

1 **Knowledge of Chagas disease in Latin American migrant population**
2 **living in Japan and factors associated with knowledge level**

3 **Short title:** Knowledge of Chagas disease of Latin American migrant in Japan

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5 **Inés María Iglesias-Rodríguez¹, Shusaku Mizukami², Dao Huy Manh², Tieu Minh**

6 **Thuan³, Hugo Alberto Justiniano⁴, Sachio Miura⁵, George Ito⁶, Nguyen Tien**

7 **Huy^{7,8,9,*}, Kenji Hirayama^{1,2,*}**

8

9 ¹Department of Global Health. School of Tropical Medicine and Global Health.

10 Nagasaki University, 1-12-4 Sakamoto, Nagasaki 852-8523, Japan

11 ²Department of Immunogenetics, Institute of Tropical Medicine (NEKKEN), Leading

12 Graduate School Program, and Graduate School of Biomedical Sciences, Nagasaki

13 University, 1-12-4 Sakamoto, Nagasaki 852-8523, Japan

14 ³Faculty of Health Sciences, McMaster University, Hamilton, Ontario, L8S 4L8,

15 Canada

16 ⁴Embassy of the Plurinational State of Bolivia in Japan. Tokyo, 106-0031, Japan

17 ⁵NPO organization. MAIKEN. Motohachiojimachi. Hachioji-shi, Tokyo, 193-0826,

18 Japan

19 ⁶Consulate General of Brazil in Japan. Ichigo Gotanda Building, 2F Higashi Gotanda 1-

20 13-12, Shinagawa-ku, 141-0022, Tokyo

21 ⁷Evidence Based Medicine Research Group, Ton Duc Thang University, Ho Chi Minh

22 City, 70000, Vietnam

23 ⁸Faculty of Applied Sciences, Ton Duc Thang University, Ho Chi Minh City, 70000,

24 Vietnam

25 ⁹Department of Clinical Product Development, Institute of Tropical Medicine

26 (NEKKEN), School of Tropical Medicine and Global Health, Nagasaki University,

27 Nagasaki 852-8523, Japan

28 *Corresponding author: Kenji Hirayama (E-Mail: hiraken@nagasaki-u.ac.jp,

29 Department of Immunogenetics, Institute of Tropical Medicine (NEKKEN), Leading

30 Graduate School Program, and Graduate School of Biomedical Sciences, Nagasaki

31 University, 1-12-4 Sakamoto, Nagasaki 852-8523, Japan) or Nguyen Tien Huy, (E-

32 Mail: nguyentienhuy@tdtu.edu.vn, Evidence Based Medicine Research Group &

33 Faculty of Applied Sciences, Ton Duc Thang University, Ho Chi Minh City, Vietnam)

34

35 **Emails:**

36 **IMIR:** inesmiglesias@hotmail.com

37 **SM:** mizukami@nagasaki-u.ac.jp (ORCID: 0000-0002-7722-4884)

38 **DHM:** daohuymanh@gmail.com (ORCID: 0000-0003-3874-5051)

39 **TMT:** tieut@mcmaster.ca (ORCID: 0000-0003-4907-664X)

40 **HJ:** justiniano@ebja.jp

41 **SM:** miurask@gmail.com

42 **GI:** georgehenrique@hotmail.com

43 **NTH:** nguyentienhuy@tdtu.edu.vn (ORCID: 0000-0002-9543-9440)

44 **KH:** hiraken@nagasaki-u.ac.jp (ORCID: 0000-0001-9467-1777)

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46

47 **Abstract**

48 **Background**

49 Chagas disease (CD), typically confined to the Latin America (LA) region, is emerging
50 as a global health problem. In Japan, as in the rest of world, the under-diagnose rate of
51 CD is alarmingly high. Various studies have highlighted the importance of informed
52 knowledge in the seeking behavior. Educational integrative activities, with
53 consideration for socio-cultural factors, can help increase the knowledge of the
54 participants. There has been no studies that analyze the difference in knowledge, before
55 and after these educational activities. This study aimed to qualitatively and
56 quantitatively investigate the knowledge, behavior and attitude toward CD among LA
57 migrants in Japan and to evaluate the effectiveness of the community educational
58 activity in increasing knowledge of CD.

59 **Methodology**

60 This cross-sectional study involved two questionnaires to analyze the knowledge of the
61 LA migrant participants before and after the community activity (CA) in four cities in
62 Japan (Oizumi, Suzuka, Hadano, and Nagoya).

63 **Principal Findings**

64 A total of 75 participants were enrolled, predominantly Bolivians from hyperendemic
65 areas. The baseline knowledge of CD was low. However, most of them were familiar
66 with the disease although less than 10% of them had been tested for CD before. Living
67 in Japan for more than 10 years and previously being tested for CD were the factors
68 associated with better knowledge. The conducted CA significantly improved the
69 knowledge of the participants. They associated the term “Chagas” mostly with fear and

70 concern. In contrast to other studies, the level of stigmatization was low. The barriers in
71 care seeking behavior were language, migration process and difficulties to access to the
72 healthcare system.

