

# The multidimensional comprehension of Chagas disease. Contributions, approaches, challenges and opportunities from and beyond the Information, Education and Communication field

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Chagas is a complex, multidimensional phenomenon in which political, economic, environmental, biomedical, epidemiological, psychological, and sociocultural factors intersect. Nonetheless, the hegemonic conceptualisation has long envisioned Chagas as primarily a biomedical question, while ignoring or downplaying the other dimensions, and this limited view has reinforced the disease's long neglect. Integrating the multiple dimensions of the problem into a coherent approach adapted to field realities and needs represents an immense challenge, but the payoff is more effective and sustainable experiences, with higher social awareness, increased case detection and follow-up, improved adherence to care, and integrated participation of various actors from multiple action levels. Information, Education, and Communication (IEC) initiatives have great potential for impact in the implementation of multidimensional programs of prevention and control successfully customised to the diverse and complex contexts where Chagas disease persists.

Key words: Chagas disease - multidimensional comprehension - information - education - communication - public health

## Limitations of the hegemonic conceptualisation of Chagas disease

As a complex problem affecting people's health and daily lives, whose etiology, impact, and widespread distribution (due to long lasting human mobility) has intersected with diverse contexts and circumstances, an exclusively biomedical perspective is insufficient for describing, understanding, and approaching Chagas disease. For this reason, as an alternative to the classical denomination of 'Chagas disease', throughout this article we will refer, as well, to 'Chagas', with a broader meaning to include also the psychological, socioeconomic and other "issues" that affect people infected by *Trypanosoma cruzi* (most of whom will never develop the disease), their relatives and societies. There is an urgent need to recognise that we are facing an intricate socio-environmental health challenge related to both rural and urban environments, in Latin America and worldwide.<sup>(1)</sup> Beyond the biomedical aspects, various elements belonging to different disciplines and sectors should be considered with the same rigor.<sup>(2)</sup> The traditional lack of understanding of Chagas as a multidimensional challenge has led

to fragmented approaches, contributing to its neglected condition and leading to incomplete responses that perpetuate various inherent challenges: the neglect and limited political voice of the affected population; low detection rates (< 10%, frequently < 1%) and frequent barriers to accessing adequate healthcare; unequal access to information and education, and lack of broad communication about both the issue itself and the rights of affected people; social challenges including stigma, exclusion, inequality, and discrimination; psychological/personal challenges such as fear, shame, and isolation (related to the disease and/or social environment); gender inequalities which intersect with the social, psychological, and cultural contexts; and economic inequalities related to diagnosis, treatment, labour and social life conditions.

Three consequent reflections are: (i) it is time to critically revise the hegemonic discourses that define Chagas as a purely medical or biological concern, and recognise the limitations they imply for understanding the problem and constructing effective solutions; (ii) contributions from diverse fields of knowledge have to be considered and incorporated to construct new, contextualised theoretical frameworks that enlighten our understanding of how to address challenges related to Chagas;<sup>(2)</sup> (iii) there is a key role for Information, Education and Communication (IEC) in the design and implementation of diverse strategies that improve the aforementioned multidimensional understanding and address transversal issues, such as the right to health of directly or indirectly affected people, including families and

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communities. Recently, the vast field of IEC has been formally included in some Chagas programs as a strategic and essential axis for prevention, care and control actions and institutional interventions.<sup>(3,4)</sup> Moreover, in 2017, the WHO Chagas disease control program added a new Technical Group on IEC (TG6-IEC).<sup>(5)</sup>

Conversely, failure to account for Chagas's multidimensional comprehension could limit IEC programs' effectiveness. Those involved in research, healthcare efforts and public health programs should reflect on the class, gender, cultural, and other differences that need to be considered to effectively communicate with people with Chagas. Class/power differentials between affected people and providers, intersecting with gender, language, and other factors, can profoundly impact communication. Further, when IEC campaigns address Chagas as a purely biomedical issue where affected people and communities simply need to be "educated" to motivate "behavior change", they ignore the daily reality where many people with Chagas must balance the desire to do something about their *T. cruzi* infection with the related intense socioeconomic and psychological pressures/challenges of daily life. Programs may recommend interventions which, though medically necessary, may have an unacceptable cost in terms of money or time for marginalised people.<sup>(6,7)</sup> Migrants may face additional legal risks/exposures when attempting to seek care. Finally, in many contexts affected people may prefer to self-medicate with either biomedical or ethnomedical treatments. Use of natural remedies may even help manage some of the psychological impacts of Chagas disease,<sup>(8)</sup> and research suggests people who use ethnomedical treatment more frequently also utilise biomedical care more often,<sup>(9)</sup>

yet often health educators disparage or discourage ethnomedical healing. IEC programs which ignore local forms of knowledge and the realities which affected people must navigate in their daily lives may not ultimately succeed in achieving effective communication goals.

The aim of this article is to provide elements for a critical, current, and contextualised understanding of Chagas emerging from reflections and dialogues between diverse experiences and perspectives, developing the foundations of the multidimensional comprehension to identify steps for implementing multidimensional approaches through and beyond the vast landscape of the IEC triad.

### Multidimensional understanding of Chagas: contributions from different perspectives

Although multidimensional approaches to Chagas are a relatively recent phenomenon, there are some historical precursors, starting by the early work of Carlos Chagas, who affirmed: "There is a disastrous pattern in the study of trypanosomiasis. Each work, each study, points a finger toward a malnourished population living in difficult conditions... a social and economic problem that causes great unease for governments, since it is a testimony to their inability to resolve a tremendous problem".<sup>(10)</sup> Similarly, Sierras Iglesias et al.<sup>(11)</sup> remind us that Salvador Mazza himself affirmed that even when looking through the microscope with the greatest magnification, one should not fail to see the person in their totality; and Carlos Chagas and Emmanuel Dias noted that "more than technical innovations, the definitive overcoming of human Chagas disease implies, above all, political will and social responsibility".<sup>(12)</sup>

