

Awareness of Chagas disease and socioeconomic characteristics of Bolivian immigrants living in Sao Paulo, Brazil

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ABSTRACT

In this study which is part of a research project on Chagas disease (CD) among Bolivian immigrants in Sao Paulo, we describe socioeconomic characteristics, knowledge of CD and implications for access to health care. We applied a structured questionnaire to a sample of 472 Bolivian adults (> 18 years) living in Sao Paulo and enrolled at the Barra Funda School Health Center. Participants' median age was 28.5 years, 75.0% were from the Bolivian department of La Paz, and >90% worked in the garment industry. Respondents had lived in Sao Paulo for a median of 5.8 years. Only 169 (35.8%) were familiar with CD, while roughly half (50.4%) had lived in natural materials houses in Bolivia, 225 (47.7%) indicated familiarity with the vector, 23.9% had seen the vector in their homes in Bolivia, and 6.4% reported having been bitten by a triatomine bug. Factors associated with awareness of CD were analyzed by chi square tests, and those with p values <0.25 were included in a multivariable logistic regression model. In the multivariable logistic regression analysis, having a relative with CD (OR=4.3, 95% CI=1.5-12.0), having lived in a house with mud or wood walls (OR=0.4, 95% CI=0.2-0.8), and having heard of the triatomine bug, or *vinchuca*, (OR=10.0, 95% CI=5.1-19.5) were significantly associated with awareness of CD. This study shows a low familiarity with CD among Bolivian migrants living in Sao Paulo, Brazil. Raising awareness of the disease through specific communication strategies should be an essential component of public health programs to reduce the burden of CD in this and other vulnerable populations.

KEYWORDS: Bolivian migrants. Chagas disease. Awareness. Healthcare access. Neglected tropical diseases.

INTRODUCTION

Chagas disease (CD) causes a greater burden of morbimortality than any other parasitic infection in the Americas, yet remains one of the world's most neglected diseases¹. Although regional collaborations such as the Southern Cone Initiative have led to a tremendous progress in curbing the vector transmission², this success has not been replicated in the healthcare context; <1% of the over 6 million people living with the disease in the America³ have been diagnosed and treated. The intense movement of human populations has been a defining feature of the past three decades and has profoundly impacted the epidemiology of CD, involving nonendemic areas including major urban centers of Latin America^{4,5}, Europe and the U.S.^{6,7}. The majority of European cases originate from Bolivia, while in the U.S. the highest numbers are from Mexico and Central America. Regional transnational

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migration within Latin America has profoundly impacted CD epidemiology, with implications for public health strategies. For instance, scientific data suggest that Bolivian migrants in Buenos Aires may represent a group with higher risk for CD⁸.

Migrants with CD confront unique challenges to accessing the healthcare system; they may possess limited economic resources; be excluded from local healthcare services; and experience difficulties communicating with providers due to linguistic, class and cultural barriers, as seen in Europe and the U.S.^{9,10}. Despite having a higher risk for CD, immigrants from Latin America are typically undiagnosed and may not have heard of the disease^{11,12}. In addition, providers in host countries are often unfamiliar with CD and not up-to-date with treatment recommendations^{13,14}. These many barriers can prevent migrants from having timely access to diagnosis and etiological treatment.

Brazil exemplifies many of the changing dynamics in CD's social and epidemiological profile. In 2006, the Pan American Health Organization certified the interruption of transmission by the main vector, *Triatoma infestans*¹⁵ but estimates suggest there are over one million people infected with *T. cruzi*^{2,16}. Internal migration from endemic rural areas has made CD a public health challenge in Brazilian cities. Sao Paulo, the fifth largest city in the world, is also a major destination for transnational migration. Over 350,000 Bolivian immigrants live in the city¹⁷ and a recent seroprevalence study in this population found 4.4% with *T. cruzi* infection¹⁸. Bolivians primarily migrate to Sao Paulo in search of job opportunities and greater economic stability for their families¹⁹⁻²¹. Prior research on Bolivian immigrants living near downtown Sao Paulo indicated a predominantly young population working mainly in garment sweatshops; the majority earning between 1-3 times minimum wage²².