73 **Conclusion**

74 Educational activities with integrative approach are useful to increase knowledge of
75 CD. The activity brings the possibility to explore not only the level of knowledge, but
76 also to reveal the experience and to understand the needs of the people at risk.

77 **Author Summary**

78 Though the incident rate of Chagas disease (CD) has fallen, more than 7 million people
79 are affected worldwide. The CD prevalence is under-estimated because just 1% of these
80 affected people can access to the diagnosis and treatment. This situation is maintaining
81 mainly for the lack of implication of socio-cultural factors in the interventions to
82 decrease the burden of the disease. Educational activities with integral approach are
83 useful to increase the knowledge of the people at risk. People that have being tested for
84 CD before or living in Japan for more than 10 years have better knowledge about the
85 disease, suggesting the importance of knowledge in the seeking behavior. The authors
86 recommend the implementation of educational activities with integral approach as a
87 strategy to improves the knowledge of Chagas disease among Latin America migrants
88 in Japan.

89 **Introduction**

90 It has been more than 100 years since the discovery of Chagas disease (CD) and although
91 the number of incident rate has fallen, more than 7 million people are affected worldwide.
92 The prevalence is under-estimated because just 1% of these affected people can access to
93 the diagnosis and treatment [1]. Each year 39,000 new cases occur of which 9,000 results
94 from congenital transmission [2]. In Latin America (LA), CD presents as one of the
95 tropical disease with the highest burden, which is measured in 806,170 disability-adjusted
96 life-years (DALYs). The economic impact is about 627 million dollars in health
97 expenditure worldwide [3].

98 As a result of increasing migration in the last few years, the disease silently
99 spreads into the United States, Europe and the Western Pacific region [4]. Japan ranks
100 third in the world for migrant population from LA. Brazilian, Peruvian and Bolivian
101 population represent the majority of the Latin American migrants living in Japan. In
102 Japan, there is an estimate of 3000 cases of CD. Nowadays, blood transfusion control
103 is implemented as the only one measure to control CD in Japan [5]. There is an
104 important gap in epidemiological data and cases reports, with most of the population
105 affected undiagnosed [6]

106 The fact that CD is an emerging disease in non-endemic countries, along with
107 the lack of awareness of the health personnel and its silent course, makes it difficult
108 for detection. In addition to this challenging situation, migrant population are exposed
109 to many barriers to access to the health system.

110 The migrant population has a disadvantageous situation compared with the native
111 citizens of the of the host country. Language, lack of adaptability of the health system
112 and prioritization of their migratory goals in the process of care seeking behavior are

113 described as main barriers. Currently less than 10% of the people affected by CD are
114 diagnosed in non-endemic countries [1,7,8]. Some studies pointed it out that the lack
115 of knowledge of the people at risk have strong influence in the care seeking behavior.

116 It is important for the population at risk of contracting CD to have the necessary
117 knowledge to be able to combat it through their daily activities. However, to have
118 better outcomes, this knowledge should not be presented as information provided by
119 the scientific community. Such knowledge should be incorporated with the population
120 beliefs and conceptions [9]. Conceptions are the knowledge that each one must explain
121 and situate themselves in their environment. These are result of their history, their
122 environment, their cultural context, their reality and the interactions between all these
123 elements. Thus, the conceptions of who learns should become the starting point of any
124 educational project [10]. Furthermore, we know that the emergence and persistence of
125 CD associated with socio-cultural factors [11] . These are the reasons why educational
126 activities to improve the knowledge should involve an integrative approach and
127 consider the affected people as main actors. However, most of the interventions do not
128 combine all clinical, environmental, sociocultural aspects together. Incorporate the
129 experience of people affected can be an important tool for developing program with
130 better outcomes. An activity presented by the group Conicet “Hablamos de Chagas”
131 is an example of integrative approach where Chagas is considered in all aspects
132 (epidemiological, biomedical, political and sociocultural) [12]. To our knowledge
133 there is no study that analyze the improvement in knowledge of CD after these
134 educational activities.

135 The primary objectives of our study are to reveal the current knowledge and attitudes
136 towards CD in LA migrant population living in Japan; to analyse the factors associated

137 with better knowledge and to evaluate the effectiveness of a community activity in
138 increasing the knowledge of CD. The secondary objective is to identify possible
139 strategies to overcome existing barriers for the migrant population to access care.

140

141 **Methods**

142 **Study design**

143 This cross-sectional study involved both quantitative and qualitative methods. The
144 quantitative part was based in two questionnaires administered pre (first questionnaire)
145 and post (second questionnaire) an educational activity where CD was covered in an
146 integrative approach.

147 More than half of the questionnaire were based on two previous studies, one
148 conducted in United States to assess the awareness among LA migrant population living
149 in Los Angeles [13] and other in Geneva, Switzerland [14]. The qualitative part was based
150 on one of the educational activities proposed in the book “Hablamos de Chagas” by the
151 Conicet group “Taller I: Construcción colectiva del caleidoscopio”. We decided to
152 modify the videos proposed originally by Conicet group of this activity. Three of the
153 videos of Juana and Mateo: “Salud y Enfermedad”, “Pregnancy” and “Ciudad” were
154 chosen to adapt to the necessities of the migrant population living in non-endemic country
155 [12].