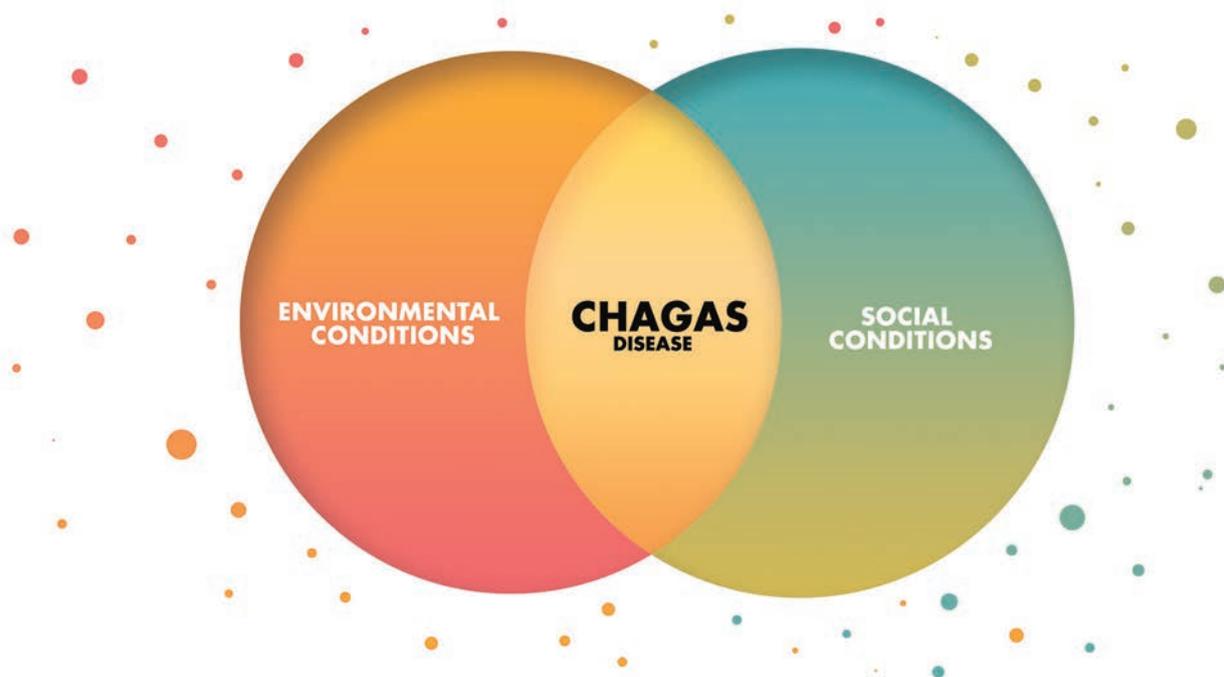


Fig. 1: environment and society in an ecohealth perspective of Chagas disease.<sup>(14)</sup> (Graphic adaptation: Iván Pasanau)

Further, three decades ago, Roberto Briceño-León<sup>(13)</sup> remarked on the enormous chasm between knowledge accumulated on biomedical aspects of Chagas and that referring to social factors. He identified, through housing, the possibility of addressing the social habitat of communities and their environments, thus contributing to a more holistic and nuanced understanding of the complex processes linked with Chagas. Later, the eco-health perspective<sup>(14)</sup> permitted Briceño-León to deepen his analysis of the intersection of social and environmental factors, and how they converge in a specific time and place during Chagas transmission (Fig. 1). In visualising this intersection, rurality, internal and international migration associated with socioeconomic forces, displacement and resettlement should all be considered, since these factors take precedence for prevention, detection, treatment and follow-up in diverse geographic, cultural, and economic contexts, even influencing legislation and planning to protect people's health.

In recent years, the need to address Chagas disease from a more comprehensive perspective has been emphasised in different geographical contexts in Latin America, Europe and the United States. Moreover, in the first celebration of the World Chagas disease Day, in 2020, the World Health Organization (WHO) published in its web Key facts: “Chagas disease is a complex socio-economic, environmental (multidimensional) health problem and its different dimensions linked in a gearing mechanism justify the necessity of multisectoral approaches”.<sup>(15)</sup> This represents a significant advance for those championing a more in-depth understanding — and approach — to the problem.

Below, we describe selected approaches central to the multidimensional framework discussed here.

*The tricycle strategy of the WHO Programme on Control of Chagas disease* - In 2010 the World Health Assembly adopted resolution WHA63.20 on control and elimination of Chagas disease,<sup>(16)</sup> recognising the need to tackle all transmission routes of *T. cruzi* in endemic and non-endemic countries; provide appropriate medical care for affected populations, starting at the primary health care level; support the mobilisation of national and international, public and private financial and human resources; promote interdisciplinary and intersectoral efforts and collaboration; and facilitate networking between organisations and partners. Based on that resolution, the WHO two-pillar strategy of 2008 (stop transmission and take care of the population infected with *T. cruzi*) was switched to a “tricycle strategy”, officially launched by the WHO Programme on Control of Chagas disease in 2013 (Fig. 2). The tricycle strategy<sup>(17)</sup> showcases the cheerful and powerful tricycle image with its four components: two power wheels (actively interrupting transmission and providing care in affected populations) and a steering wheel (implementing a global information and surveillance system and providing IEC strategies) for the “tricyclists” or key people to be involved. The world information and surveillance system of WHO is an open-source system used to collect information on Chagas disease from different sources (official documents, WHO emergency management system, medical supplies distribution system, and the WHO pharmacovigilance system in collaboration with the Uppsala Monitoring Centre, among others), detect possible epidemiological silences (in time and space) and facilitate: (i)



Fig 2: tricycle strategy of the World Health Organization Programme on Control of Chagas disease.<sup>(17)</sup> (Graphic adaptation: Iván Pasanau)

access to disease statistics, maps, dashboard elements and Chagas visualisation; (ii) monitoring and guidance on the control and elimination of the disease; and (iii) verification of achievements. The IEC strategies, which include a new WHO course on control of Chagas, are essential to increase awareness, reduce biomedical and psychosocial barriers to accessing diagnosis and care; keep the maximum number of actors involved; and reach the affected population, including family, friends and society in general. In this metaphor, the fourth component -given by the human actors (tricyclists) — is crucial; because social actors are involved in moving the “mechanism”, for example implementing country programmes for Chagas control.

*The kaleidoscopic puzzle model* - Due to a partial and overly static understanding of Chagas from a hegemonic perspective, as a “monochromatic kaleidoscope” with few fixed pieces, the progress made in some disciplines has not proportionally impacted the health and welfare of those affected by Chagas.<sup>(18)</sup> Consequently, since 2012, in Argentina, the group *¿De qué hablamos cuando hablamos de Chagas?* (What are we talking about when we talk about Chagas?) discusses and works on the subject from a comprehensive perspective and from at least four dimensions: biomedical, epidemiological, socio-cultural, and political. In their framework, each dimension offers and adds groups of unique pieces or “coloured beads,” with their special shapes and peculiar colours that interact and fit with the others in a “ka-

leidoscopic” proposal.<sup>(19)</sup> In this “model”, the dynamic combination of elements conveys the complexity of the problem. Thus, the proposed dimensions are conjugated, metaphorically, in a kaleidoscopic puzzle (Fig. 3), where the parts become meaningful when considering their mutual dependence and interrelationship within the whole and, in turn, the particular interests or analytical perspectives from which they are observed.

