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## **Bolivian migration and Chagas disease: boundaries for the action of the Brazilian National Health System (SUS).**

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Migration provoke changes in epidemiological profiles impinging on the health care systems of reception countries. Immigrants come to Brazil from neighbor countries usually having precarious insertion in metropolitan areas. Chagas disease is endemic in Bolivia, something that has to be taken into account by the SUS. This paper analyzes both action and limits regarding health professionals who provide services to Bolivians in SUS with a focus on Chagas disease. Interviews were applied to primary, secondary and tertiary health services in the central region of São Paulo, the main destination of Bolivian immigrants. The precarious living conditions of Bolivians are the cause of health inequities. Language and culture also hamper their understanding about care. There is a lack of knowledge about clinic and epidemiology aspects of Chagas disease among the professionals who attend these immigrants. It is necessary to rethink strategies of health care and control of Chagas disease.

*Keywords:* Migration. Bolivians. Chagas disease. Health care. Health professionals.

### **Introduction**

Human migration is the movement by people, in various historical moments, from one country, place, or locality to another. The complex interplay of the migration process is caused by a variety of reasons, including economic, social and political factors, situations of armed conflict, or environmental disasters, among others. Nevertheless, migration flows have quantitative and qualitative heterogeneous dimensions in contemporary times, with various aspects and complexities in the context of a globalized world, formed by extreme interdependent relations with unfolding which generates deep inequalities. Consequently, there is a growing challenge both to understand the complexity of these population shifts and to the formulation of social policies and practices arising from the changes undergone in the receiving societies of the displaced individuals and social groups<sup>1-3</sup>.

The American countries, particularly the Central and South American countries, have migration patterns among them that differ greatly from those of other continents: they are fundamentally associated with precarious living conditions, marked by important profiles of social inequality among the regions.<sup>4</sup>

Two South American countries, Argentina and Brazil, have attracted immigrants from neighboring countries from the second half of the twentieth century. They usually enter both territories without official papers and compose the precarious workforce in the service and textile manufacturing sectors in large urban centers<sup>5,6</sup>.

The migration processes generate a large amount of changes. Among them, the impact of the migration flows on the health systems of receiving countries is highlighted, as they lead to changes in the epidemiological profiles and demand a review of the disease control and health care strategies. In this context, Chagas disease emerges as one of these concerns, notably in the Brazilian territory<sup>7</sup>.

Chagas disease is endemic in Latin America and its transmission is by triatomine bugs. The disease can be transmitted orally, by consumption of food contaminated with *Trypanosoma cruzi* -- the parasite that causes Chagas disease --, an infected mother to her newborn, infected blood and blood products, organ transplants from infected donors, and by accidents with biological material. Around 6

million people worldwide are estimated to be infected with *Trypanosoma cruzi*. Chagas disease is present in almost all the national territory of Bolivia, representing a serious public health problem<sup>8-11</sup>.

The World Health Organization (WHO) established control over the transmission of Chagas disease in 2010<sup>12</sup>. In Brazil, the interruption of vector-borne transmission was recognized by the Pan-American Health Organization (PAHO) in 2006, and in São Paulo state this condition had already been verified in the 1970s<sup>13</sup>.

The challenge in the Brazilian context, therefore, is keeping Chagas disease under control by permanent and qualified health actions involving all levels of healthcare. It has already been warned that Chagas disease has been left out of the agenda of health policy priorities. However, it is a highly important matter, strengthened by the new social reality constituted by human migration processes. Furthermore, we must bear in mind that the Bolivian population is one of the most numerous among the current migration flows in Brazil, and largely concentrated in São Paulo<sup>14-16</sup>.

Therefore, it is worth emphasizing the need to understand how the Brazilian health services and their professionals have been meeting the healthcare demands in the contexts of migration flows, notably referring to Chagas disease.

In this perspective, this paper aims at analyzing both performance and limits of health professionals providing healthcare services to Bolivian immigrants in the Brazilian Unified Health System (SUS), focusing on the Chagas disease issue in healthcare services located in the central region of São Paulo City, in Brazil.

## **Methodology**

This study is part of the research “Chagas disease in the Bolivian migrant population in São Paulo city: an analysis of the *Trypanosoma cruzi* infection prevalence, the Chagas disease morbidity, the population knowledge on the disease, and the access to different levels of healthcare” (CNPq, 404336/ 2012-4). The research project was approved by the Research Ethics Committee of the Hospital das Clínicas,

University of São Paulo Medical School (FMUSP), under protocol number 196.698 / 2013.