156 **Study areas and study population**

157 The activity was held from March to June of 2018 in four cities in central Japan:
158 Oizumi (Gunma prefecture), Hadano (Kanagawa prefecture), Nagoya (Aichi prefecture)
159 and Suzuka (Mie prefecture). They were selected for the high number of LA migrant
160 population. We sought 100 participants. Inclusion criteria were LA migrant adult
161 population (18 years old or more) who are residing in Japan.

162

163 **Recruitment method**

164 We collaborated with the Bolivian embassy who worked with the leader of the
165 community to recruit the participants. The activity was also informed by different media
166 directed to Latin-American migrant population living in Japan: radio, magazine and
167 social network. During the day of the activity, the people that came to the embassy for
168 other issues were invited to participate.

169 **Data collection**

170 After having signed the written informed consent, the first questionnaire was
171 administered to the participant after enrollment. Then the educational activity was
172 conducted. Finally, the second questionnaire including similar questions to the first
173 questionnaire was given. All the communication and education activities with the
174 participants were conducted in Spanish by a native speaker.

175 The discussion of the educative activity starts with the question “What is the first
176 thing that came to your mind when you hear the word “Chagas”?”. The participants wrote
177 what came in their mind in a piece of paper. It would be pasted in a mural divided in the
178 four dimensions of CD: biomedical, epidemiological, political and socio-cultural.
179 Constructing a kaleidoscopic image of the multidimensionality of CD helps discuss about
180 the problematic in a focal group discussion (FGD) format. Then, some videos of Juana
181 and Mateo was projected and recap of ideas from the videos was conducted [15]. The
182 activity followed with a discussion about barriers that migrant population found in Japan
183 and their suggestion to overcome these problems.

184 **Variables**

185 The first questionnaire contained 33 questions, 10 of them related to knowledge in the
186 disease. The first questionnaire included questions with regards to demographic

187 information: age, sex, education level, country and city of origin and place of residence.
188 There were questions related to the risk factors of CD: age, living in rural area, living in
189 adobe house, hearing about CD, having a family member who has CD, knowledge of the
190 vector, the risk of being infected by blood transfusion and any information for blood
191 transfusion in LA countries. In addition, there were question related to the risk of
192 transmission: risk of congenital and blood transfusion transmission and risk during the
193 time living in Japan. There were question related to the level of vigilance and policies for
194 CD, in their previous resident areas: living in another country, previously tested for CD
195 and previously treated. There were questions related to knowledge about CD: the
196 magnitude of the problem, severity, routes of transmission, existence of treatment,
197 epidemiology of the disease, symptomatology, difference between disease and positive
198 result of CD diagnostic test and efficacy of the treatment. Questions regarding barriers to
199 access the Health system in Japan and stigmatization were also included.

200 **Data analysis**

201 The total punctuation was 14.5. To analyse the quantitative data, cross tabulation was
202 conducted for questions not related to knowledge with Stata 2015. For the ones related to
203 knowledge, we calculated the total point of the first questionnaire and divided in 2 groups
204 with a cut off in 60%. To analyse the knowledge of the participants we use R core Team
205 (2018) R. Bivariate analysis was conducted for factors between two groups. The factors
206 with p value less than 0.2 were include in the multivariable analysis. Paired t-test was
207 conducted to analyse if there was improvement after the CA by comparing the total point
208 of people before and after. The FGD was transcribed verbatim in Spanish and translated
209 into English after for publication. Transcription were grouped into categories and by
210 groups to analyse. ArcGIS online was used to create the map that illustrate the Cities of
211 residence of the participants.

212

213 **Ethic statements**

214 This study received the approval of the ethics committee of Institute of Tropical
215 Medicine (NEKKEN) of Nagasaki University with the approval number 18031188.
216 Informed written consent was obtained from all participants. All the data collected
217 during the quantitative and qualitative part was anonymized by code number and
218 privacy was protected.

219

220 **Results**

221 **Description of the participants**

222 A total of 75 participants were recruited into the study. The participants age ranged
223 between 20 and 70 years old, with a mean of 44.5 ± 13.2 years old. There were slightly
224 more women than men, 54,1% and 45.8%, respectively. Almost 95% of the women had
225 children. Most of the participants had secondary education (62.1%). The Bolivian
226 migrant population represents 95.5% of the participants. More than half of the
227 responders (57,6%) came from endemic areas for CD. The most common city of origin
228 was Santa Cruz in Bolivia (44%), followed by Riberalta (22%). Most of the participants
229 have been living in Japan for more than 10 years (81.1%). Mie prefecture and
230 Kanagawa prefecture had the highest number of participants (Fig. 1). In addition, 9.6%
231 of the participants came from other prefectures including Tokyo (n=8,8 %) and
232 Ishikawa (1.6%) (Table 1).

