


# BMJ Open Knowledge, behaviour and attitudes towards Chagas disease among the Bolivian migrant population living in Japan: a cross-sectional study

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## ABSTRACT

**Objectives** This study aimed to investigate the knowledge, behaviour and attitudes towards Chagas disease (CD) among Latin American migrants in Japan and to evaluate the effectiveness of an educational activity (EA) in increasing knowledge of CD.

**Design** A cross-sectional, mixed-methods study employing a preknowledge and postknowledge test and focus group discussion, conducted from March 2018 to June 2018.

**Participants** Seventy-two participants were included, all born in Bolivia and residents in four Japanese cities. Fifty-nine of them participated in the EA.

**Interventions** The EA comprised showing three videos about CD and a group discussion covering different dimensions of CD and was evaluated with questionnaires to analyse the knowledge of the participants before and after.

**Results** Seventy-two participants were enrolled, predominantly from highly endemic CD areas of Bolivia. Though most participants were familiar with vector-borne transmission, epidemiology and symptomatology of CD, the baseline knowledge of CD was low. Less than 10% of them had been tested prior for CD. The dominant factors associated with better knowledge were living in Japan for more than 10 years (OR=8.42; 95% CI 1.56 to 48.62) and previously testing for CD (OR=11.32; 95% CI 1.52 to 105.9). The EA significantly improved the CD knowledge of the participants (p value <0.0001; 95% CI 2.32 to 3.84). The participants associated the term 'Chagas' mostly with fear and concern. The level of stigmatisation was low, in contrast to the results of other studies. The barriers encountered in care-seeking behaviour were language, the migration process and difficulties to access the healthcare system.

**Conclusion** EA with an integrative approach is useful to increase the knowledge of CD within the Bolivian migrant population living in Japan. The activity brings the possibility to explore not only the level of knowledge but also to reveal experiences and to understand the needs of the people at risk. Considering them as actors towards healthcare solutions could lead to better outcomes for the success of future policies and interventions aimed to decrease the global burden.

## Strengths and limitations of this study

- Most of the participants were not previously tested for Chagas disease, thus providing a snapshot of the knowledge, conceptions and representations of the disease which were not strongly biased or impacted by previous contact with the healthcare system.
- The questionnaires used in this study were mostly based on previous studies and were not independently evaluated.
- The study does not measure the sustained effect of the educational activity on knowledge over the time.

## INTRODUCTION

It has been more than 100 years since the discovery of Chagas disease (CD) and although the estimated number of infected people has fallen, almost 6–7 million people are affected worldwide.<sup>1–3</sup> Just 1% of the affected people can access diagnosis and treatment.<sup>4</sup> Each year, 39 000 new cases occur, of which 9000 result from congenital transmission.<sup>1</sup> In Latin America (LA), CD is one of the tropical diseases with the highest burden, measured as over 800 000 disability-adjusted life-years. The economic impact is about 685 million dollars annually in health expenditure worldwide.<sup>5</sup>

Bolivia is the country with the highest prevalence of CD worldwide (6.1%).<sup>1</sup> It has the highest incidence rate of vectorial transmission (0,0810 per 100 habitants over 1 year) and accounts for 92.6% of all new cases in the Southern Cone Subregion.<sup>1</sup> During the last few decades, political, economic and social factors accounted for a major migration of Bolivians into urban areas as well as overseas. This urbanisation plays an important role in the change in the paradigm of CD.<sup>6</sup>

Nowadays, the disease silently persists among population of migrants living in the



USA, Europe and Western Pacific region.<sup>7</sup> Japan with nearly 300 000 migrants from LA countries is one of the leading countries for migration from LA.<sup>8</sup> Brazilian (74%), Peruvian (18%) and Bolivian (2%) populations represent the majority of the Latin American migrants living in Japan.<sup>5</sup> In Japan, there are estimated 3000 cases of CD.<sup>7</sup> Blood transfusion control is the only measure implemented to limit CD in Japan.<sup>9</sup> There is an important gap in epidemiological data, with most of the affected population undiagnosed.<sup>10</sup>

CD detection is difficult in non-endemic countries because it is an emerging disease, and health personnel's lack awareness of its silent course. Moreover, the migrant population is confronted with multiple barriers to access the healthcare system. The migrant population is disadvantaged compared with the native citizens of the host country; specifically, the process of care-seeking behaviour can be impeded by language, lack of adaptability of the healthcare system and prioritisation of their migratory goals. Currently, less than 10% of the people affected by CD are diagnosed in non-endemic countries.<sup>2 4 11</sup> Studies suggest that lack of knowledge of the people at risk strongly influences their care-seeking behaviour.<sup>12–16</sup>