Nineteen semi-structured interviews were conducted in the second half of 2015 among professionals with high school, undergraduate and graduate degrees, working for the public health services in the central region of São Paulo city. The interviewees were selected according to sample to represent the different technological densities in the health services organization, which are subdivided into three sectors: Primary (Primary Health Care Units – UBS), Secondary (Emergency Services) and Tertiary (Maternity Services) care.

The chosen area of study was the public health service centers in the central region of São Paulo because of two reasons: the presence of studies about Bolivian immigrants with Chagas disease prevalence and morbidity in one of these services (CNPq, 404336 / 2012–4); and the high concentration of this population in that specific part of the Brazilian territory<sup>16</sup>.

The interviews were conducted at the healthcare services, digitally recorded and transcribed. Next, contents from the transcribed texts were selected based on the following topics guiding the interview script: health services organization; recognition of Bolivian immigrants' demands and needs; recognition of health professionals' limits and performance strategies towards the Bolivian immigrants' demands and needs; and Chagas disease knowledge, markedly regarding the Bolivian population.

In order to protect the interviewees' identities, we have chosen to classify the selected interview excerpts by using increasing numbers according to three levels of care: Primary (doctor – 1, doctor – 2, nurse – 3, social worker – 4, administrative assistant – 5, and administrative assistant – 6); Secondary (doctor – 7, social worker – 8, nurse – 9, nurse – 10, nurse – 11, administrative assistant – 12, pharmacist – 13, and doctor – 14); and Tertiary (doctor – 15, nurse – 16, social worker – 17, doctor – 18, and social worker – 19).

## Results and Discussion

## Health Services Organization

A comprehensive discussion and all efforts of the Public Management towards the organization and logic that must guide the health services organization to ensure its effectiveness in caring for the population's demands and needs is of great relevance in the context of the Brazilian Unified Health System (SUS).

From this perspective, the proposition of Health Care Networks presents the best solutions to overcoming the organizational form of services, enabling more comprehensive and horizontal lines of care. Notwithstanding, its effective implementation represents a huge challenge to be faced. It requires great efforts to overcome barriers, notably those regarding communication aspects between health services and professionals<sup>17,18</sup>.

These issues are tackled in this study when interviewees recognize the health care organization at the local level both in their care work process – reference and counter-reference networks – and in the very trajectory of the Bolivian immigrants who use the health services offered and their insertion into the territory.

On the other hand, it can be perceived problems in operational access and strategic communication of these Health Care Networks services, expressed in the assurance of a timelier assistance, in the effectiveness of outpatient follow-up, and in the communication relationship. It is worth mentioning that these problems can weaken the effective access of the assisted population, as shown in the following excerpts from the interviews:

Most [women] live here in the area. The majority use the Primary Health Care Units of Santa Cecília, Sé, Bom Retiro, Centro de Saúde Escola Barra Funda and Boraceia [Primary Health Care Units in the central region of São Paulo city]. Some of the women we've been watching come from Casa Verde and Vila Maria boroughs [located in the northern region of São Paulo city], but they are few, in quite a small number. Most of them come from the central region. (Interviewee 17)

(...) We have a level of care that is assisted by the emergency department. As the doors are open [to anyone], it ends up getting the major demand. We offer ambulatory care; however, the demand for this care service by the population is no longer significant. The female patient who goes to the ambulatory center nowadays is either the one who had already been assisted at the emergency department or hospitalized here and referred. So, they're our major clients. Sometimes, she's referred by another network service. (Interviewee 15)

There are difficulties in scheduling appointments (...) Sometimes, they need a sooner appointment, but the waiting time is too long to get one. (Interviewee 8)

(...) It's been increasing the percentage of pregnant women without prenatal care monitoring in other health care units, resulting in direct emergency department visits (...), many times with more complex intercurrents, overloading the hospital unit with more complicated outcomes for the parturients and their newborn children. (Interviewee 18)

They [the referral services that had attended the patients] don't send us the reports we've requested. The majority doesn't send them. We even request them with a carbon-based prescription pad, pleading them to send an updated report of what's being done with the patient, but only the minority sends it (...) (Interviewee 3)