In this study, which is part of a larger research project on CD among Bolivian residents in Sao Paulo, we describe socioeconomic characteristics, awareness of CD and implications for health care in a sample of Bolivian immigrants. The goal is to gain knowledge and insight for strengthening healthcare policies and the delivery of services to help this migrant population overcoming the various barriers to diagnosis and treatment of CD.

METHODS

A cross-sectional study was carried out through the application of a structured questionnaire to a sample of 472 Bolivian adults (>18 years old) living in Sao Paulo who were registered at the Dr. Alexandre Vranjac Escola Barra Funda Health Center (CSEBF is its Portuguese acronym),

a primary care clinic which is part of the Brazilian Public Health System. The sample size was estimated by stratifying the population, considering an estimated 7% prevalence of Chagas disease in migrant adults and assuming a variability of the estimate of 20% (95% confidence interval). The CSEBF, located in the central part of the city, is a reference center for the organization of assistance and care with the specific aim of guaranteeing healthcare access for this population²³, providing free primary healthcare services to individuals regardless of their immigration status. From July to November 2013, participants were recruited while attending appointments at the CSEBF for various reasons. Participants who agreed to participate in the study underwent an informed consent process in Spanish. Roughly 95% of the patients who were approached agreed to participate.

The questionnaire was pre-tested and validated, being applied by professionals duly trained for this purpose and fluent in the Spanish language. The investigators created and used a Spanish-language questionnaire with multiple choice questions on sex, age, time living in Sao Paulo, education, income, employment situation and other socioeconomic variables. Participants were also asked about familiarity with the "vinchuca" (the common name for the triatomine bug vector in Bolivia) and with CD, including its transmission and symptoms. Other questions focused on risk factors for CD and women of childbearing age were asked on the access to Brazilian maternal/reproductive health services. After asking for the patients' consent, Spanish-speaking interviewers applied the questionnaire and checked to ensure the respondents' comprehension. All the participants were tested for CD.

Questionnaire data were coded and stored in a database for subsequent analysis. Statistical analyses were performed using the Epidat v. 3.5.1 (Dirección Xeral de Saúde Pública, Galicia, Spain) and the SPSS v. 25.0. (IBM, Armonk, NY, USA). In an initial univariate analysis, we calculated proportions and used chi-square tests to identify factors associated with the awareness of CD; $p \leq 0.05$ was considered significant. We then used a multivariable logistic regression model, including variables with a p value less than 0.25 in the univariate analysis²⁴, to identify variables independently associated with the knowledge of CD.

The study is part of a larger research project entitled "Chagas disease in the Bolivian population of Sao Paulo: an analysis of prevalence of *Trypanosoma cruzi* infection, morbidity, knowledge, and access to healthcare", which was financed by the National Council for Scientific and Technological Development-Department of Science and Technology CNPq/ DECIT, Ministry of Health, Brazil (grant N° 404336/2012). The Ethics approval was given

by the Committee of Ethics in Research from the Clinical Hospital of the School of Medicine of the University of Sao Paulo (N° 196.698/2013), and written informed consent was requested from all the participants.

RESULTS

There were slightly more females (n=255, 54%) than males (n=217, 46%), and more than half of the respondents fell into the 18-29 age range, while <15% (n=67) were over 40. Three quarters of the respondents (n=358) were born in the Bolivian department of La Paz (Table 1). The median age was 28.5, and participants had lived in Sao Paulo for a median of 5.8 years. Most respondents (n=252, 53.4%) had lived in Sao Paulo between 1-5 years, though 209 (44.3%) indicated >5 years' residence. Two thirds of the respondents (n=320) had completed a high school education, though only 22 had continued to college. Nearly all the respondents (99.0%) lived in two neighborhoods, Bom Retiro and Barra Funda. Over 90% (n=428) worked in the garment industry. While 102 participants (21.6%) reported a per-person family income of less than 678 BR or 299 US dollars, which was the minimum wage at the time²⁵, 250 (52.9%) earned between 1-2 times the minimum wage. Neither the time living in Sao Paulo nor the education level were associated with significant differences in the income.

