle against silence. It’s time to win the battle against Chagas disease”.

Acknowledgements

We wish to thank the members of associations of people affected by Chagas disease and the specialists who responded to the survey and made this study possible.

Collaborators

The authors worked together in all the steps of the paper's production.

References

1. World Health Organization. Working to overcome the global impact of neglected tropical diseases [Internet]. First WHO report on neglected tropical diseases. WHO/HTM/NTD/2010.1. Genève: WHO; 2010. Disponible en: http://whqlibdoc.who.int/publications/2010/9789241564090_eng.pdf
2. World Health Organization. Sustaining the drive to overcome the global impact of neglected tropical diseases. Second WHO report on neglected tropical diseases. WHO/HTM/NTD/2013.1. Genève: WHO; 2013.
3. Coura JR, Borges-Pereira J. Chagas disease: 100 years after its discovery: a systemic review. *Acta Trop*. 2010; 115(1-2):5-13.
4. Coura JR, Viñas PA. Chagas disease: a new worldwide challenge. *Nature*. 2010; 465(7301 Supl):S6-S7.
5. Basile L, Jansà JM, Carlier Y, Salamanca DD, Angheben A, Bartoloni A, et al. Working group on Chagas disease. Chagas disease in European countries: the challenge of a surveillance system. *Euro Surveill*. 2011; 16(37): 18-27.
6. Velarde-Rodríguez M, Avaria-Saavedra A, Gómez-i-Prat J, Jackson Y, Oliveira Júnior. WA, Camps-Carmona B, et al. Need of comprehensive health care for *T. cruzi* infected immigrants in Europe. *Rev Soc Bras Med Trop*. 2010; 42 Supl. 2:92-5.
7. Sanmartino M. Transición epidemiológica y enfermedad de Chagas: aportes para abordar un problema complejo. *Rev Papeles Población*. 2015. [Manuscrito en prensa].
8. Uchôa E, Firmo JOA, Pereira MSN, Contijo ED. Signos, significados e ações associados à doença de Chagas. *Cad Saude Publica*. 2002; 18(1):71-9.
9. Avaria A, Gómez i Prat J. "Si tengo Chagas es mejor que me muera". El desafío de incorporar una aproximación sociocultural a la atención de personas afectadas por Enfermedad de Chagas. *Enferm Emerg*. 2008; 10 Supl 1:40-5.
10. Briceño-León R, Galván JM. The social determinants of Chagas disease and the transformations of Latin America. *Mem Inst Oswaldo Cruz*. 2007; 102 Supl1:109-12.

11. Jackson Y, Angheben A, Carrilero-Fernandez B, Jansa JMLV, Jannin J, Albajar-Vinas P. Prise en charge de la maladie de Chagas en Europe. Expériences et défis en Espagne, Suisse et Italie. *Bull Soc Pathol Exot.* 2009; 102(5):326-9.
12. Sanmartino M. "Tener Chagas" en contexto urbano: concepciones de varones residentes en la región de La Plata (Argentina). *Rev Biomed.* 2009; 20(3):216-27.
13. Oliveira Júnior WA. Relação médico-paciente em cardiologia: um olhar psicossomático. *Psicossom Sul Min.* 2005; 4:41-6.
14. Oliveira Júnior WA. Atenção integral ao paciente chagásico: uma proposta para o cuidar. *Arq Bras Cardiol.* 2005; 84(1):1-2.
15. Sanmartino M, Menegaz A, Mordeglia C, Mengascini A, Amieva C, Ceccarelli, et al. La problemática del Chagas en 4D: representaciones de docentes de nivel inicial y primario de La Plata. In: *Actas de las III Jornadas de Enseñanza e Investigación Educativa en el campo de las Ciencias Exactas y Naturales; 2012; La Plata, Argentina.* La Plata: Facultad de Humanidades y Ciencias de la Educación, Universidad Nacional de La Plata; 2012; 729-38.
16. Sanmartino M, Mengascini A, Menegaz A, Mordeglia C, Ceccarelli S. Miradas caleidoscópicas sobre el Chagas una experiencia educativa en el Museo de La Plata. *Rev Eureka Enseñanza Divulg Ciencias.* 2012; 9(2):265-73.
17. Médicos Sin Fronteras. *Mobilización popular y enfermedad de Chagas.* Río de Janeiro: MSF; 2012.
18. Araya Umaña S. *Las representaciones sociales: ejes teóricos para su discusión.* Cuaderno de Ciencias Sociales 127. San José (Costa Rica): FLACSO; 2002.
19. Spink MJ. O conceito de representação social na abordagem psicossocial. *Cad Saude Publica.* 1993; 9(3):300-8.
20. Jodelet D. La representación social: fenómenos, concepto y teoría. In: *Moscovici S, organizador. Psicología Social II. Pensamiento y vida social. Psicología Social y problemas sociales.* Barcelona: Paidós; 1984. p. 469-94.
21. Camargo-Ramos CM, Pinzón-Villate GY. La promoción de la salud en la primera infancia: evolución del concepto y su aplicación en el contexto internacional y nacional. *Rev Facultad Med.* 2012; 60 Supl 1:62-74.
22. Avaria A, Gómez i Prat J. Mujer derivada por médico de familia para descartar enfermedad de Chagas. In: *Unidad de Medicina Tropical y Salud internacional Drassanes. 50 casos clínicos de salud internacional - 25 años de trabajo de la Unidad de Medicina Tropical y Salud internacional Drassanes.* Barcelona: UMTSID; 2008. p.229-36.