### **Recognition of Bolivian immigrants' demands and needs**

In this perspective, it can be clearly seen the connection between the migration process and the precarious insertions in the social fabric the Bolivian population is part of, determining their way of life. Such condition is expressed in these users' contacts with the health services, being acknowledged and contextualized by the health professionals in health care work:

Most of them [Bolivian patients] are seamstresses, working from twelve to fourteen hours a day and taking care of their children right there, in home and work environments. (Interviewee 17)

(...) Many enter Brazil clandestinely and need to regularize their papers, and we end up contacting the Bolivian Consulate and giving them the necessary guidelines. (Interviewee 4)

They arrive in São Paulo, come [to us], make a SUS card (...). They say that there are no doctors there [in Bolivia], and that it's very difficult for them to get a medical appointment. (Interviewee 14)

From a more comprehensive analytical perspective, it can be noticed that there was the creation of a transnational space, in the twentieth century, in which arose, and still arises, the migration processes. That comprised the production internationalization and the world economy reorganization phenomena, which exposes the complexity of international contexts. Taking this into account, the circulation of workers is an additional flow, among others, that intensively triggers social relations in an international context. Consequently, there is a breakdown in the traditional work structure, giving rise to the creation of labor market spaces for organized subcontracting and to the possibility of emerging small business. In other words, it allows that old work systems based on the domestic sphere with family-based organization and artisanal work characteristics can expand and build international extensions through the migration flows. As widely investigated in research studies, the consequences of this internationalization process usually lead to a clandestine organization network of labor relations, structured mainly in an informal market with deleterious effects on individuals, families and groups<sup>4,19</sup>.

These living and working conditions to which most Bolivian immigrants are subjected determine specific illness profiles that usually require health services. The interviewees predominantly report suffering respiratory, dermatological and gastrointestinal disorders, and tuberculosis as the most recurrent problem linked to



their living conditions. An additional research study carried out in Argentina with Bolivian immigrants whose conditions were very close to the Brazilian reality indicates tuberculosis as a serious health problem<sup>20</sup>:

They [the Bolivian immigrants] always attend [the health service], every day (...). (Interviewee 9)

There are many Bolivian immigrants with tuberculosis. They complain a lot about their living conditions, as living without sun. We often receive one [patient] with diarrhea symptoms, and suddenly comes a lot of them with the same symptoms, as most of them live in the same area. (Interviewee 6)

Talking about the Bolivian population in general, they have many skin problems and pediculosis, as they live in clusters and that ends up making it easier [to have such health problems]. (Interviewee 14)

Regarding the frequency of care services use identified by the interviewees at the different levels of care, women – mainly pregnant women – are the largest user group, followed by children. In the context of women's care, the complex issue of domestic violence is often veiled. This specific situation exposes a tension between the demands presented by the segment of Bolivian immigrants, especially concerning gender relations, and the needs observed by the health services<sup>16,21</sup>:

(...) The [Bolivian] women are coming very often for the prenatal care and the pap [papanicolaou test]. The children [the Bolivian children] are also coming a lot for childcare (...). (Interviewee 3)

The [Bolivian] mothers require Paediatrics a lot, bringing their children, or [there are] even [Bolivian] women who come looking for the pregnostican [pregnancy test] for figuring out whether they are pregnant. (Interviewee 8)

There's always someone [some Bolivian women] who has been abused. I have already seen some [patients], and the aggression comes either from their own husband or from the people who live in the same house. That happens occasionally. We end up guiding them what to do (...). (Interviewee 19)

### **Recognition of health professionals' limits and performance strategies towards the Bolivian immigrants' demands and needs**

The use of the Bolivian health services by the Bolivian immigrants brings a markedly social and specific complexity to the health units, and especially to the exercise of professional practices and work process engendered by that use. Such complexity may many times be strange (for being different) to the reality of Brazilian users, even if they belong to vulnerable social segments. The daily work health demands go beyond biological impairment. Therefore, the need for professional action providing care to this population is confronted with a "complexity of medical-social problems" imposing limits both on the professional-user and service-user relationships, thus provoking, in this context, psychic suffering among workers due to the frustration level in their effective action<sup>22</sup>.