Nearly half (n=225, 47.7%) of the participants indicated familiarity with the triatomine vector ("vinchuca"); 106 (22.5%) had seen the vinchuca in their homes in Bolivia, and 30 (6.4%) recalled being bitten by a triatomine. In Bolivia, 277 participants (58/7%) had lived in the rural area and 209 (44.3%) had worked in the rural area. Additionally, slightly over half of the respondents (n=238, 50.4%) had lived in houses made of natural materials (mud or wood). When asked if they knew what CD is, only 169 participants (35.8%) responded affirmatively. Of these, 119 (70.4%) claimed that the disease was transmitted by a triatomine insect (known in Bolivia as the vinchuca), but only 26 (15.4%) recognized the "enlargement of the heart" as a potential sign of CD.

We assessed the awareness of CD and its association with demographic variables and known risk factors (Table 2). Male gender, being born outside the department of La Paz, having a relative with CD, not having lived in a house with mud or wood walls, having heard of the vinchuca, and having seen or been bitten by a vinchuca were all significantly associated with the awareness of CD in the univariate analysis. We included all the variables with a p value <0.25 in the univariate analysis in a multivariable logistic regression model (Table 3). Having a relative with CD (OR=4.3; 95% CI=1.5-12.0 p=0.006), having lived in a

Table 1 - Sociodemographic characteristics of participants (N=472), study of Chagas disease (CD) awareness among Bolivian migrants in Sao Paulo.

Category	N	%
Sex		
M	217	45.9
F	255	54.1
Age group (years)		
18 – 29	251	53.2
30 – 39	154	32.6
> 40	67	14.2
Residence in São Paulo (years)		
< 1	11	2.3
1 – 5	252	53.4
> 5	209	44.3
Lives with		
Family	216	45.8
Relatives	135	28.6
Friends	106	22.4
Other	15	3.2
Marital status		
Single	143	30.2
Married	155	32.8
Stable relationship	161	34.1
Other	13	2.9
Occupation		
Garment industry	428	90.6
Other	44	9.4
Family income		
≤ 1 minimum salary	102	21.6
1-2 times the minimum salary	250	52.9
>2 times the minimum salary	120	25.5
Education level		
Primary or less	15	3.2
Some secondary	137	29.0
High school graduate	298	63.1
College	22	4.7
Risk factors to CD		
Recalls being bitten by a "vinchuca"	30	6.4
Recalls vinchucas in the home	106	22.5
Lived in a house of mud or wood	238	50.4
Has a relative with Chagas disease	48	11.7
Lived in a rural area of Bolivia	277	58.7
Worked in a rural area of Bolivia	209	44.3
Chagas disease awareness		
Knows the vector ("vinchuca")	225	47.7
Knows of Chagas disease	169	35.8
Transmitted by triatomines ("vinchucas")	119	70.4*
May cause enlargement of the heart	26	15.4*

*percentage within those who know about Chagas disease (n=169)

Table 2 - Awareness of Chagas disease (CD) in Bolivian migrants in Sao Paulo.