233

234 **Table 1. Socio- demographic characteristic of the population**

	Mean (standard deviation)/number (%)
Age (n=64)	44.5 (13.2)
Sex	
- Male (n=33)	33 (45.8)
- Female (n=39)	39 (54.1)
Education	
- Primary	3 (4.5)
- Secondary	41 (62.1)
- Universitary	22 (33.3)
Country of origin	
- Bolivia	65 (95.5)
- Argentina	1 (1.4)
- Brazil	1 (1.4)
- Japan	1 (1.4)
City of origin	
- Hyperendemic	30 (50.8)
- Low endemic	4 (6.7)
- No endemic	25 (42.3)
Duration living in Japan	
- 5 years	9 (13.0)
- 5-10 years	4 (5.8)
- 10 years	56 (81.1)
Resident prefectures in Japan	

- Gunma	8 (12.9)
- Mie	25 (40.3)
- Kanagawa	14 (22.5)
- Aichi	9 (14.5)
- Tokyo	5 (8.0)
- Ishikawa	1 (1.6)
Having lived in other countries different to the country of origin.	
Non-endemic	
- Spain	4 (36.0)
- France	1 (9.1)
- USA	1 (9.1)
Latin America countries	
- Bolivia	2 (18.1)
- Brazil	1 (9.1)
- Argentina	1 (9.1)
- Brazil & Spain	1 (9.1)
Female with children	36 (94.74)
People who have donated blood	20 (28.2)

235

236 **Fig 1. Cities of residence in Japan.** ArcGIS online was used to illustrate the Cities of
 237 residence of the participants.

238

239

240 **Characteristic of the participants related with risk factors of Chagas disease**

241 Most of the responders had heard about CD (82.2%). However, just five responders
242 (7.2%) had been tested for Chagas before. More than half of the responders came from
243 rural areas (60.3%). Nearly a third of the responders have lived in an adobe house
244 (31.67%). Most of the responders did not recognize the vector (63,5%). Out of the
245 people that saw the insect (n=27), 12 of them saw it at home.

246 In our study, 22.7% of the responders had at least one family members infected by CD.
247 Just two participants referred that their mothers were infected by CD. Regarding blood
248 transmission, 10% of the responders received blood transfusion in LA countries. Nearly
249 30% of the participants had donated blood previously (Fig. 2).

250

251 **Stigmatization of the disease**

252 Most of the responders would like to be tested (94.4%) and treated (97.2%) for CD, if
253 they had the opportunity. Nearly 30% would be worried if another person knew that
254 they had CD (Fig 2).

255

256 **Fig 2. Answers of the participants related with risk factors of CD, stigmatization of**
257 **CD, access to the Health System, identification of Chagas Disease as a problem and**
258 **assign the real magnitude of the problem.**

259 CD, Chagas Disease; LA, Latin America

260

261 **Access in terms of coverage and satisfaction to the health system.**

262 Most of the responders reported to have health insurance in Japan (88.6%) and in
263 general, they were satisfied with the care received in health centers (95.6%) (Fig. 2).

264

265 **Knowledge of the participants**

266 **Baseline knowledge of the participants on Chagas disease.** Our results showed that
267 the total score of knowledge was low with the average at 6.7 ± 2.5 . However, the
268 participants could identify important points of the disease: epidemiology, transmission,
269 symptomatology and treatment of CD. Most of the participants identified CD as a
270 problem in LA countries (85.7%) and also in Japan (71.6%). Nearly 80% of them
271 believed that CD was a severe disease (79.4%) (Fig. 2).

272 Most of the responders knew that CD was endemic in LA (n=27, 42.2%) with slightly
273 difference in a second group that identified it worldwide (n=25, 39,0%). Nearly two
274 thirds of the responders were familiar with the vector-borne transmission in first place
275 (n=38). Most of the women (n=28, 84.8%) considered that the disease can affect their
276 children if they are infected, just (n=12, 38.2%) of them answered vertical transmission
277 as a possible route. Low knowledge about the oral transmission was reported between
278 the participants. No misidentification of person to person route as hugs and kisses were
279 answered by the responders.

280 A majority of the responders identify cardiac disease as a symptom of CD (n=53,
281 91.4%). Cardiac disease alone was the most popular answer with 58.6% of the answers
282 (n=34). The next most answer was heart and digestive problems, both as part of the
283 symptom of CD (n=17, 29.3%).

284 Two third of the responders considered a positive result to be interpreted as sick
285 (n=40, 66,6%). Just 20% (n=12%) of the responders differentiated between infection
286 and disease. Most of the responders (n=53, 79.1%) knew that there was treatment for
287 CD and 69.2% (n=36) of them know that is not useful in severe cases.

288 **Factors associated with better knowledge.** Bivariable analysis showed that
289 participants who had been living longer in Japan, heard about the disease, and had been
290 tested for Chagas were significantly associated with the higher knowledge (P-value \leq

291 0.2). Our multivariable logistic regression analysis indicated that longer living in Japan
 292 and prior test of Chagas were independently associated with the higher knowledge.
 293 Participants who lived in Japan for more than 10 years were 8 times (OR = 8.42,
 294 95%CI: 1.56-48.62) more likely to be knowledgeable on CD than those who lived for
 295 shorter time. Participants who had been tested for CD were eleven times (OR. 11.32;
 296 95%CI. 1.52-105.9) more likely to be knowledgeable on CD.