Beyond the precarious living conditions determined by the migration flow, an additional dimension that hampers health actions refers to language and culture. In addition to the linguistic barrier, there are also the interferences derived from the lack of understanding of cultural traits and the different conceptions on health and illness that hold off the parties involved in the communication processes, creating a conflict among the very distinct sociocultural contexts<sup>23,24</sup>.

If, on the one hand, the interviewees' statements reveal quite well this dilemma concerning care services provided to the Bolivian immigrants, on the other it is also in this sphere that it can be observed a rich process of initiatives and attitudes that the health professionals develop in the daily practice when they attempt to overcome the various obstacles they face.

From the perspective of the interviewees, Bolivian immigrants have no treatment adherence because of their living conditions and the way they take care of their health according to their own needs. For the health professionals interviewed, the migration situation, added to the working conditions and the lack of a social-family network to support those immigrants undermine the conduct of the health care processes, while requiring different strategies of the health services so that satisfactory results in the care service may be reached:

The reason they give [of non-adherence to outpatient follow-up] is usually for working in the sewing rooms. The bosses don't allow them to leave. They work as slaves. We [the health service professionals] try to make it easier for them [the Bolivians], checking what is the most flexible time, what they have on Saturdays. We are quick to help them (...), as their absences [not attending routine medical appointments] are very high. (Interviewee 5)

There are some [Bolivians] that I don't understand at all. The ones arriving now [from Bolivia] then, they are terrible! I think the greatest difficulty to deal with them is the language. (Interviewee 6)

What happens is that many Bolivians come from [Bolivian] rural areas and sometimes do not speak well, even Spanish. They speak aboriginal dialects, but we can communicate. (Interviewee 7)

The cause of absenteeism [not attending a medical appointment] could be our [the health service] difficulty in explaining him [the Bolivian user] the situation, that is, why he should return, the importance of a return visit, and mainly when we are performing a preventive work. (Interviewee 1)

In fact, what creates difficulty (...) is not really knowing where he [the Bolivian attended in the health service] lives, as they usually don't report the correct residential address. (Interviewee 9)

(...) But I have my own strategies. I spell words letter by letter, I draw. For example (...), I show him [the Bolivian patient] a small glass and I ask him if he understands. (...) They usually come with someone who has been living in Brazil for a longer time. Many times, the translator is the oldest brother. (Interviewee 4)

I myself do not speak Spanish, and I try to communicate [with the Bolivian patient] by mimicking (...). (Interviewee 1)

The interviewees report facing great difficulty in managing cases treated in the tertiary service, particularly when there is evidence of preterm birth, which requires the hospitalization of the parturient woman. According to the reports, however, many of those women argue against their hospitalization. Moreover, in many cases, their husbands also argue against their hospital stay for fearing that the temporary withdrawal from work may lead to their wives' job loss. In those cases, there are reports of hospital evasion, followed by the patient's emergency department admission, but in very precarious health conditions -- such as women delivering their babies on the way to the hospital, resulting, many times, in the newborn infant death as well as in negative consequences for the mothers:

(...) They [the Bolivian women] fail a lot [attending the health services]. They have this problem of non-adherence to health care treatment, and it's necessary to hold them here somehow as soon as they come to us. For instance, let's take the case of a pregnant woman in preterm labor. It's very difficult to hospitalize her because her husband doesn't accept it. He fears the work, fears her job loss. (...) They [the Bolivian women] are very quiet. We notice that there's some sort of [husbands'] intimidation going on. Just to give you one example, we've had a patient in labor with a breech presentation, first pregnancy, who needed a C-section, but it was difficult to intervene as she was afraid to stay because of her work, for labor issues. She [the Bolivian patient] refused the hospitalization and left. She fled the hospital, returning a week later with the baby dead and hanging. Why?

Because he started to be delivered and, as it was a breech delivery, [which is] a bit more complicated, she ended up losing her baby. (Interviewee 15)

Therefore, the limits faced by the health professionals towards the Bolivian immigrants' demands and needs were placed by their inability to modify something that precedes the patient's attendance by the health service, that is, the social conditions and inequities that affect this population group.