It is important that the population at risk of contracting CD has the necessary knowledge to combat it through their daily activities. However, to have better outcomes in knowledge improvement, it is necessary to incorporate underlying population beliefs and conceptions with scientific knowledge.<sup>12</sup> The conceptions of those affected are the result of their history, environment, cultural context, reality and interactions between these elements. The emergence and persistence of CD are associated with sociocultural factors,<sup>13</sup> and thus understanding the prior conceptions of a target group should become the starting point of any educational projects.<sup>14</sup>

Educational activities (EAs) to improve disease knowledge should involve an integrative approach and consider the affected people as main actors where all dimensions of CD are incorporated. Involving the experience of people affected can be an important tool for developing programmes with better outcomes. One example of an integrative approach where CD is considered in epidemiological, biomedical, political and sociocultural aspects is an activity presented by the group Consejo Nacional de Investigaciones Científicas y Técnicas (CONICET) 'Hablamos de Chagas' (Let's talk about Chagas).<sup>17</sup> To our knowledge, there is no other study that analyses the improvement in knowledge of CD after these EAs.

The primary objectives of our study are to reveal current knowledge and attitudes towards CD in the LA migrant population living in Japan, to analyse the factors associated with better knowledge and to evaluate the effectiveness of an EA in increasing the knowledge of CD. The secondary objective is to identify possible strategies to overcome the existing barriers for the migrant population to access care.

## METHODS

### Study design

This cross-sectional study involved both quantitative and qualitative methods and was conducted following the Strengthening the Reporting of Observational Studies in Epidemiology guidelines as presented in the online supplementary table S1.

The quantitative part was based on two questionnaires administered pre (first questionnaire) and post (second questionnaire) an EA where CD was covered in an integrative approach.

More than half of the questions were based on two studies, one conducted in the USA to assess the awareness among the LA migrant population living in Los Angeles<sup>15</sup> and the other in Geneva, Switzerland.<sup>18</sup>

The qualitative part was conducted in the format of four focus group discussions (FGDs). It was included in an EA based on a workshop proposed in the book 'Hablamos de Chagas' by the CONICET group 'Taller I: Construcción colectiva del caleidoscopio' (Collective kaleidoscope construction). The EA considers CD from an integrative approach where the superposition of different experiences and skills creates a complex and complete image about CD. In this activity, the intervention of a moderator is minimum, and the participants serve as the main actors.

We modified the video originally proposed by the CONICET group and replaced the video, 'CHAGAS. Reconocer miradas, sumar voces, acortar distancias' ('CHAGAS. Recognize looks, add voices, shorten distances'), with three videos of Juana and Mateo.<sup>19</sup> The videos were 'Salud y Enfermedad' (health and disease), 'Embarazo' (pregnancy) and 'Ciudad' (city), chosen to adapt the information to the necessities of the migrant population living in a non-endemic country. These videos illustrate a case of CD in an urban context, a case of congenital transmission of CD and an interview with a medical doctor. The content of the videos is related to the indeterminate form; the organs affected in the symptomatic patients and the transmission routes: mother-to-child, blood transfusion and vectorial. The videos also describe the importance of screening in pregnant women and the efficacy of treatment in children.

### Variables (quantitative part)

The first questionnaire (Q1) contained 33 questions, 10 of which relate to knowledge of the disease, including CD demographic information, risk factors and the risk of transmission, also included were questions related to the level of vigilance and policies for CD in their previous resident areas. Questions regarding barriers to access the healthcare system in Japan and stigmatisation were also included.

The second questionnaire (Q2) included only the questions related to knowledge in Q1.

### Study areas and study population

The study was held from March to June of 2018 in private rooms of multipurpose buildings in four cities in central

Japan: Oizumi (Gunma prefecture), Hadano (Kanagawa prefecture), Nagoya (Aichi prefecture) and Suzuka (Mie prefecture). The cities were selected for their large LA migrant population. The locations and dates were arranged according to the planned itinerant consulate of the Bolivian embassy. We sought 100 participants. Inclusion criteria were LA migrant adult population (18 years old or more) who were residing in Japan.

### Recruitment method

The research team and the Bolivian embassy worked with community leaders to recruit the participants. The activity was also informed by radio, magazine and social network media directed to the Latin American migrant population living in Japan. During the day of the activity, the people who came to the itinerant consulate of the Bolivian embassy for other issues also were invited to participate.

### Data collection

After signing the written informed consent and enrolment, the Q1 was administered to the participant. The EA was then conducted with a total duration of approximately 1 hour. Immediately following the EA, the Q2 was administered for the participants. All communication with the participants was conducted in Spanish by a medical doctor from Spain.