297

298 **Table 2. Univariate and multivariate analysis of factors associated with high**
 299 **knowledge of participants on the Chagas disease**

	Univariate analysis					Multivariate logistic regression analysis				
	Low knowledge		High knowledge		p-value	Odds ratio	95% CI	p-value		
Age						0.8 (t-test)				
Sex	MALE	FEMALE	MALE	FEMALE	0.942					
	7	8	26	31						
Education	1	2	3	1	2	3	0.991			
	0	8	6	3	33	16				
Area of origin	HE	LE	NE	HE	LE	NE	0.9168			
	5	3	6	24	1	20				
Time in Japan	<5	5-10	>10	<5	5-10	>10	0.1971	8.42	1.56-48.62	0.0130
	4	1	10	5	3	46				
Lived in rural area	YES	NO	YES	NO	0.3744					
Lived in adobe house	5	9	14	32	0.7495					
Lived in other country	3	12	10	43	1					
Chagas test before	3	10	2	54	0.0429	11.32	1.52-105.9	0.0194		
Treatment received	1	14	1	54	0.3851					
Heard about CD	14	1	46	12	0.2057	2.5	0.35-51.26	0.4258		
Recognize the triatomine	7	9	20	38	0.5631					
Seen the triatomine at home	3	13	9	49	0.7147					

300

301 CD, Chagas Disease; CI, Confident Interval; 1, Primary education; 2, Secondary
 302 education; 3, University; 5, less than 5 years living in Japan; 5-10, 5 to 10 years living
 303 in Japan; 10, more than 10 years living in Japan; HE, Hyperendemic area; LE, low
 304 endemic area; NE: non-endemic area.

305

306 **Knowledge improvement after community activities.** Sixty-one participants (out of
307 75) participated the CA (81.3%), while three people left the activity earlier and 11
308 arrived late to the venue. Among 61 participants participated in the CA, 50 (82%) of
309 them performed the Questionnaire 1 and 2 (Fig. 3).

310

311 **Fig 3. Flow chart of the participants included in Community Activity and**
312 **participants who answered Questionnaire 1 and Questionnaire 2.**

313 Q1, Questionnaire 1; Q2, Questionnaire 2; CA, Community Activity.

314

315 Our paired sample t-test indicated an improvement in total knowledge of participants on
316 CD (mean knowledge score: post-activities 9.8 ± 2.6 vs. pre- activities 6.7 ± 2.5 , P-
317 value < 0.0001 ; 95% CI: 2.32-3.84).

318 Before the community activities, only 32% of the participants (n=16) exhibited a high
319 knowledge, however, 70% of the participants (n=35) had the high knowledge after the
320 CA. As a result, more than 80% of the responders improved their punctuation after the
321 activity (n=43, 86%). Just 2% (n=1) had worse punctuation after the CA and 12% (n=6)
322 did not improved. Among the group that improved, the increase in points ranged from
323 0.5 to 10. Among the group that decreased their punctuation, the average reduction in
324 point was 2.5.

325

326 **Qualitative analysis**

327 **Baseline knowledge.** The responders were familiar with the disease and had prior
328 knowledge about the epidemiology, vector-borne transmission and cardiac problems
329 (S1 Table). Most of the participants were familiar with the word “Chagas”. They
330 located the disease in their countries and their habits related to the high-attitude tropical

331 areas. None was familiar with the flow of the disease into non-endemic areas (PC1 and
332 2).

333 The vector-borne transmission was most frequently identified as the only way of
334 transmission. Some people who recognized blood transfusion as a way of transmission
335 had the experience of a relative that was diagnosed during blood donation. Since they
336 couldn't donate blood, they associated the transmission with blood transfusion. Other
337 routes as mother to child, organ transplantation or oral route were not considered before
338 they were given information about it (PC3-4).

339 The participants identified the symptom of the disease mostly with cardiac
340 problems. Digestive problem was less recognized but also was commented during FGD
341 (PC5-7).

342 **What is the first word that came to your mind when I say “Chagas”?** The most
343 frequent answer was related to the feelings of fears, worries and memories.
344 Fear. The fear was linked to CD for many participants. They expressed to have it for
345 lack of information, for the severity of the disease and the belief fast death. Other
346 participants manifested the fear of being ill out of their country of origin as a migrant
347 (PC8-9).

348 Worries. Concerns were expressed for the transmission of the disease to their relatives.
349 Women expressed more the concern when they learnt about the possibility of mother to
350 child transmission (PC10-11).

351 Memories. The memories expressed during the FGD were related to the recent cases of
352 CD that they experienced and were linked to feelings as fear or pain (PC12-13).
353 They also associated with the vector “vinchuca” and related with symptoms. The
354 symptoms described were non-specific, related with pains or heart problems (PC14-15).