### **Knowledge about Chagas disease, particularly in the Bolivian population**

Given the complexity of Bolivian immigrants' social reality and their precarious insertion in the Brazilian environment, particularly in São Paulo, and considering the limits of the health professionals in providing healthcare to this population, the Chagas disease problem tends not to emerge as a concern in the Brazilian health care context. Therefore, Chagas disease cases are not identified, and timely and necessary therapies are not established for avoiding and/or controlling the disease worsening and progression.<sup>14</sup>

The lack of preparedness of health practices in our context regarding Chagas disease is a matter of concern that goes beyond the Bolivian migration flow surveyed in the present study. Possibly because of the elimination of vector transmission in the country, this approach is neither emphasized in professional development<sup>7</sup> nor in the guidelines that guide the work processes of the Brazilian health services. Hence, that represents a huge problem for the health system for not providing healthcare services to many of those asymptomatic chagasic individuals, impacting, in several cases, on healthcare. That situation is worsened when we are faced with the healthcare services provided to the Bolivian immigrants, who come from a country where the Chagas disease transmission has not yet been interrupted, and thus reaching a large part of the population<sup>25-27</sup>.

These issues respecting the current knowledge on the status of Chagas disease were verified in the interviews we have conducted with the health professionals, who

showed both a very generic understanding of the Chagas disease and not being suitably aware of the serious harm faced by the Bolivian population.

Although the interviewees showed lack of awareness of a protocol for Chagas disease, there is a reference to an initiative in one of the health services concerning screening Bolivian pregnant women for Chagas disease that corroborates the need of technical training and care protocols:

Regarding the [Chagas disease] diagnosis, in fact it's much more a matter of tracking. It's necessary to note that there's an epidemiological problem, there's an immigrant population. A screening test needs to be done, as we did in the eighties for people coming from [Brazilian] states whose [Chagas disease] transmission was known. (Interviewee 7)

No [I don't know about Chagas disease in the Bolivian population]. I'm aware of it now [with this research], because in the six years I've been here [working in the health service] I've had several opportunities to provide care for just one Bolivian patient, and I know he has a heart problem, but not Chagas disease. (Interviewee 11)

It's usual, we do ask for [a serological test for Chagas disease in Bolivian pregnant women]. It's our willingness [a provision of our service] to require this test. It's not part of the city hall protocol [São Paulo Municipal Health Department]. When the patient is Bolivian, we ask him the usual questions, such as whether he lived in the country, the type of housing, etc. I always ask him if he's ever done that test and if he'd like to be doing it. (Interviewee 2)

Yes, it would make it much easier [to have a specific protocol for Chagas disease], and even, if possible, a brief training [on Chagas disease research and treatment] for those who work in primary care, because, as I've already told you, If I take a case I'll have to ask for help, as even in college we don't have much of that subject. (Interviewee 3)

I don't know [about Chagas disease protocol]. What would be the relationship of Chagas disease? I would need to know about the disease to tell you what could affect the pregnancy, the transmission to the newborn, the eventual need for immediate treatment (...) We have many Bolivian women hospitalized here [in the Maternity Services] (...). (Interviewee 17)

### **Final Considerations**

The poor living conditions of the Bolivian population using the Brazilian healthcare services characterize relevant processes of health inequities. Their insertion in the work process is regarded as a determinant factor for suffering health problems and limitations to health care.

The situation of the female Bolivian immigrant is emphasized as extremely vulnerable. Dimensions of gender relations, work and maternity are perceived in the everyday health services, confronting the health professionals with strong tensions, difficulties and feelings of helplessness towards certain demands and needs they impose.

Furthermore, linguistic and cultural barriers are limiting aspects in providing healthcare to the Bolivian population. This issue may, for example, generate problems in the patient's understanding concerning the need for continuous use of medication, which can be an element of non-effectiveness of the treatment in chronic diseases, such as Chagas disease.

The lack of knowledge about the clinical and epidemiological profile of Chagas disease among the health professionals who were interviewed for this study is of great concern for the comprehensive care of the population they attend, especially in the current scenario of migration flows in Brazil.

In sum, taking into consideration the aforementioned issues, it is highly important to promote a joint action of SUS managers, the institutions responsible for the professional development of human resources and the society to formulate strategies guiding the comprehensive care to the population, as well as incorporating the specificities of the migration groups.

## Collaborators

Nivaldo Carneiro Junior and Cássio Silveira participated actively in the writing, discussion of the results, review, and final draft of the paper. Lia Maria Brito da Silva and Maria Aparecida Shikanai Yasuda participated in the discussions and review of the paper.

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