The EA started with the FGD. The discussion started with the question ‘What is the first thing that came to your mind when you hear the word “Chagas?”’. The participants wrote their answer on a piece of paper, which would be pasted in a mural divided into the four dimensions of CD: biomedical, epidemiological, political and socio-cultural. The videos were then projected and a recap of ideas from the videos was conducted.<sup>19</sup> The goal of the EA was to construct a kaleidoscopic image of the multidimensionality of CD. The activity finalised with a discussion about barriers that the migrant population found in Japan and their suggestions to overcome these problems.

### Data analysis

The total questionnaire score was 14.5 (online supplementary table S2). To analyse the quantitative data, cross-tabulation was conducted with Stata V.2015 for questions not related to knowledge. For questions related to knowledge, we calculated the total points and divided into two groups (high knowledge and low knowledge) using a Bloom’s cut-off point of 60% (corresponding to a score of 8.7).<sup>20–22</sup> To analyse the knowledge of the participants, we used R Core Team (2018) R. Univariable analysis by Chi-test or Fisher-exact test was conducted to identify factors associated with higher knowledge.<sup>23</sup> The factors with p values less than 0.2 were included in the multivariable analysis based on previous studies.<sup>24 25</sup> Paired t-test was conducted to analyse whether there was an improvement after the EA by comparing the total points of people before and after. Associations were estimated with ORs

and their respective 95% CIs. Results were considered statistically significant if the two-tailed p value was <0.05.

Qualitative research was conducted in a total of 59 participants. The FGD was audio-recorded and transcribed verbatim in Spanish in Word and then analysed and coded using a grounded theory approach. It was translated into English for publication.

ArcGIS Online was used to create the map that illustrates the cities of residence of the participants and copyright permission was obtained from Esri, Japan.

### Ethical considerations

Informed written consent was obtained from all participants. All data collected during the quantitative and qualitative parts were anonymised by code number and privacy was protected.

### Patient and public involvement

Patients and the public were not involved in the design or conduct of the study.

## RESULTS

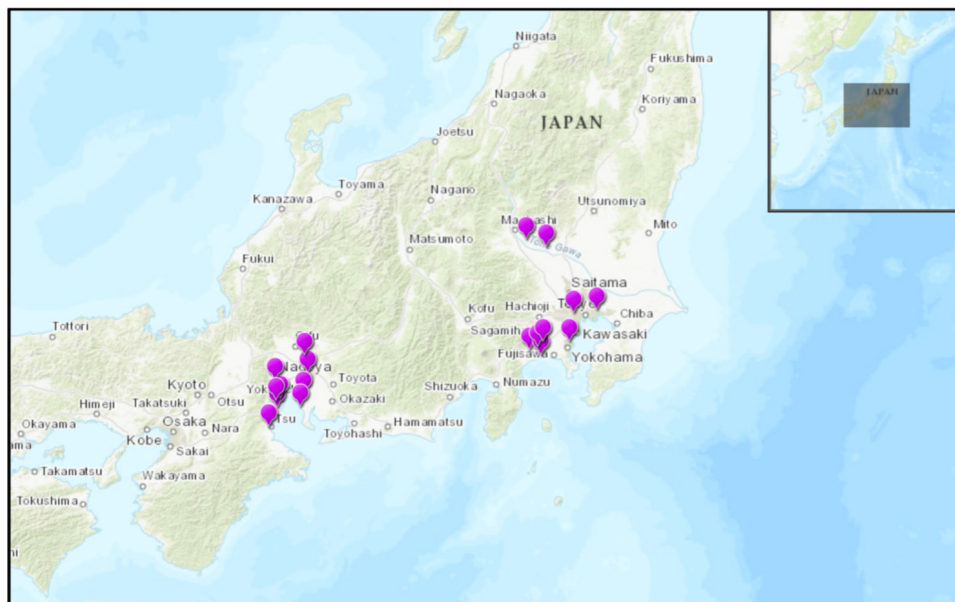
### Description of the participants

A total of 72 participants from Bolivia were recruited into the study. Participant ages ranged between 20 and 70 years old, with a mean of 45±11.9 years old, and 55% were women. Almost 95% of the women had children. Most of the participants had secondary education (high school education; 62.5%). More than half of the responders (57.1%) came from areas endemic for CD. The most common department of origin was Santa Cruz (50%), followed by Beni (34%). Most of the participants have been living in Japan for more than 10 years (80.3%). Mie prefecture and Kanagawa prefecture had the highest number of participants (figure 1). In addition, 37% of the participants came from other prefectures including Gunma (13.5%), Aichi (13.5%), Tokyo (8.4%) and Ishikawa (1.6%) (table 1).

### Characteristics of the participants related to risk factors of CD

Most of the responders had heard about CD (82.8%), although just four responders (6%) had been tested for CD before, two of which were positive for the causative agent, *Trypanosoma cruzi*. More than half of the responders came from rural areas (62.2%) and a third of the responders had lived in an adobe house (33.3%). Most of the responders did not recognise the triatomine insect vector (64.7%). Of the people who had seen the insect (n=25), 11 of them saw it at home.