Variable	Aware of CD (N=169) N (%)	Not aware of CD (N=303)	% aware in category	Odds Ratio (95% CI)	P value
Sex					
female	78/169 (46.2)	177/303 (58.4)	30.6	0.61 (0.42-0.89)	0.010
male	91/169 (53.8)	126/303 (41.6)	41.9		
Age (years)					
≥30	87/169 (51.5)	134/303 (44.2)	39.4	1.34 (0.92-1.95)	0.130
<30	82/169 (48.5)	169/303 (55.8)	32.7		
Department of birth					
La Paz	109/169 (64.5)	249/303 (82.2)	30.4	0.39 (0.26-0.61)	<0.001
other	60/169 (35.5)	54/303 (17.8)	52.6		
Education					
high school graduate	123/169 (72.8)	197/303 (65.0)	38.4	1.44 (0.952-2.17)	0.083
<high school	46/169 (27.2)	106/303 (35.0)	30.3		
Lived in rural Bolivia*					
Yes	100/169 (59.2)	177/299 (59.2)	36.1	1.01 (0.69-1.49)	0.945
No	69/169 (40.8)	122/299 (40.8)	35.8		
Worked in rural Bolivia*					
Yes	74/164 (45.1)	135/299 (45.2)	35.4	1.00 (0.68-1.47)	0.995
No	90/164 (54.9)	164/299 (54.8)	35.4		
Have a relative with CD					
Yes	36/169 (21.3)	13/303 (4.3)	72.9	5.23 (2.67-10.25)	<0.001
No	123/169 (72.8)	239/303 (78.9)	34.0		
Don't know	10/169 (5.9)	51/303 (16.8)	17.7		
Received a blood transfusion					
Yes	11/169 (6.5)	16/303 (5.3)	40.7	1.25 (0.57-2.76)	0.582
No	158/169 (93.5)	287/303 (94.7)	35.5		
Type of housing in Bolivia					
Mud or wood	71/169 (42.0)	167/303 (55.1)	29.8	0.59 (0.40-0.86)	0.006
Brick/cement	98/169 (58.0)	136/303 (44.9)	41.9		
Knows the triatomine vector (vinchuca)					
Yes	140/169 (82.8)	85/303 (28.1)	62.2	12.38 (7.72-19.85)	<0.001
No	29/169 (17.2)	218/303 (71.9)	11.7		
Saw a triatomine in the home					
Yes	71/169 (42.0)	35/303 (11.6)	67.0	5.55 (3.48-8.84)	<0.001
No	85/169 (50.3)	185/303 (61.0)	31.5		
Don't know	13/169 (7.7)	83/303 (27.4)	13.5		
Remembers being bitten by a vinchuca					
Yes	21/169 (12.4)	9/303 (3.0)	70.0	4.00 (1.77-9.06)	<0.001
No	105/169 (62.2)	180/303 (59.4)	36.8		
Don't know	43/169 (25.4)	114/303 (37.6)	27.4		
Went hunting in Bolivia					
Yes	56/169 (33.1)	119/303 (39.3)	32.0	0.77 (0.52-1.14)	0.186
No	113/169 (66.9)	184/303 (60.7)	38.0		
Handled game in Bolivia					
Yes	63/169 (37.3)	126/303 (41.6)	33.3	0.84 (0.57-1.23)	0.360
No	106/169 (62.7)	177/303 (58.4)	37.5		

Table 3 - Multivariable logistic regression of factors associated with awareness of Chagas disease.

Variable	Strength of association (confidence interval)	p value
Female sex	0.7 (0.4-1.3)	0.284
Age >30 years	1.7 (0.9-3.1)	0.100
High school education	1.0 (0.5-2.0)	0.954
Relative with Chagas disease	4.3 (1.5-12.0)	0.006
Born in La Paz	1.0 (0.5-2.2)	0.970
Lived in a mud or wood house	0.4 (0.2-0.8)	0.005
Went hunting	0.7 (0.3-1.3)	0.250
Recalls triatomine in home	0.7 (0.4-1.2)	0.170
Recalls triatomine bite	1.5 (0.5-4.2)	0.452
Has heard of the triatomine vector	10.0 (5.1-19.5)	<0.001

house with mud or wood walls (OR=0.4; 95% CI=0.2-0.8, p=0.005), and having heard of the triatomine vector (“vinchuca”) (OR=10; 95% CI=5.1-19.5, p<0.001) were significantly associated with the awareness of CD (Table 3).

Nineteen of twenty-five participants with positive serology for *T. cruzi* were female; the total CD prevalence in this sample was 5.3%. Four of the seropositive individuals had previously donated blood (two in Bolivia, one in Brazil, and one did not indicate the place), whereas one had received a blood transfusion. Of the 255 females in the sample, only 31 (12.2%) were 40 or older, 246 (96.5%) were of childbearing age (10-49 years old) and 199 (78%) had children. While 73.7% of the mothers had received prenatal care (71.8% in Brazil and 26.6% in Bolivia), in only 5.3% of these cases the CD testing was included, and only 1.5% informed that their infants had been tested for CD. Of the women who had had prenatal care, >90% were aware of and had used the Brazilian Unified Health System (SUS) for this service; 1.5% had coverage of private insurances and 2.6% paid for medical care.