23. Avaria A. Migrar, enfermar–sanar lejos de casa. Bolivianos en Barcelona, experiencia hecha carne. In: Agar L, coordinador. Migraciones, salud y globalización: entrelazando miradas. Santiago de Chile: OIM, OPS, MINSAL; 2010. p. 199–214.
24. Sanmartino M. Faire face à la maladie de Chagas en partant des conceptions des populations concernées [thèse]. Genève: Section des sciences de l'éducation, Faculté de psychologie et des Sciences de l'éducation, Université de Genève; 2006. Disponible en: <https://archive-ouverte.unige.ch/unige:381>.
25. Sanmartino M. Abordaje integral para el Chagas urbano: primeros pasos de una investigación–acción colaborativa en un Centro de Atención Primaria de Salud del Gran La Plata. In: Actas de las VIII Jornadas Nacionales de Debate Interdisciplinario de Salud y Población; 2009; Buenos Aires, Argentina. Buenos Aires: Instituto de Investigaciones Gino Germani, Facultad de Ciencias Sociales, Universidad de Buenos Aires; 2009. CD–ROM.
26. Avaria A. "Un cuerpo vale más que mil palabras". Mujeres y hombres bolivianos en Barcelona. Corporización de la migración: cuerpo migrante, cuerpo trabajador, cuerpo enfermo [tesis]. Barcelona: Departamento de Geografía e Historia. Universidad de Barcelona. 2014.
27. Sanmartino M. Vinchucas, barbeiros y muchos más: indagando en las concepciones sobre los triatomíneos. In: Costa Neto EM, compilador. Entomologia Cultural: ecos do I Simpósio Brasileiro de Entomologia Cultural 2013. Feira de Santana: Universidade Estadual de Feira de Santana; 2014. p. 293–308.
28. Sanmartino M. Juana y Mateo contra el Chagas: la serie, la guía y el detrás de escena de toda la propuesta [Internet]. Artículo 900. Memorias del Congreso Iberoamericano de Ciencia, Tecnología, Innovación y Educación. Buenos Aires: OEI; 2014. Disponible en: <http://www.oei.es/congreso2014/memoriactei/900.pdf>
29. Figueiredo MFS, Rodrigues Neto JF, Leite MTS. Health education in the context of family health from the user's perspective. Interface (Botucatu). 2012; 16(41):315–329.
30. Freitas FV, Rezende Filho LA. Modelos de comunicação e uso de impressos na educação em saúde: uma pesquisa bibliográfica. Interface (Botucatu). 2011; 15(36):243–56.

Translated by Service of the Language Services Unit, World Health Organization Headquarters.

#