In our study, 23.8% of the responders had at least one family member infected by CD. Just two participants referred that their mothers were infected by CD. Regarding blood transmission, 10.4% of the responders received a blood transfusion in LA countries. Nearly 30% of the participants had donated blood previously (figure 2).



**Figure 1** Cities of residence in Japan. ArcGIS online was used to illustrate the cities of residence of the participants. Copyright permission was obtained from Esri, Japan.

### Stigmatisation of the disease

Most of the responders reported that they would like to be tested (94.2%) and treated (97%) for CD if they had the opportunity. Nearly 30% reported being worried if another person knew that they had CD (figure 2).

### Access in terms of coverage and satisfaction to the healthcare system

Most of the responders reported to have health insurance in Japan (87.8%) and, in general, they were satisfied with the care received in health centres (95.3%; figure 2).

### Knowledge of the participants

#### Baseline knowledge of the participants on CD

The total knowledge score was low with an average of  $6.8 \pm 2.7$ . However, the participants could identify important points of CD, specifically, epidemiology, transmission, symptomatology and treatment. Most of the participants identified CD as a problem in LA countries (85%) as well as in Japan (70.3%). Nearly 80% of them believed that CD was a severe disease (78.4%; figure 2).

Most responders knew that CD was endemic in LA (27/61; 44.2%), slightly more than a second group that identified it worldwide (23/61; 37.7%). Nearly two-thirds of the responders were familiar with vector-borne transmission (36/60; 60%). Most of the women (27/38; 71%) considered that the disease can affect their children if they are infected, whereas fewer (13/33; 39.3%) understood vertical transmission as a possible route. Low knowledge about oral transmission was reported between the participants. No misidentification of person to person routes, such as hugs and kisses, was answered by the responders.

Most responders identified cardiac disease as a symptom of CD (50/55; 90.9%). Cardiac disease alone was the most popular answer as part of the symptoms of CD with 58.1%

of the answers (32/55), followed by heart and digestive problems (16/55; 29%).

Two-thirds of the responders considered a positive result in Chagas test to be interpreted as sickness (37/57, 64.9%), and just 21% (12/57) of the responders differentiated between infection and disease. Most responders (50/64, 78.1%) knew that there was pharmacological treatment for CD and 69.3% (34/49) knew that it is not useful in severe cases.

### Factors associated with better knowledge

The univariable analysis showed that participants who had been living longer in Japan and had been tested for CD had significantly higher knowledge ( $p$  value  $\leq 0.2$ ) (table 2). Our multivariable logistic regression analysis indicated that longer living in Japan was independently associated with higher knowledge. Participants who lived in Japan for more than 10 years were eight times ( $OR=8.40$ , 95% CI 1.57 to 47.82) more likely to be knowledgeable on CD than those who lived for a shorter time (table 2).

### Knowledge improvement after EA

Fifty-nine participants (out of 72) took part in the EA (82%), while 3 people left the activity earlier and 10 arrived late to the venue. Among 59 participants who joined in the EA, 50 (84.7%) of them performed Q1 and Q2 (figure 3).

Our paired sample t-test indicated an improvement in total knowledge of participants on CD (mean knowledge score: postactivities  $9.8 \pm 2.6$  vs preactivities  $6.8 \pm 2.6$ ,  $p$  value  $< 0.0001$ ; 95% CI 2.35 to 3.89). Before the EA, only 20.8% of the participants ( $n=15$ ) exhibited a high knowledge, whereas 45.8% of the participants ( $n=33$ ) had high knowledge after the EA. As a result, more than 80% of the

**Table 1** Sociodemographic characteristics of the population

	n/N	(%)
<b>Age</b>		
<40	18/61	(29.5)
≥40	43/61	(70.4)
<b>Sex</b>		
Male	31/69	(45)
Female	38/69	(55)
Female with children	36/38	(94.7)
<b>Education</b>		
Primary	3/64	(4.7)
Secondary	40/64	(62.5)
University	21/64	(32.8)
<b>Department of origin</b>		
Santa Cruz	28/56	(50)
Beni	19/56	(34)
La Paz	4/56	(7.1)
Pando	5/56	(8.9)
<b>Endemicity in place of origin</b>		
High	28/56	(50)
Low	4/56	(7.1)
Non-endemic	24/56	(42.9)
<b>Duration living in Japan</b>		
<5 years	9/66	(13.6)
5–10 years	4/66	(6.1)
>10 years	53/66	(80.3)
<b>Resident prefectures in Japan</b>		
Gunma	8/59	(13.5)
Mie	23/59	(38.9)
Kanagawa	14/59	(23.7)
Aichi	8/59	(13.5)
Tokyo	5/59	(8.4)
Ishikawa	1/59	(1.6)
People who have donated blood	19/68	(27.9)

responders improved their score after the activity (n=41, 83.6%). Just 2% (n=1) had a worse score after the EA and 14.2% (n=7) did not improve. Among the group that improved, the increase in points ranged from 0.5 to 10. Among the group that decreased their score, the average reduction in points was 2.5.