DISCUSSION

The epidemiology of CD in the twenty first century has been framed in part by the social and economic forces driving globalization^{4,5}. Our study provides insight on South-South migration, which has important implications for the distribution of CD and access to healthcare. Of note, awareness of CD in at-risk populations and its importance for health care have rarely been considered in Brazil. The majority of respondents were not familiar with CD. Nonetheless, the prevalence of CD in the sample was 5.3%, and many had been

exposed to risk factors including triatomines and/or housing susceptible to triatomine infestation, as was discussed in an earlier report¹⁸. In our study, the multivariable analysis indicated a significantly lower awareness among people who had lived in houses with mud or wood walls. Nonetheless, this group may be at higher risk for CD. A study in Santa Cruz, Bolivia documented a higher risk for CD²⁶ among patients with cardiomyopathy who had lived in houses with mud or wood walls. In our study, patients with a history of residing in houses of mud or wood may have had lower access to health information and education on CD, resulting in a lower awareness.

Salm and Gertsch surveyed 480 participants from different regions of Bolivia, members of indigenous groups (the majority from Ayoreo, Guarani, Quechua, and Chiquitano communities), while 31.4% were from major cities (La Paz and Santa Cruz de La Sierra). In these urban centers, the distribution by sex and age and the educational level were similar to our sample. The authors found that 88.5% of all the participants were familiar with CD, although awareness was the lowest among respondents from La Paz (74.2%)²⁷. The authors have also indicated that Quechua and Ayoreo respondents were less familiar with transmission routes than Guarani and Chiquitano participants. In our study, knowledge of the vector was the strongest predictor of knowledge of CD. Similarly, Salm and Gertsch found that awareness of CD was strongly associated with the vector in Bolivia.

Other studies have noted varying levels of CD awareness among different immigrant populations. Ramos *et al.*²⁸ colleagues found that 63% of Bolivian immigrants in a sample in Elche, Spain, had heard of CD. In another study in Valencia, Spain, of 96 Bolivian immigrants, 73 (76%) had some awareness of CD, and most recognized that CD has an asymptomatic phase²⁹. In a sample of 43 Bolivians in Munich, Germany, 30 (69.8%) indicated they had previously received information about CD, but the majority considered they had limited familiarity with transmission and symptoms, and >90% had not been previously tested³⁰.

Bolivians in our sample exhibited lower familiarity with CD than in these studies. This could be explained by the respondents' relative youth, perhaps because the household vector transmission in many parts of Bolivia was under control early in the millenia³¹. By comparison, knowledge of CD was significantly higher in older individuals among Bolivians in Valencia²⁹. Another possibility is that the bulk of respondents in our study were from La Paz, which has lower levels of CD compared to other departments and was certified free of domiciliary vector transmission by *Triatoma infestans*³².

Awareness appears to be lower in North American migrants. In a sample of Latin American immigrants in Los Angeles, most of whom were from Mexico and Central America, only 14% had previously heard of CD¹¹. Similarly, in a sample of migrants at the Guatemala-Mexico border, 80% had not previously heard of CD¹².

Twenty-five participants had positive serology for *T. cruzi*, as was reported in a previous article¹⁸, which found that seropositive respondents were significantly more likely to have knowledge of CD and the vector. Most testing positive were females, yet only 5.3% of mothers had received CD testing as part of their prenatal care. Four of the seropositive individuals indicated they had previously donated blood, whereas one had received a blood transfusion. Of the four donors, two indicated they had given blood in Bolivia and one in Brazil (the fourth did not specify the location).