In puzzles, all pieces (dimensions) contribute the same weight to the image we want to assemble/observe, and if one is missing, we cannot complete the whole picture. Similarly, in kaleidoscopes, the richness of the images we observe is made possible by the contribution of each of the coloured beads (every component of each dimension, every actor, and every bit of knowledge involved). The relationships established within and among the dimensions mean that today, at a certain place in the world, the snapshot of Chagas emerges with particular features, contrasting with the snapshot in other regions and historical moments. According to Sanmartino and colleagues<sup>(19)</sup> 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’s manifestation, diagnosis, treatment, and transmission;
- The epidemiological dimension concerns aspects that characterise the situation on a population scale, using parameters such as prevalence and incidence, dis-

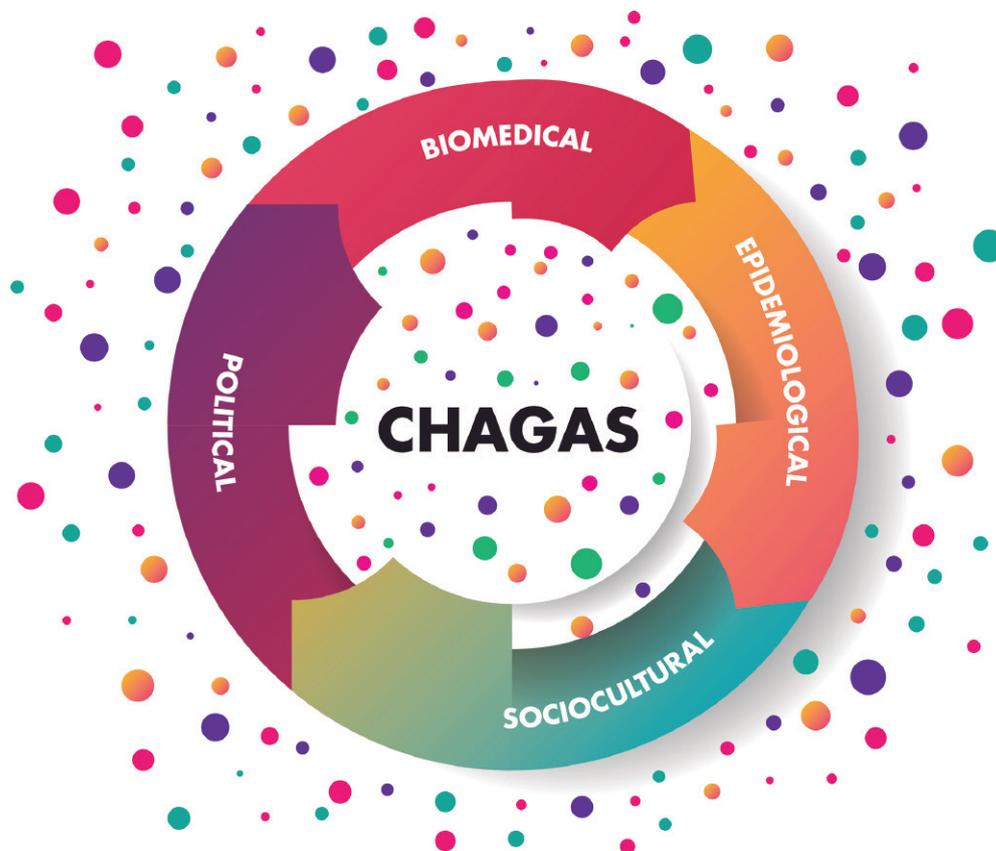


Fig. 3: the “kaleidoscopic puzzle” of Chagas.<sup>(19)</sup> (Graphic adaptation: Iván Pasanau)

tribution, and infestation rates. Migration, which influences current configurations of the problem, is also considered in this dimension;

- The sociocultural dimension is related to cultural patterns and cosmovisions, housing conditions, environmental management, the distinctive features of both rural and urban contexts, different models of health / healing, and social representations and prejudices that reproduce, for example, discrimination and stigmatization;

- The political dimension involves, apart from economic conditions, features related to public management and health, plus educational, legislative, and economic decisions at local, regional, and global levels. Furthermore, this dimension includes differences in class, power, “social capital”, and the impact it has on communication between affected people and health personnel; and the position and decisions that each person assumes when facing Chagas in different environments (research, teaching, communication, health care, and others).

*Multidimensional framework for addressing Chagas disease healthcare access barriers* - Inspired by the kaleidoscopic puzzle model,<sup>(19)</sup> another four-dimensional framework was applied to analysis of healthcare barriers confronting people with Chagas in the United States, though it could be relevant for other settings.<sup>(20)</sup> This framework comprises four dimensions: clinical, psychosocial, systemic, and structural. The structural dimension, based on structural violence in medical anthropology,<sup>(21)</sup> refers to historically rooted inequalities which place vulnerable groups at greater risk for Chagas disease while limiting options for healthcare. These include the difficulty of getting time off for appointments for people working in service or informal jobs, restrictions on healthcare access and information for migrants, and limited insurance coverage for Latinos/as and rural residents. Clinical barriers encompass biomedical challenges including the lack of reliable biomarkers, difficulties in diagnosis, and side effects from drug treatment. The systemic dimension acknowledges that key gaps exist in the U.S. public health system, such as a lack of information about where to get testing and treatment, and a lack of investment in new drugs and diagnostic technologies, which further limits options for care of affected people.<sup>(22)</sup> Psychosocial barriers include stigma, fear, and anxiety about the disease. Like the kaleidoscopic puzzle model, this framework argues that the different dimensions are interdependent. Thus, a multidimensional approach is needed to improve access to healthcare for people affected by Chagas. Even if it may not be feasible for healthcare providers to address a major structural barrier such as systematic persecution of migrants in the United States, it is important for this reality to be faced and mitigated in the construction of programs, for example, by providing services in a safe, confidential space. A biomedical breakthrough, such as a safer, more effective treatment, will only succeed if it is free or low cost and easily accessible in communities where affected people live.

### **Information, education and communication: main considerations to address the “multidimensionality” (and other challenges)**

Understanding the “multidimensionality” surrounding the complex contexts and diverse people and communities affected by Chagas represents a first step in finding timely, contextualised, effective and sustainable solutions. From here, the key challenge is ensuring these solutions consider and reflect the various dimensions, given that, as Ventura-Garcia et al pose, “[T]here is a paradox: although the importance of social and cultural factors is broadly acknowledged, current approaches to neglected tropical diseases (NTDs) almost always neglect aspects of the socio-cultural - biological - environmental triad. This results in a narrower understanding of Chagas disease and hampers sustainable prevention and control”.<sup>(23)</sup> To overcome the neglect that reinforces this paradox, IEC initiatives have great potential in terms of tools and bridges, both to optimise traditional responses and strategies, and to generate new, alternative approaches in diverse contexts, advancing and including new actors and territories (geographic, institutional, cultural, symbolic). It is worth clarifying that we define IEC initiatives as a wide range of proposals, resources and strategies belonging to different levels of intervention that involve the design, development, implementation/distribution, and evaluation of everything from large-scale communication campaigns to day-to-day acts of communication within medical consultations. They also include graphic and audiovisual materials; the realisation of demonstrations, workshops and courses; the diverse forms and characteristics adopted by media (according to scale, geographic place, and historical and political moment); everything involved within Information and communications technology (ICT), and various other formats and scenarios.