355 **Attitudes**

356 **Normalization.** Most of the participants never had been tested and they did not ask for
357 the diagnosis test of Chagas. They represented a situation of normalization
358 /naturalization of the disease (PC16). The fact of being sick or having some difficulties
359 in the day life after the age of 50 was considered normal by the participants (PC17).

360 **Stigmatization.** During the FGD, the stigmatization of the disease did not become as a
361 topic or commentary. When asked directly if they think that stigmas existed around CD
362 or what they thought about the fact that some communities expressed stigma of
363 CD, they denied the existence of stigmas. However, two participants thought
364 differently. A participant expressed a situation of stigmatization, because of misbeliefs
365 related to the route of transmission (PC18-19).

366 **Resignation.** Commentaries of resignation in front of a situation where death is
367 inescapable had been described during FGD. This participant described the resignation
368 in front a possibility to be infected linked to severe development of illness (PC20).

369 **Barriers**

370 Even most of the participants were satisfied with the health system in Japan.
371 Participants identify barriers related to the language, the cost of healthcare and
372 familiarity with the health system in Japan that may affect the care seeking behavior of
373 the participants. Also, their prioritization of the job as the main tool of support in a
374 foreign country hindered them from getting care (PC21).

375 Language was described as one of the main barriers. They complained about the
376 accuracy of the official translations and lack of intimacy (PC22).

377 They expressed prioritization other issues related with their migratory goals and
378 not related to health if it was not necessary. Keeping the job position was one of the
379 most important priorities (PC23-24).

380 The participants expressed problems in access to the health services. They were
381 asked for more information if they wanted to make the diagnostic test of Chagas. They
382 expressed the need to have the information in Spanish (P25).

383 **Participants proposals to overcome the actual problematic**

384 Most of the participants claimed that more information should be provided. The
385 participants considered that the spread of information in Spanish and by different media
386 was an intervention that could improve the situation of CD in Japan. They proposed
387 using the Internet as the most effective way to transmit information and offered a
388 development of a website in Spanish with translated information. Furthermore, it is
389 suggested to perform distribution of brochures or activities like the one held in our
390 study in venues where LA migrant population tended to gather such as church, Latino
391 meetings or health centers (PC26)

392 They expressed the importance to distribute information not just for people at
393 risk, but also between the health sector personnel (PC27).

394 The participants highlighted the importance to have enough information before
395 having the Chagas test. They remarked the need for accessible diagnosis, treatment and
396 system of care (PC28-29).

397 **Discussion**

398 To our knowledge, no study has analyzed the effect of educational activities in CD
399 related to the knowledge of the participants. The fact that this activity included the
400 participants as the main actors by sharing their knowledge and experiences, could have
401 an important impact on the improvement of knowledge.

402 One of the factors that clearly had a significant influence on acquiring a high
403 knowledge was being tested for CD in the past. People that had been tested before
404 for CD had more information about the disease resulting a change in their care

405 seeking behavior. One study conducted in Spain described that knowledge about the
406 treatment efficacy could influence the decision to get the test of CD [16]. In our
407 study, all participants who had been previously tested for CD were women, except
408 one. This can be influenced by their reproductive role, as it was explained in other
409 studies [17,11]. Living in Japan for more than 10 years also enhanced the knowledge
410 probably due to the decrease of infested houses in the recent years in Bolivia and the
411 urbanization of the population, along with the lack of prevention and care
412 interventions [18,19]. This population migrated more than 10 years ago was more
413 familiar with the vector. The urbanization of the population was proposed as a
414 phenomenon that affected the awareness of the disease for its visualization in an area
415 far from the traditional ruralism [20,11].

416 Similar to the result of other studies about CD knowledge of LA migrants, the baseline
417 knowledge of our participants was low [21-24]. Due to high representation of Bolivian
418 population recruited, results of our study were more similar to Blasco- Hernandez et al.
419 study, conducted in Madrid in a group of Bolivian women [16]. The participants of our
420 study had knowledge of CD including vector habitat, epidemiology, transmission by
421 vector-borne and the cardiac problems associated with CD. The knowledge of blood
422 transfusion transmission was achieved from previous experiences of having a relative
423 diagnosed by CD during blood donation. Low knowledge of mother-to-child
424 transmission was found in the women of our study. Therefore, this area required
425 essential improvement to reduce new cases. Oral transmission was rarely considered as
426 a way of transmission, which was indicated in another study [25]. Endemic countries
427 have focused on reduction of the infestation by the vector; however, there are still lack
428 of programs to control other ways of transmission, which can influence the awareness
429 of the people.