## Qualitative analysis

### Baseline knowledge

The responders were familiar with the disease and had prior knowledge about the epidemiology, vector-borne transmission and cardiac problems (online supplementary table S3). Most of the participants were familiar with the word ‘Chagas’. They located the disease in their

countries and related it to the endemic areas. None was familiar with the flow of the disease into non-endemic areas (PC1 and 2).

Vector-borne transmission was most frequently identified as the only way of transmission. People who recognised blood transfusion as a route of transmission associated it with previous experience in which a relative had been diagnosed when going to donate blood. Other routes were not considered before they were given relevant information (PC3 and 4). The participants mostly identified cardiac problems as a disease symptom, and digestive problems were less recognised (PC5–7).

What is the first word that came to your mind when I say ‘Chagas’?

The most frequent answer was related to feelings of fears, worries and memories. Fear was linked to CD for many participants. They expressed having it for lack of information, for association with disease severity, and the belief of a fast death. Other participants manifested a fear of being ill out of their country of origin (PC8 and 9).

That gives me fear (...) because you do not know, when you are not in your country. Something weird, because here is the first time you know. I would be afraid to know. (PC9: woman, group 2)

Concerns were expressed for the transmission of the disease to their relatives. Women expressed important concerns when they knew about the possibility of mother to child transmission (PC10 and 11).

Preoccupation to find out if I have the disease and my children. (PC10: woman, group 2)

The memories expressed during the FGD were related to experienced cases of CD and linked to feelings as fear or pain (PC12 and 13). Participants also associated with the vector and related with non-specific symptoms such as pains or heart problems (PC14 and 15).

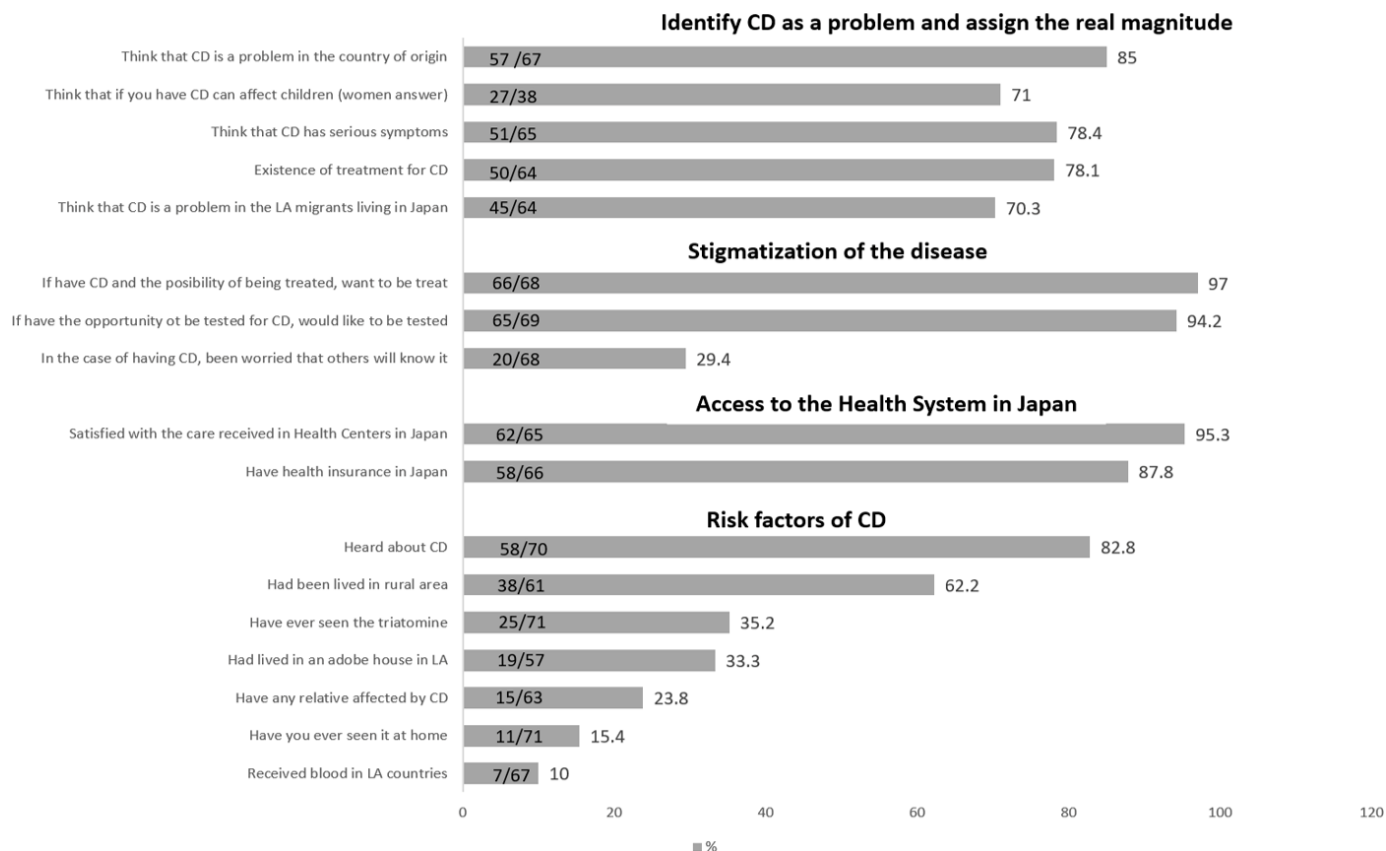
I just do not know. I wrote, “Pain”, right? so I also lived in Bolivia and at the East [of the country, an endemic area of CD]. Maybe I have (...) (PC14: woman, group 3)