Importantly, low awareness is one of numerous barriers impacting the access to diagnosis and treatment for immigrants and other groups afflicted by CD. Awareness can only be understood and addressed in terms of its interrelationship with socioeconomic inequalities, gaps in the public health response to CD (often a function of political decisions impacting public funding and concerning the populations and health issues to be prioritized), and navigation of cultural and linguistic differences. Farmer³³ points out that entrenched global political and economic structures largely shape the disease epidemiology; vulnerable groups who bear the heaviest burden and also have the least access to healthcare resources and the strongest limitations on their agency. Sao Paulo has attracted large numbers of migrants in search of employment; this population faces significant barriers to accessing healthcare³⁴⁻³⁶. Bolivians in Sao Paulo are primarily young, and while most have attained a high school education, their income level remains low. Concentrated in Sao Paulo's garment industry, they often confront difficult living and working conditions^{35,36}, which exacerbate health risks, especially for tuberculosis and other infectious diseases³⁴. Moreover, awareness of CD is also a key concern within the local health system; vector transmission was interrupted in the Sao Paulo State in the late 1960s^{15,37}, and many providers in the SUS are unfamiliar with CD³⁸. While Bolivians are a population at particular risk of CD, systematic screening, even for women during prenatal care, is not widely implemented. In our study, only 5.3% of women received CD screening as part of their prenatal care, which represents a missed opportunity to halt the vertical transmission and prevent a lifelong disease. Furthermore, the bulk of our sample was under the age of 40, and could therefore still benefit, if seropositive, from a timely etiological treatment to prevent future complications

of chronic CD. Such treatment also acts as an effective means of eliminating the vertical transmission^{8,39,40}.

Our study has some limitations. The individuals interviewed were attending the CSEBF, and may not reflect the wider Bolivian community in Sao Paulo or elsewhere in Brazil, in particular those individuals who do not frequently attend healthcare services. The CSEBF has a history of working with the Bolivian community and has developed expertise in the health needs of this population, but this could have influenced respondents' perceptions regarding the healthcare access in Brazil. Additionally, we only asked respondents if they knew about Chagas disease and certain aspects of its etiology and symptomology. Our study largely does not assess whether patient concepts of the disease differ from the biomedical model. A prior research in Bolivia suggests people with CD essentially adopt a biomedical understanding of the disease, but may use alternative approaches to treatment, including ethnomedical remedies⁴¹. Another potential bias is that because our sample consisted of migrants predominantly under the age of 40, it might be healthier than the population at large and potentially less concerned about CD, whose chronic symptoms are usually observed in individuals older than 30⁴².

Our study, possibly the first to assess CD knowledge among a transnational migrant population in Brazil, indicates that the awareness of CD in this at-risk group is low. This, in combination with limited discussion of CD in education campaigns or mass media, serves to suppress patient-driven demand for screening, underscoring the importance of both, more intensive CD awareness initiatives directed toward this population, and proactive screening initiated by providers. Simply "getting to know" about CD does not always translate into increased demand for testing and treatment, as people in endemic areas with difficult access to healthcare have often adapted a strategy of normalizing or naturalizing the existence of CD as a coping strategy^{27,43,44}. Therefore, awareness campaigns need to be linked with a broader framework of actions to improve healthcare access for people at risk of CD.

Recent policy developments in Brazil reinforce the need to develop strong communication strategies to raise awareness of CD in vulnerable groups⁴⁵. A Clinical Protocol for Diagnosis and Treatment of CD, approved in late 2018⁴⁶, provides a specific framework for screening, diagnosing and treating patients, and a national policy of official reporting of chronic CD cases, enacted in early 2020, should serve to reinforce epidemiological surveillance and follow-up of patients. Our study also suggests that familiarity with the vector or with the disease (when it affects relatives) are important drivers of CD awareness within this sample. Education campaigns to improve

awareness of CD, which are culturally and linguistically tailored to the Bolivian population of Sao Paulo, should be accompanied by intensified training and capacitation of primary care personnel at facilities which see large numbers of Bolivian patients.

Diagnosis of CD can be emotionally devastating and may entail stigmatization or anxiety, which can actually discourage patients from seeking testing. Ideally, healthcare for CD should use a holistic approach, addressing not only the disease, but its social determinants and emotional consequences³⁹. Finally, care should be taken to heighten awareness in a way that does not create an unfavorable image or contribute to stigmatization of Bolivians and/or immigrants.

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AUTHORS' CONTRIBUTIONS

Conception and design: MASY, RAS, DMVW, RML, EJAL, NCJ; data analyses: RAS, EJAL CF; data interpretation: DMVW, MASY, RAS, CF; drafting and revision of the manuscript for important intellectual content: RAS, DMVW, CF, MASY; final approval: MASY, RAS, DMVW, RML, EJAL, NCJ.

CONFLICT OF INTERESTS

The authors declare no conflict of interests.

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