430 Knowledge about symptoms and significance of a positive diagnosis were not achieved
431 as baseline knowledge, as in the study of Blasco-Hernandez [16]. Many participants
432 clarified the symptom as suffering for unspecific pain. The association with pain was
433 also expressed in children in endemic area [25]. This may be influenced by the non-
434 specificity of the CD clinic. The course of the disease is not well-known and it is
435 irremediable associated with high mortality. The main difference with the study of
436 Blasco-Hernandez et al., is that our participants were not CD-diagnosed population.
437 Despite the prior knowledge about the disease, only 7.2% of the participants had been
438 previously tested for CD. Most of the studies explained the low rate of diagnosis by the
439 implication of socio-cultural factors on the representation of the disease. The most
440 common factors are the stigmatization and the normalization of the disease
441 [11,12,16,17, 20,21,26,27].
442 Dissemination of the information about CD was considered one of the most important
443 strategies for improving the seeking for care. It was remarked by other studies
444 conducted in non-endemic countries [24]. As in other studies, religious meetings, social
445 association and graphic materials was proposed for disseminate information. However,
446 it was proposed that the Internet was the most effective way to provide the information.
447 Most of the population at risk of CD are highly stigmatized and have experienced
448 discrimination. However, our participants showed a low level of stigmatization. One of
449 the possible explanations is that most of them migrated at the age of 30 years-old. They
450 remembered cases of CD of old relatives, but not proximal generation. This might make
451 them less familiar to the reality of CD in their socio-cultural context and feel less
452 vulnerable. Another possible explanation is that most of our participants were not
453 diagnosed with CD, in contrast with other studies that shows a high level of
454 stigmatization [28]. As in most of the populations analyzed for CD, our participants

455 showed a high level of normalization/naturalization of the disease. The un-specificity of
456 symptoms and the lack of impact on day-to-day activities as described in many studies
457 contributes to the normalization of the disease. Also, similar to the study by Blasco-
458 Hernandez et al, the participants of our study were normalized to be ill at the age of 50.
459 The low social-relevance of CD was influenced by the low expected age of life in
460 Bolivia in the last decade. However, this data is changing nowadays [28].

461 The representation of the disease for the participants were similar to the one
462 described previous studies. They presented a disease caused by the “vinchuca”, an
463 insect that affects the heart and leads in a high mortality. The reactions and associations
464 with CD after this representation, were predominated by feelings of fears, worries, and
465 memories of affected relatives. As previously described, this emotional burden led to
466 the attitudes of resignation until the irremediable in some participants. The long period
467 asymptomatic and a late diagnosis contributed to the maintenance of this representation.
468 This study was conducted in Japan, a country that has an important gap in
469 epidemiological data for CD. The literature of CD in Japan is limited to cases report and
470 one study of prevalence in the Brazilian population [29]. This is the first study to
471 analyze the LA migrant population living in Japan, as a population at risk of CD.
472 However, most of participants were Bolivians. This representation could cause a
473 recruitment bias, since the Embassy of Bolivia was the only embassy to be part of the
474 study. Santa Cruz was the most popular area of origin. This was expected because the
475 migration in the Japanese citizens to Bolivia after the second world war II. They were
476 installed in the district of Santa Cruz, a high endemic area. Two Japanese colonies near
477 the city of Santa Cruz were founded in the 50s, “Okinawa Colony” and “San Juan of
478 Yapacaní Colony”.

479 As migrant population, several barriers were identified in the process of seeking
480 for health care in Japan. Preconceptions conceived in the country of origin may act as a
481 barrier in the host country. The barriers found in Japan included language barrier,
482 migratory process, and difficulties to access the health care system. These results are
483 similar to the barriers experienced by the LA migrant population in other non-endemic
484 countries [30, 11, 17, 31].

485 Barriers of accessing to the health system for migrants are highly documented
486 in different studies. The lack of adaptability to facilitate the access of migrant
487 population is constant in host countries [17, 21, 31, 32, 33]. In our study, most of the
488 participants had not known where to seek for care in case of desire to be tested for
489 CD. This can be responsible by the organization of the Health System in Japan,
490 where the role of family doctor is uncommon, which adds difficulties for the people
491 at risk to find the integrative care for a disease such as Chagas.

492 On the other hand, there has still not been study conducted in Japan to
493 analyze the knowledge of Japanese doctors about tropical diseases. However, this
494 knowledge is expected to be low as happening in most of the non-endemic countries
495 [34].

496 The understanding of the implications of social and cultural factors described
497 in care seeking behavior of the migrant population is a key for designing policies,
498 control and preventive interventions. These interventions should avoid the traditional
499 specific disease-centered due to the low impact on the population [11].

500 One of the main strengths of this study is the transnational approach. Most of
501 the participants were not tested for CD before. It provides a naïve vision of the
502 knowledge, conceptions and representations of the disease in the population at risk.

503 The study was conducted in Spanish by a native speaker to ensure the cultural
504 competence and the feasibility of the data in the qualitative part.

505 We did not identify the most successful gathering method. However, most of
506 the participants coming to the venue had some other issues to resolve with the
507 Embassy of Bolivia. It leads in a low representation of other LA countries with high
508 representation in Japan such as Brazil, Peru and Argentina. This can lead to a
509 possible recruitment bias. Also, the activities were held on Saturday, which is a
510 working day in Japan. The questionnaires used in this study were mostly based on
511 previous studies. However, it has not been validated. This activity demonstrates an
512 increase of knowledge. However, it could have a memory bias and we did not
513 identify the impact of the impact of knowledge on care seeking behavior. The
514 population that did not participate in the community activity were much younger
515 than the participated ones. Improvement should be designed to reach to young
516 population. A virtual format in networks, a more actual way of communication or
517 approaches in venues which are more familiar to teenagers such as schools or
518 activity clubs should be considered.