## Attitudes

### Normalisation/Naturalisation

The participants represented a situation of normalisation/naturalisation of CD and considered it a part of a normal life (PC16). The possibility of being sick or having some difficulties in daily life after the age of 50 was considered normal (PC17).

And in Santa Cruz that I knew, when I came, they said ah! the Chagas [tone of nonchalance]. For me it was always the bite of the vinchuca and no more. For me it was that. But now, in detail, I see the concern, which is not unnn, it's not something simple. (PC16: woman, group 1)



**Figure 2** Answers of the participants related to risk factors of CD, stigmatisation of CD, access to the healthcare system, identification of CD as a problem and assigning the magnitude of the problem. CD, Chagas disease; LA, Latin America.

### Stigmatisation

Stigmatisation of the disease was not widely reported in the FGD. With the exception of two participants, they denied the existence of stigmas, after being asked if they think that stigmas exist around CD or what they thought about the fact that some communities express stigma of CD. A participant expressed a situation of stigmatisation because of misbeliefs related to the route of transmission (PC18 and 19).

### Resignation

Commentaries of resignation in front of a situation where death is inescapable had been described during FGD (PC20).

### Barriers

Although most participants were satisfied with the healthcare system in Japan, they identified several barriers. The language was described as a main barrier, and they reported about the accuracy of the official translations and lack of communication intimacy (PC21). The participants expressed problems in access to health services, mainly for lack of information about the healthcare system and language barrier (P22). Their prioritisation of other issues hindered them from seeking care, such as problems related to their migratory goals and their job as the main support in a foreign country (PC23–25).

### Participants' proposals to overcome the observed problems

Most participants considered that the spread of information in Spanish and by different media was an intervention that could improve the situation of CD in Japan. The internet was proposed as the most effective way to transmit information. It was suggested to distribute brochures or hold activities like the one held in this study; in venues where LA migrant population tends to gather, such as churches, Latino meetings or healthcare centres (PC26).

They also expressed the importance to distribute educational information between health sector personnel (PC27).

The participants highlighted the importance of having background information before receiving a Chagas test. They remarked on the need for accessible diagnosis, treatment and systems of care (PC28 and 29).

## DISCUSSION

To our knowledge, no study has analysed the effect of EA on CD knowledge for participants in a non-endemic country. In this study, the EA included the participants as the main actors, sharing their knowledge and experiences, and this approach could have a substantial impact on knowledge improvement.

The factor that had a significant influence on acquiring a high knowledge was having lived in Japan for more

**Table 2** Univariable and multivariable analyses of factors associated with high knowledge of participants of CD

	Univariable analysis				Multivariable analysis			
	Low knowledge	High knowledge	OR	CI	P value	OR	CI	P value
Age (mean:45±SD:11.9)	45.8±11.3	45.3±12.17	0.99	-7.02 to 8.04	0.8			
Sex								
Male	6	25	1.11	Reference	0.8			
Female	8	30		0.34 to 3.63				
Education								
1	0	3		Reference				
2	8	32	1.83	0.09 to 38.46				
3	5	16	2.33	0.10 to 52.65				
Place of origin								
HE	5	23		Reference	0.93			
LE	3	1	11.48	1.097 to 375.52				
NE	5	19	1.21	0.28 to 5.13				
Time in Japan								
<5	4	5		Reference	<b>0.17</b>			
5–10	1	3	0.47	0.01 to 6.07				
>10	9	44	0.26	0.06 to 1.29		8.40	1.57 to 47.82	0.0124
	Yes	No	Yes	No				
Lived in rural area	10	3	28	20	0.42	0.10 to 1.72	0.33	
Lived in adobe house	5	8	14	20	1.12	0.30 to 4.15	1	
Lived in other country	3	11	8	43	0.68	0.15 to 3.01	0.69	
Chagas test before	2	10	2	52	0.19	0.02 to 1.52	<b>0.14</b>	8.40 0.86 to 84.661 0.0544
Treatment received	1	13	1	52	0.25	0.15 to 4.27	0.37	
Heard about CD	13	1	45	11	0.31	0.04 to 2.67	0.43	
Recognise the triatomine	6	9	19	37	0.77	0.24 to 2.49	0.76	
Seen the triatomine at home	3	12	8	48	0.67	0.15 to 2.90	0.68	
Donated blood	4	11	15	38	1.09	0.30 to 3.95	1	
History of blood transfusion	2	13	5	47	0.69	0.12 to 3.98	0.64	