In health interventions, given the predominant biomedical focus used to address Chagas, within public health actions there has been a tendency to forget or undervalue IEC, so essential for the development and implementation of appropriate strategies. Part of this lack of recognition is because IEC implies a questioning of the conditions in which health problems are (re)produced and requires incorporating new actors, and forms of knowledge and language. This further highlights the necessity of a multidirectional exercise of transformation (as much of the “target audience” as of those who propose and develop the initiatives).

When critically rooted, IEC proposals have immense value for fostering new perspectives that encourage dynamics of dialogue, capacity-building, and information-sharing by the communities themselves through a process that transforms them into actors capable of making decisions and becoming leaders of health promotion actions and prevention of Chagas disease (and other issues). However, different studies note that educational “interventions” for Chagas have been mainly developed in school environments from rural contexts, employing a limited, biomedically centered viewpoint and disregarding the knowledge and experiences provided by the indi-

viduals considered merely “recipients” of such interventions.<sup>(24)</sup> Paradoxically, the current landscape demands that IEC initiatives for Chagas be contemplated in all possible contexts: areas with or without vector transmission; inside and outside of Latin America; rural, periurban, and urban areas; formal (all educational levels, including professional formation) and no formal contexts (fairs, museums, social organisations, clubs, cultural events, waiting rooms, the media). These observations also apply to strategies and resources of information and communication, where often technical themes are emphasised or fragmented outlooks are reproduced, frequently utilising language that reproduces stereotypes and reinforces stigmatisation of people and places “affected” by Chagas.<sup>(5,19)</sup> The ideal starting point in these cases are IEC proposals that lay out transformative objectives based on a multidisciplinary approach within a realistic time frame, considering evaluation of processes and impacts, in order to install critical and sustainable practices over time. On this basis, the TG6-IEC Chagas proposed addressing these three axes initially considering three links: Information-awareness, Education-transformation, Communication-sharing.<sup>(5)</sup>

Moreover, the development and implementation of IEC strategies in highly complex and diverse contexts requires being aware of not only the multiple dimensions involved, but conditions of class, gender, identity, and ethnic origin, in particular. Key focal points are contextualised below:

- Women of childbearing age and pregnant women face particular challenges linked to the possibility of connatal transmission, which often implies multiple (and invisible) psychological, family, social, and medical consequences;

- People who are highly marginalised or oppressed/exploited, while sometimes excessively targeted for particular interventions are often completely neglected, due to indigenous origin, migratory status, or for living in conditions of exclusion or vulnerability;

- People who live near borders, or are highly mobile due to family and labour relations or traditional customs, and therefore move within and between rural, urban, border, and transnational contexts, face particular challenges in exercising healthcare and other political rights.

Thus, the implementation of IEC programs demands a critical rethinking of the frames of reference from which we understand healthcare actions, and a questioning of the hegemonic frameworks from which we inform, educate, and communicate about Chagas. We highlight:

- Outdated and stereotyped misconceptions about Chagas and how to confront it, including: that Chagas is a strictly rural phenomenon, exclusively affects the poor, is found only in Latin America, is inevitably fatal, and/or that no treatment exists;

- Stereotypes and prejudices which assume that affected people lack knowledge, ability, or agency;

- Pervasive misinformation, low interest, lack of social demand and weak political commitment to solve problems related to Chagas;

- Insufficient scientific research and development related to prevention, transmission interruption, detection and comprehensive care, including diagnosis, treatment, medicinal presentations, social aspects, and IEC tools;

- The need to go beyond biopsychosocial approaches which, even though they transcend a strict focus on the physical conditions of people with Chagas, frequently employ a narrow focus on the individual / personal level, excluding or minimising the collective and social level (including family, community, support networks).

Additionally, health economics perspectives provide valuable input to the other elements we have described. Several studies assess the financial burden of Chagas disease from multiple perspectives such as health care costs or productivity lost.<sup>(25)</sup> Other work estimates the investments required (2015-2030) to achieve WHO targets for vector control.<sup>(26)</sup> This type of analysis helps us understand the magnitude of the costs required to overcome Chagas disease at different levels (country or global). In particular, the literature demonstrates it is cheaper and more impactful to act on Chagas prevention and achieve early diagnosis and treatment.<sup>(27,28,29,30,31)</sup> However, little is known about the combined cost and effectiveness of IEC strategies for Chagas.<sup>(3,32)</sup> Generally, IEC strategies are relatively cheap to implement compared to other health interventions; nevertheless, their impact is not always fully evaluated.

Finally, it is essential to both recognise the multiple dimensions that intersect and characterise Chagas and develop IEC proposals that effectively consider, approach, and engage with these dimensions. It is necessary to confront not only the challenge of considering all the elements involved, but to simultaneously maintain a harmonious and flexible dynamic within interdisciplinary and intersectoral roots- and consequently, interoperability (that is, not only assuring that different disciplines maintain dialogue through an overarching “product”, but also that different sectors involved communicate and, finally, operate in an interactive manner in the design, development, implementation, and validation of the proposed initiatives).

### **On innovative proposals, tested methodologies and validated experiences or how to incorporate and integrate multiple dimensions in practice**

The next important consideration is how to design, develop and implement IEC programs for Chagas which are fundamentally based on a multidimensional approach. Below we briefly describe different experiences that, for various reasons, exemplify “good practices” for incorporating multiple dimensions into IEC actions.