Bold values denote only two factors with p value less than 0.2 (longer living in Japan and previous Chagas diagnostic test) were included in the multivariable analysis, based on previous studies.<sup>24 25</sup>

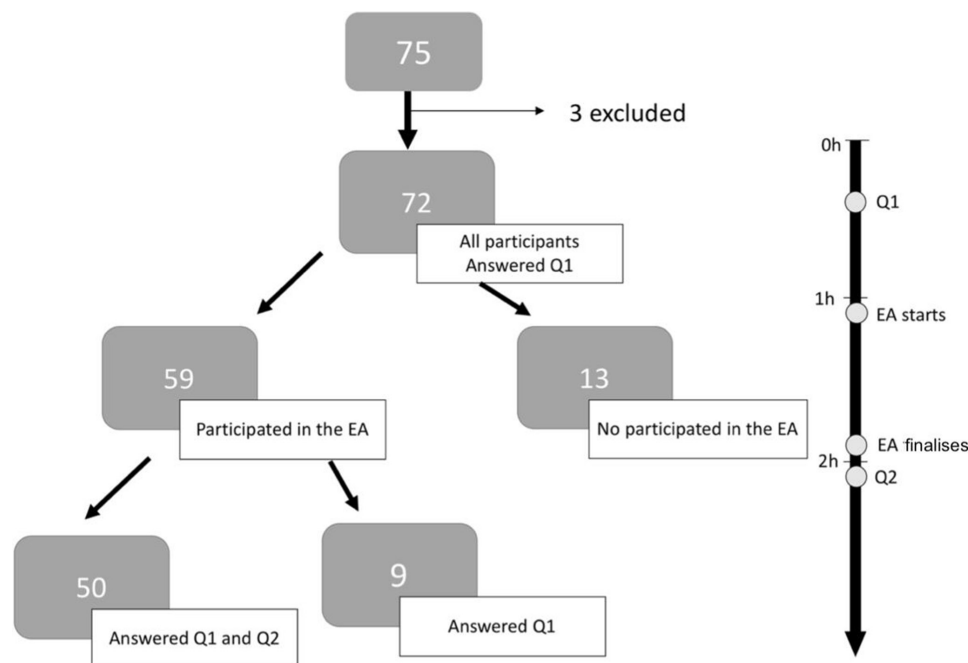
1, primary education; 2, secondary education/high school education; 3, university; <5, less than 5 years living in Japan; >10, more than 10 years living in Japan; 5–10, 5 to 10 years living in Japan; CD, Chagas disease; HE, highly endemic area; LE, low endemic area; NE, non-endemic area.

than 10 years. This can be explained by changes in vector control over the last decade, prior the level of infestation of Bolivian houses was higher, and thus their occupants were more familiar with CD. Today Bolivia shows greater urbanisation,<sup>26 27</sup> and this trend may have affected awareness of a disease associated with traditional ruralism.<sup>6 13</sup>

Similar to the result of other studies about CD knowledge by LA migrants, the baseline knowledge of our participants was low.<sup>15 28–30</sup> The results of our study were similar to the Blasco-Hernandez *et al*'s study conducted in Madrid with a group of Bolivian women.<sup>31</sup> During the quantitative and qualitative evaluations, the participants showed knowledge about aspects of CD such as vector habitat, epidemiology, vector-borne transmission and

cardiac problems. However, knowledge of other areas was low.

Mother-to-child transmission knowledge was reported by the women of our study. As in previous studies, oral transmission was rarely considered for the participants.<sup>32</sup> Endemic countries have focused on the reduction of vector infestation; however, there is still a lack of programmes to control other routes of transmission, and this absence can influence the awareness of the population. Knowledge about symptoms and the meaning of a positive diagnosis were not achieved, as in the study of Blasco-Hernandez *et al*.<sup>31</sup> The symptoms described for the participants in the qualitative part are represented for unspecific pain, as in previous studies.<sup>32</sup> This may be



**Figure 3** Flowchart of the participants included in the EA and participants who answered Q1 and Q2. EA, educational activity; Q1, questionnaire 1; Q2, questionnaire 2.

influenced by the non-specificity of the CD clinic. The course of the disease is not well known, and it is irremediably associated with high mortality. This leads to feelings of fears, worries and memories of the affected relatives. As described, this emotional burden led to the attitudes of resignation when confronted by the irremediable. The long asymptomatic period and a late diagnosis contributed to maintain this representation.