*CorArte Project: Heart with Art. Humanising the waiting room (Brazil)* - The CorArte: “Heart with Art” Project began in 2014, as part of the program of the Ambulatório de Doença de Chagas/Insuficiência Cardíaca (Hospital Universitário Oswaldo Cruz) and the Associação dos Portadores de Doença de Chagas e Insuficiência Cardíaca (Chagas Disease and Heart Failure Outpatient Clinic of the University Hospital Oswaldo Cruz and the Pernambuco Association of Chagas and Heart Disease Patients). Comprehensive care for people with Chagas,

taking into account the complexity of the disease, requires a multidisciplinary team that considers biological, social, and psychological determinants.<sup>(33)</sup> Diverse forms of artistic expression are used as tools to foment dialogue and share experiences with clinical treatment and psychosocial needs. Waiting room activities, coordinated by an occupational therapist with a peer educator, utilise traditions from popular culture (principally through “cordel” writing, poetry, graffiti and music) to address themes related to Chagas. Both patients and companions participate in these actions, as learners or even assuming teaching roles. This work has awakened self-confidence in the group, through testimonies that show the expansion of their own comprehensive vision, through feeling the capability of learning or teaching something new. There is an improved understanding of their place as principal actors in the therapeutic process, overcoming the condition of being sick, and strengthening individual identity, confidence and self-esteem.

*On-site screening in a European context (Catalonia)* - In 2008 the health centre *Centre de Salut Vall-d’Hebron-Drassanes* participated in the Fiesta Nacional de Bolivia (Bolivian National Festival) in Badalona, Catalonia. On that occasion information on Chagas was handed out to participants, and *T. cruzi* infection tests were offered by setting up appointments at the health centre. Given the positive reception to these efforts, on-site screening was launched in 2014 in the city of Barcelona, through activities with high participation from the Bolivian migrant community, including celebrations of Bolivian national holidays and concerts.<sup>(34,35,36)</sup> A multidisciplinary team has formed to carry out these activities in the community. Team members include healthcare professionals, agentes comunitarios de salud (ACS, community health agents), and peer educators (members of ASAPECHA, a local organisation of people affected and concerned by Chagas) who have been trained as part of a Chagas “Expert Patient Programme”.<sup>(37)</sup> Key components of the experience are: (1) participant recruitments through community information activities realised by the ACS and peer educators; (2) the latter are trained through the aforementioned “Programme”, which involves nine training sessions, using a range of IEC materials (videos, music, animations, presentations); (3) multidisciplinary teams including healthcare personnel (doctors specialised in public and community health, infectious disease specialists, microbiologists, nurses, and community health agents) and professionals from the governments of Catalonia (public health department and blood bank) and Bolivia.

*An opportunity to strengthen a grass-roots organisation (Ecuador)* - Through an initiative with a community epidemiology approach,<sup>(38)</sup> the Centro de Epidemiologia Comunitaria y Medicina Tropical (CECOMET, Center of Community Epidemiology and Tropical Medicine) and the San Lorenzo Health District, and six AWA indigenous communities in northern Esmeraldas province, the discovery of triatomines gave rise to a process of participatory investigation involving health promoters, community leaders, and members of the AWA Indigenous Federation (FCAE) to identify triatomine species, evaluate the risk of Chagas transmission, identify people who test

positive, and eventually define a program of treatment and control. A key ingredient in the process, developed from 2013-2018, was the inclusion of a permanent IEC strategy respectful of the time needed for internal discussion in the communities, and which facilitated dialogue between actors and shared decision making between the community organisation and the technical team to undertake activities. The principal results of the process have been:<sup>(39)</sup> (1) clinical evaluation of individuals with seropositive results and their treatment realised in collaboration with the Health District and health promoters; (2) documentation of a *T. cruzi* transmission focus in AWA communities; (3) community monitoring for the presence of triatomines; and (4) the strengthening of community organisation and the AWA Federation.

*Supporting the formation of critical professionals in a public university (Argentina)* - Since 2011, the group “What are we talking about when we talk about Chagas?” ([www.hablamosedechagas.org.ar](http://www.hablamosedechagas.org.ar)) has advocated for addressing Chagas with a comprehensive and innovative approach in diverse educational contexts (within and beyond institutions).<sup>(19)</sup> Among its activities, a program was implemented in 2014 for university students of any level, field of study, or institution. This complementary degree activity, entitled “What are we talking about when we talk about Chagas? Kaleidoscopic views to tackle a complex problem” is offered through the Facultad de Ciencias Naturales y Museo, Universidad Nacional de La Plata (School of Natural Sciences and Museum of the National University of La Plata). Some of its main objectives are to increase understanding of Chagas through an interdisciplinary approach highlighting its complexity; disseminate and develop didactic, educational, and communications resources on the topic as a means of contributing to students’ overall academic formation; promote the use of theoretical-practical tools for critical reflection on interdisciplinary approaches to complex issues; and support the learning of practices for planning and development of university extension activities as a substantial component of university activities and learning. This experience (which has thus far trained six student cohorts from 2014-2019) has demonstrated great potential for incorporation of the subject at institutional (university or other) levels. Efforts are ongoing to formalise its inclusion in university curricula.<sup>(40)</sup>

*IEC to increase access to diagnosis and treatment (Colombia)* - From 2017-2020, an IEC plan was implemented in areas of Colombia with recent interruption of vector transmission, a joint effort between the Ministerio de Salud y Protección Social (Ministry of Health and Social Protection - MHSP) of Colombia, the Drugs for Neglected Diseases initiative (DNDi), and local departmental and municipal governments. The plan focused on two main groups: people with Chagas and community healthcare personnel. Qualitative research enabled development of communication tools to address barriers identified during interviews and focus groups, including a perceived lack of treatment (often reinforced by healthcare professionals), discrimination, stigma, and fears surrounding the disease. These tools (print and radio broadcasts), which formed part of the IEC plan, were

validated by the MHSP, affected communities (including associations of people with Chagas), and other stakeholders. Accompanied by awareness raising activities, they are helping improve quality of care through reinforcing key messages, such as the existence of treatment for Chagas, and that the disease does not represent a death sentence. DNDi's project to eliminate access barriers to diagnosis and treatment, of which the IEC plan forms part, is based on a collaborative "4D" approach: Diagnose, Design, Deliver, and Demonstrate Impact.<sup>(41)</sup>

*Rebuilding despite the neglect: Chagas through an intersectoral experience (Chile) - The chaochagaschile.cl project (Project FONIS SA18I0056, 2019-2021) - with public funding and executed through a cooperation between the Universidad Autónoma de Chile (Autonomous University of Chile) and the Ministerio de Salud de Chile (National Ministry of Health) - emerged as a means of making people with Chagas visible and generating a multidimensional and intersectoral program through applied, localised investigation. This national project was launched in 2019 in three regions: Tarapacá, Atacama, and Metropolitana (the first two have a high prevalence of Chagas, and all have large migrant populations); and utilises an interinstitutional and interdisciplinary approach. In each region, universities and health and social science specialists form working teams to reach, in a coordinated manner, the local (national and migrant) population and local health teams. Regionally, technical capacities are extended, with a multidimensional and intersectional perspective, methodological skills in qualitative research, and community intervention and participation. The project aims to build IEC tools for Chagas directed principally toward women (pregnant or of childbearing age), blood donors, and members of health teams. Material is developed based on qualitative research within the territories, considering the transversal axes of migration, a sociocultural approach, and gender. Understanding the views of these diverse actors enables the design of free public health materials, while also enhancing technical standards for local strategies and national and international recommendations.*

### **Lessons learned for a multidimensional look at the future**

From the examples presented, among many others, it is clear that in recent decades there has been increasing recognition of the complexity of Chagas, in theoretical and practical approaches. Nonetheless, much work remains to consolidate and deepen key aspects, and for implementation of IEC strategies attuned to the current landscape and integrated, in particular, with other health activities, research and public policies. Identifying the multiple dimensions involved in the occurrence and persistence of Chagas is fundamental, and implies an unavoidable recognition of the various, diverse actors, knowledge systems, languages, and contexts that need to be identified, gathered and engaged in dialogue. In a general sense, the multidimensional perspective is an opportunity to change the paradigm of how public health challenges are confronted.

The evidence indicates that this process of paradigmatic transformation locally impacts various dimensions and rights,<sup>(20,42)</sup> transforming limitations into situated responses that recognise agency, that is, the ability of social subjects to act on their behalf, self-advocate, and resist oppression.<sup>(20,23,43)</sup> Likewise, a multidimensional approach has a direct impact on the work of health teams, through creative and innovative actions, effective strategies to approach the population, the inclusion of the affected people themselves, and the resulting enhancements of strategies of detection, adherence to treatment, and follow-up,<sup>(36,44)</sup> since this implies appropriate interventions for the needs of individuals, their families and communities. On the other hand, multidimensional understanding recognises (or strengthens) the leadership of people and their organisational capacities, as it highlights the importance of participation and social impact,<sup>(36)</sup> it directly affects public health policies (some eloquent examples from **WHO, Argentina and Campinas and Pernambuco** in Brazil), and even facilitates various strategies with a transnational approach.<sup>(45)</sup>

We encourage new reflections which pave the way for creative inquiries that permit a wider understanding of questions (and answers) relevant to research, healthcare, and public policy development, based on new foundations and employing a critical perspective. The epistemological transformation underlying the proposals of this article "will allow enhancing the delimitation of the problem 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 organisations, the media, etc."<sup>(2)</sup>

Once a multidimensional comprehension has been internalised, it should serve as a platform for launching particular IEC approaches needed for each context and intervention strategy. IEC proposals should be implemented along the continuum of health promotion, disease prevention, transmission interruption, diagnosis, treatment and follow-up, facilitating their integration within the health system, academic and public policy structures, as well as measurement of different process outcomes. Along this path "we will find the signals to overcome the dichotomies accounting for practices of disqualification and *non-existence*,<sup>(46)</sup> in the end, of social exclusion: ill/healthy, ignorant/expert, poor/not poor, endemic/non endemic, patient/agent, voiceless/with 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."<sup>(2)</sup>

Visualising the multiple components that Chagas comprises, in various geographic settings, and also its heterogeneous and infinite possibilities of interconnection, requires creativity in order to "turn and interconnect" the multiple elements in a complex and dynamic interplay, as an infinite/inexhaustible system of interlocking gears. Fig. 4 depicts the interconnections of the different components. Its flexibility permits us to prioritise the multiple elements which provide an overarching order and structure that is nonetheless, dynamic and in constant transformation.



Fig. 4: interlocking gears to address the multidimensionality of Chagas (Illustration: Iván Pasanau). Each gear represents a key component to consider in a multidimensional strategy for Chagas. Key aspects of each gear are described below. IEC APPROACHES (Information, Communication and Education tools, strategies, methodologies, social media, technology), TERRITORIES (rural, urban, local, regional, national, global, borders), INTERSECTORAL ACTIONS/INSTITUTIONS (health systems -national, local, international; public administration; educational settings; universities and technical schools; media; and legislative and operative public and private institutions involved in labour, housing, migration, and the environment, NGO, macro structures), INTERSECTIONALITY (gender, sexual orientation, race / ethnicity, nationality, social class, vital cycle, physical abilities), INTERVENTION LEVELS (awareness, prevention, care, follow-up, primary and secondary systems, individual, family and community levels), POLITICAL & SOCIAL ACTORS (associations of people with Chagas, other social organisations, decision makers, educators and communicators, specialists, artists, health workers, activists).

Finally, the system of interlocking gears enables us to engage with new actors, elements, and settings, incorporating emerging aspects, such as contemplating other problems and realities affecting people's health. In this way, we can clearly visualise main future challenges:

(1) Face Chagas through a multidimensional perspective; assess in each setting the critical points (including dimensions and levels of intervention) where “multidimensionality” is not addressed.

(2) Employ a broad, intersectional perspective in IEC program design, considering not only the social and cultural particularities of diverse territories, but power

differentials arising from historically rooted social inequalities based on gender, class, sexuality, race/ethnicity and other relevant factors.

(3) Consider the use of technological resources as mechanisms which enhance the flow of information to people and improve communication as well as access, detection, treatment, and follow-up.

(4) Make Chagas IEC a transversal component of every program for prevention, detection, treatment, and follow-up of affected people. IEC should not be an afterthought of Chagas interventions, but a fundamental pillar of any multidimensional approach, which increases,

through various possibilities of intervention, the quality of life and access to health rights of people (by increasing awareness; impacting the training of health teams; increasing access to treatment, detection and monitoring; championing appropriate legislation and guidelines, and promoting social participation, to mention some of its advantages and direct impacts).

(5) A multidimensional IEC approach requires the participation of as many and as diverse a range of social actors as possible: all types of specialists, politicians, academics, local and national governments, health care teams and others. The representation and social organisation of affected people is a principal axis; their participation in decision making should be always guaranteed.

(6) Integrate impact evaluation (including cost-benefit) into Chagas IEC programs from their initiation.

(7) Systematically incorporate local knowledge and experience into IEC proposals; this means including experts and leaders from diverse systems of knowledge and healing who represent cosmovisions that can strengthen the impact of the proposed activities.

(8) Consider an ongoing revision of language, ensuring it is inclusive of diverse groups, is neither fragmented nor stigmatising, and avoids reproducing social exclusion and inequalities.

(9) Incorporate other media including music, poetry, narrative prose, and photography, among others, into IEC proposals to strengthen creative mechanisms that promote dialogue between health and knowledge systems (epistemologies) and foment critical and transformative perspectives.

(10) Cooperation in a broad sense, shared initiatives, exchange of ideas, and communication via diverse platforms are essential for enhancing a multidimensional perspective of Chagas. The IEC triad represents an opportunity to transcend geographic, cultural, and social boundaries.