Despite prior knowledge about the disease, only 6% of the participants had been previously tested for CD. Multiple factors contribute to underdiagnosis such as lack of diagnostic tests available in the local healthcare system or minimal awareness among providers.<sup>33</sup> However, most of the studies explained the low rate of diagnosis by the implication of sociocultural factors on the representation of the disease. The most common factors are the stigmatisation and the normalisation of the disease.<sup>6 13 17 28 31 34–36</sup> Even though most of the population at risk of CD are highly stigmatised, our participants showed a low level of stigmatisation. One of the possible explanations is that most of them migrated at roughly 30 years of age. They remembered cases of CD of older relatives but not proximal generation. This might make them less familiar with the ability of CD in their sociocultural context to provoke a feeling of invulnerability. Another possible explanation is that most of our participants were not diagnosed with CD, in contrast with other studies that show a high level of stigmatisation.<sup>31</sup> As in most of the populations analysed for CD, our participants showed a high level of normalisation/naturalisation of the disease influenced by the unspecificity of symptoms and lack of impact on daily events in the active age. In Bolivia, in the last decade, the shortened

life expectancy influenced the low social relevance of CD, although these data are changing.<sup>37</sup>

This study was conducted in Japan, where the literature on CD is limited to case reports and one study of prevalence in the Brazilian population.<sup>38</sup> This is the first study to analyse the population at risk of CD in Japan. However, the participants represent solely Bolivians and not larger LA. Santa Cruz, a high endemic area, was the most common area of origin. This result was expected because of the migration of Japanese citizens to Bolivia after the World War II and relocation to Santa Cruz where two Japanese colonies were founded, 'Okinawa Colony' and 'San Juan of Yapacaní Colony'. We did not ask participants if they were decedents. However, the descendants of Japanese emigrants might represent an important proportion of LA migrants in Japan because of their advantage for long-term visas.

As a migrant population, several barriers were identified in the process of seeking care in Japan, including language barriers, migratory processes and difficulties to access the healthcare system. These results are similar to the barriers experienced by the LA migrant population in other non-endemic countries.<sup>13 35 39 40</sup>

The lack of adaptability of the host healthcare system to facilitate access by the migrant population is constant.<sup>16 28 35 40 41</sup> Our study showed that most of the participants had not known where to seek care for CD testing, and this is perhaps due to the organisation of the healthcare system in Japan, where the role of the family doctor as a coordinator is uncommon.

Studies conducted in other non-endemic countries noted that the dissemination of CD information was considered an important strategy for improving care



seeking.<sup>30 42</sup> The internet was the most effective way to provide information.

An integrative educational approach is considered excellent for education, allowing visualising a complex and complete image about CD. The understanding of the implications of socialcultural factors described in the care-seeking behaviour of the migrant population is critical for designing policies, control and preventive interventions. The interventions of CD, as the EA presented, should consider the sociocultural factors instead of a traditional specific disease-centred approach.<sup>13</sup>

The strength of our study is that most of the participants had not been tested for CD, thus providing a snapshot of the knowledge, conceptions and representations of the disease which was not strongly biased or impacted by previous contact with the healthcare system. Limitations of the study include no evaluation of knowledge over the time and no description of the impact of knowledge on care-seeking behaviour. Further, our study is focused on the Bolivian population, which might not be representative of the larger LA migrant population living in Japan. Due to a possible recall bias, the effect on knowledge over the time needs to be evaluated in future research.

Finally, the EA described here needs to be evaluated as a possible EA for health personnel in non-endemic countries. To date, no study has analysed the knowledge of Japanese doctors about CD; noting here that this knowledge is expected to be low, similar to the status of most non-endemic countries.<sup>43</sup>

## CONCLUSION

In conclusion, EAs with an integrative approach are useful to increase the short-term knowledge of CD in the Bolivian population living in Japan. This activity brings the possibility to explore not only the knowledge but also the characteristics, experiences, opinions and needs of those at risk. This information is essential to guide the efforts to improve CD healthcare, by considering the people at risk as part of the improvement and development. This EA has the potential to be applied in different settings. However, the effectiveness of this activity should be evaluated in different geographical areas. We would need to assess the impact of these interventions in the long-term knowledge. Longitudinal research will bring more information on how the knowledge acquired by integral activities influences the care-seeking behaviour in CD.

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