Ultimately, we hope that these pages will support the construction of future proposals for activism, research, health systems and public policy that seek to address and modify relations of inequality, based on a more complex and grounded understanding of people's health around the world.

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#### AUTHORS' CONTRIBUTION

MS participated in all work instances and coordinated the article writing process; CJF, AA, JGiP and MV-R participated in the writing of the article and general revision of the text. Additionally, CJF performed the English proofreading / translation task; PA-V carried out the general review and contributed fundamental aspects in the final stages of the work. All the authors participated in the instances of organisation of the text and discussion of the content.

#### REFERENCES

1. Coura JR, Albajar-Viñas P. Chagas disease: a new worldwide challenge. *Nature*. 2010; 465: S6-7.
2. Sanmartino M, Saavedra AA, Ávila LT. A social approach to Chagas disease: a first step to improve access to comprehensive care. In Pinazo MJ, Gascon J, orgs. *Chagas disease - A neglected tropical disease*. New York: Springer; 2020. doi.org/10.1007/978-3-030-44054-1\_4.
3. OPS - Organización Panamericana de la Salud, Centro Latinoamericano de Perinatología, Salud de la Mujer y Reproductiva. Informe de la Consulta Técnica sobre Información, Educación y Comunicación (IEC) en Enfermedad de Chagas Congénita, mayo 2007, Montevideo: CLAP; 2007. (OPS/HDM/CD/476/07).
4. Catalá S. Información, Educación y Comunicación (IEC) Componentes esenciales en la prevención y vigilancia de la enfermedad de Chagas. In Crocco L, org. *Chagas, educación y promoción de la salud*. Córdoba: Sima Editora; 2011. p. 165-8.
5. WHO - World Health Organization. Report of the first meeting of the technical group on information, education and communication to control Chagas disease. Geneva: WHO; 2018.
6. Martínez-Parra AG, Pinilla-Alfonso MY, Abadía-Barrero CE. Sociocultural dynamics that influence Chagas disease health care in Colombia. *Soc Sci Med*. 2018; 215: 142-50. doi:10.1016/j.socscimed.2018.09.012.
7. Forsyth CJ, Hernandez S, Flores CA, Roman MF, Nieto JM, Marquez G, et al. "It's like a phantom disease": patient perspectives on access to treatment for Chagas disease in the United States. *Am J Trop Med Hyg*. 2018; 98(3): 735-41. doi:10.4269/ajtmh.17-0691.
8. Forsyth C. From lemongrass to ivermectin: ethnomedical management of Chagas disease in tropical Bolivia. *Med Anthropol*. 2018; 37(3): 236-52.
9. Reyes-García V, Paneque-Gálvez J, Luz AC, Gueze M, Macía MJ, Orta-Martínez M, et al. Cultural change and traditional ecological knowledge. An empirical analysis from the Tsimane' in the Bolivian Amazon. *Hum Organ*. 2014; 73(2): 162-73. doi:10.17730/humo.73.2.3In1363qgr30n017.
10. Castagnino H. Mazza y la lucha contra el mal de Chagas. *Todo es Historia* (Buenos Aires). 1986; 41(225): 8-31.
11. Sierra Iglesias J, Storino R, Rigou D. Antecedentes históricos. Em Storino R, Milei J, editors. *Enfermedad de Chagas*. Buenos Aires: Doyma Argentina; 1994.
12. Dias JCP. Present situation and future of human Chagas disease in Brazil. *Mem Inst Oswaldo Cruz*. 1997; 92: 13-5.
13. Briceño-León R. La casa enferma. Sociología de la enfermedad de Chagas. Caracas: Fondo Editorial Acta Científica Venezolana-Consortio de Ediciones Capriles; 1990.
14. Briceño-León R. La enfermedad de Chagas en las Américas: una perspectiva de ecosalud. *Cad Saude Publica*. 2009; 25(Suppl. 1): S71-82.
15. WHO - World Health Organization [homepage on the Internet]. Chagas disease (also known as American trypanosomiasis) [updated 2020 March 11; cited 2020 July 9]. Available from: [https://www.who.int/news-room/fact-sheets/detail/chagas-disease-\(american-trypanosomiasis\)](https://www.who.int/news-room/fact-sheets/detail/chagas-disease-(american-trypanosomiasis)).
16. WHO - World Health Organization. Resolution WHA63.20. Chagas disease: control and elimination. In Sixty-three World Health Assembly. Geneva, 17-22 May 2010. Resolutions and decisions, annexes. Geneva: World Health Organization; 2010. Available from: <https://apps.who.int/iris/handle/10665/4455>.
17. WHO - World Health Organization. Sustaining the drive to overcome Chagas disease in non-endemic countries. Report of the Third WHO Meeting of the Non-Endemic Countries Initiative on the Control of Chagas disease. Florence; 2013; 4-6 June.

18. Amieva C, Carrillo C, Mordeglia C, Gortari MC, Scazzola MS, Sanmartino M. A kaleidoscope of words and senses to (re)think the problem of Chagas. In Corbin H, Sanmartino M, Hennessy E, Urke H, editors. Arts and health promotion: tools and bridges for practice, research and social transformation. New York: Springer; 2021. In press.
19. Marti GA, Amieva Nefa SC, Balsalobre A, Carrillo C, Medone P, Mordeglia C, et al. Hablamos de Chagas. Aportes para (re) pensar la problemática con una mirada integral. Buenos Aires: CONICET; 2015.
20. Forsyth C, Meymandi S, Moss I, Cone J, Cohen R, Batista C. Proposed multidimensional framework for understanding Chagas disease healthcare barriers in the United States. *PLoS Negl Trop Dis.* 2019; 13(9): e0007447. doi:10.1371/journal.pntd.0007447.
21. Farmer P. On suffering and structural violence: a view from below. *Daedalus.* 1996; 125(1): 261-83.
22. Manne-Goehler J, Reich MR, Wirtz VJ. Access to care for Chagas disease in the United States: a health systems analysis. *Am J Trop Med Hyg.* 2015; 93: 5.
23. Ventura-Garcia L, Roura M, Pell C, Posada E, Gascón J, Aldasoro E, et al. Sociocultural aspects of Chagas disease: a systematic review of qualitative research. *PLoS Negl Trop Dis.* 2013; 7(9): 1-8.
24. Sanmartino M, Mateyca C, Pastorino IC. What are we talking about when we talk about education and Chagas? A systematic review of the issue. *Biochim Biophys Acta Mol Basis Dis.* 2020; 1866(5): 165691. doi.org/10.1016/j.bbadis.2020.165691.
25. Lee BY, Bacon KM, Bottazzi ME, Hotez PJ. Global economic burden of Chagas disease: a computational simulation model. *Lancet Infect Dis.* 2013; 13(4): 342-8. doi:10.1016/S1473-3099(13)70002-1.
26. WHO - World Health Organization. Investing to overcome the global impact of neglected tropical diseases. Third WHO report on neglected tropical diseases. 2015. Available from: [https://www.who.int/neglected\\_diseases/9789241564861/en/](https://www.who.int/neglected_diseases/9789241564861/en/).
27. Vazquez-Prokopec GM, Spillmann C, Zaidenberg M, Kitron U, Gurtler RE. Cost effectiveness of Chagas disease vector control strategies in Northwestern Argentina. *PLoS Negl Trop Dis.* 2009; 3(1): e363.
28. Ramsey JM, Elizondo-Cano M, Sanchez-González G, Peña-Nieves A, Figueroa-Lara A. Opportunity cost for early treatment of Chagas disease in Mexico. *PLoS Negl Trop Dis.* 2014; 8(4): e2776. doi:10.1371/journal.pntd.0002776.
29. Imaz-Iglesia I, Miguel LG-S, Ayala-Morillas LE, García-Pérez L, González-Enríquez J, Blasco-Hernández T, et al. Economic evaluation of Chagas disease screening in Spain. *Acta Trop.* 2015; 148: 77-88. doi:10.1016/j.actatropica.2015.04.014.
30. Requena-Méndez A, Bussion S, Aldasoro E, Jackson Y, Angheben A, Moore D, et al. Cost-effectiveness of Chagas disease screening in Latin American migrants at primary health-care centres in Europe: a Markov model analysis. *Lancet Glob Health.* 2017; 5(4): e439-e447. doi:10.1016/S2214-109X(17)30073-6.
31. Bartsch SM, Avelis CM, Asti L, Hertenstein DL, Ndeffo-Mbah M, Galvani A, et al. The economic value of identifying and treating Chagas disease patients earlier and the impact on *Trypanosoma cruzi* transmission. *PLoS Negl Trop Dis.* 2018; 12(11): e0006809. doi:10.1371/journal.pntd.0006809.
32. Flores EWP, Billot C, Claire NM, Zanabria EC, Torrico F, Beltrán DFL. Implementación de un modelo de comunicación en Chagas basado en la estrategia de educación por pares. *Gaceta Médica Boliviana.* 2019; 42(2): 117-21.
33. Oliveira Jr W. All-around care for patients with Chagas disease: a challenge for the XXI century. *Mem Inst Oswaldo Cruz.* 2009; 104(Suppl. 1): 181-6. <https://doi.org/10.1590/S0074-02762009000900024>.
34. Essadek HO, Guiu IC, Mendivelso JC, Sulleiro E, Pastoret C, Navarro M, et al. Cribado in situ de la enfermedad de Chagas con una intervención comunitaria: ¿puede mejorar la accesibilidad al diagnóstico y al tratamiento? [On site-screening for Chagas disease supported by a community intervention: can it improve accessibility for diagnosis and treatment?]. *Gac Sanit.* 2017; 31(5): 439-40. doi:10.1016/j.gaceta.2017.04.007.
35. Gómez i Prat J, Peremiquel-Trillas P, Guiu IC, Choque E, Souto IO, Delcor NS, et al. A community-based intervention for the detection of Chagas disease in Barcelona, Spain. *J Community Health.* 2019; 44(4): 704-11. doi:10.1007/s10900-019-00684-z.
36. Gómez i Prat J, Peremiquel-Trillas P, Guiu IC, Mendivelso JC, Choque E, de los Santos JJ, et al. Comparative evaluation of community interventions for the immigrant population of Latin American origin at risk for Chagas disease in the city of Barcelona. *PLoS One.* 2020; 15(7): e0235466. doi:10.1371/journal.pone.0235466.
37. Guiu IC, Mendivelso JC, Essadek HO, Mestre MAG, Albajar-Viñas P, Gómez i Prat J. The Catalan Expert Patient Programme for Chagas disease: an approach to comprehensive care involving affected individuals. *J Immigr Minor Health.* 2017; 19(1): 80-90. doi:10.1007/s10903-016-0345-y.
38. Tognoni G, Anselmi M, Prandi R, Montano CC, Figueroa MM, Armani D, et al. Epidemiología comunitaria: las periferias toman la palabra. *Esmeraldas: Ediciones CECOMET;* 2010. 269 pp.
39. Anselmi M, Guevara A, Vicuña Y, Vivero S, Prandi R, Caicedo C, et al. Community epidemiology approach to parasitic infection screening in a eemote community in Ecuador. *Am J Trop Med Hyg.* 2019; 101(3): 650-3. doi:10.4269/ajtmh.19-0187.
40. Mordeglia C, Sanmartino M, Scazzola MS. Integrando docencia y extensión para el abordaje de la problemática de Chagas en la Universidad Nacional de la Plata. En Giordano CJ, Morandi G, orgs. Memorias de las 2ª Jornadas sobre las Prácticas Docentes en la Universidad Pública. La enseñanza universitaria a 100 años de la reforma: legados, transformaciones y compromisos. La Plata: Universidad Nacional de La Plata; 2019.
41. Batista C, Forsyth CJ, Marchiol A, Herazo R, Certo M. A four-step process for building sustainable access to diagnosis and treatment of Chagas disease. *Pan Am J Public Health.* 2019; 43: e74. <https://doi.org/10.26633/RPSP.2019.74>.
42. Sanmartino M, Saavedra AA, Gómez i Prat J, Albajar-Viñas P. Chagas and health promotion: dialogue inspired by the Curitiba Statement. *Health Promot Int.* 2019; 34(Suppl. 1): i82-i91. <https://doi.org/10.1093/heapro/day105>.
43. Saavedra AA. Migrar, enfermar-sanar lejos de casa. Bolivianos en Barcelona, experiencia hecha carne. In Agar L, coord. Migraciones, salud y globalización: entrelazando miradas. Santiago de Chile: Edición OIM, OPS, MINSAL; 2010.
44. Soriano-Arandes A, Basile L, Ouvarab H, Claveria I, Gómez-Prat J, Cabezas J, et al. Controlling congenital and paediatric Chagas disease through a community health approach with active surveillance and promotion of paediatric awareness. *BMC Public Health.* 2014; 14(1): 1201.
45. Pinazo MJ, Pereiro A, Herazo R, Chopita M, Forsyth C, Lenardón M, et al. Interventions to bring comprehensive care to people with Chagas disease: experiences in Bolivia, Argentina and Colombia. *Acta Trop.* 2020; 203: 105290. doi.org/10.1016/j.actatropica.2019.105290.
46. Santos BS. Descolonizar el saber, reinventar el poder. Montevideo: Ed. Trilce, Extensión Universitaria UDELAR; 2010.