519 In conclusion, educational activities with integral approach are useful to
520 increase the knowledge of CD. This activity brings the possibility to explore not only
521 the knowledge but also the characteristic, experiences, opinions and needs of those at
522 risk. This information is essential in order to guide the efforts to improve the CD
523 problem, considering the people at risk as part of the improvement and development.
524 However, the effectiveness of this activity should be evaluated in different
525 geographical areas. Longitudinal research will bring more information on how the

526 knowledge acquired by integral activities influences the seeking behaviour in Chagas
527 disease.

528 **Supporting information**

529 **S1 Table. Qualitative analysis commentaries** Each participants commentaries (PC)
530 was numbered as PC1-28 shown in the supplement table (S1).

531

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540

541

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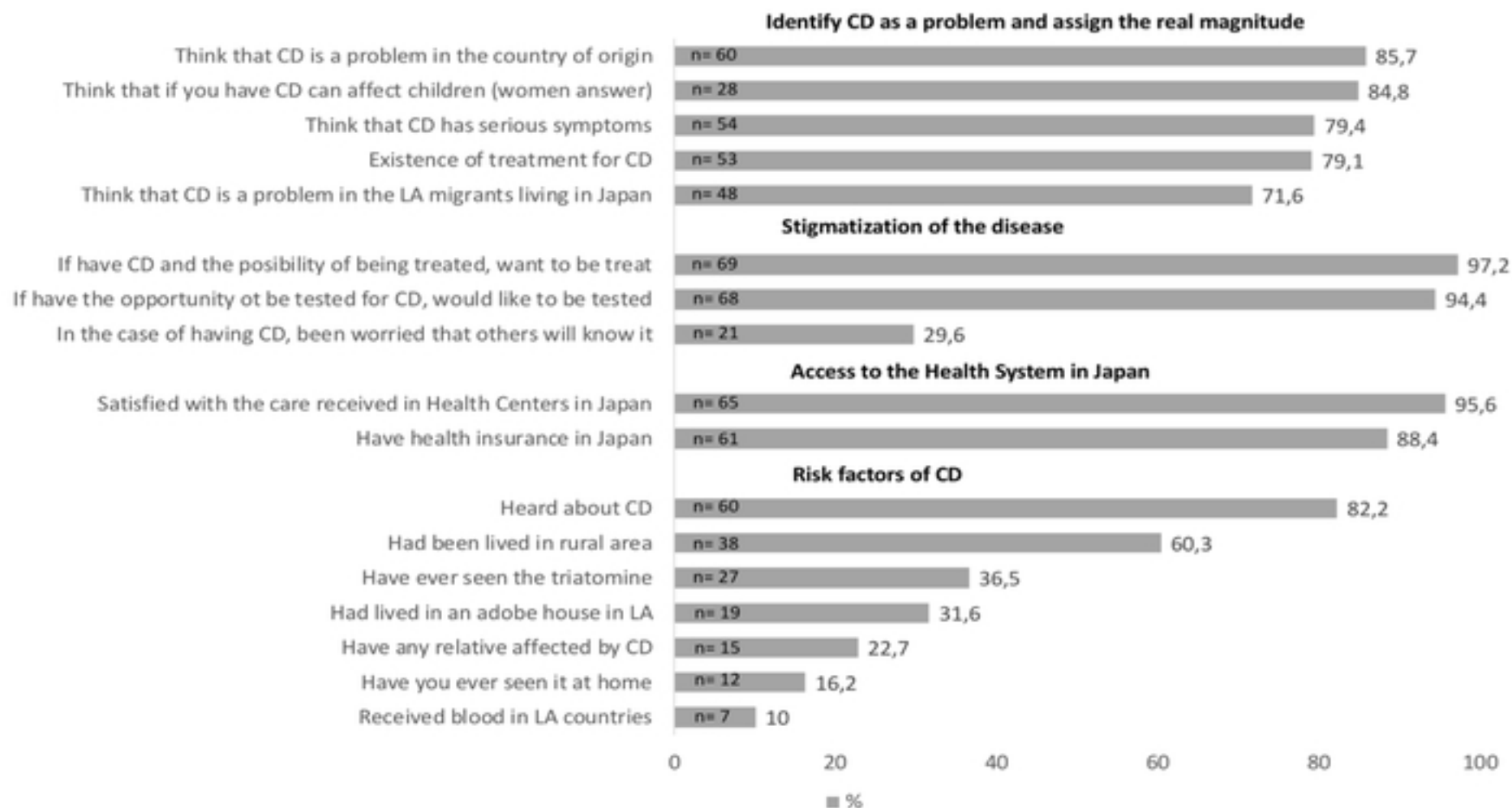


Fig 3. Answers of the participants related with risk factors of CD, stigmatization of CD, access to the Health System, identification of Chagas Disease as a problem and assign the real magnitude of the problem.

CD, Chagas Disease; LA, Latin America

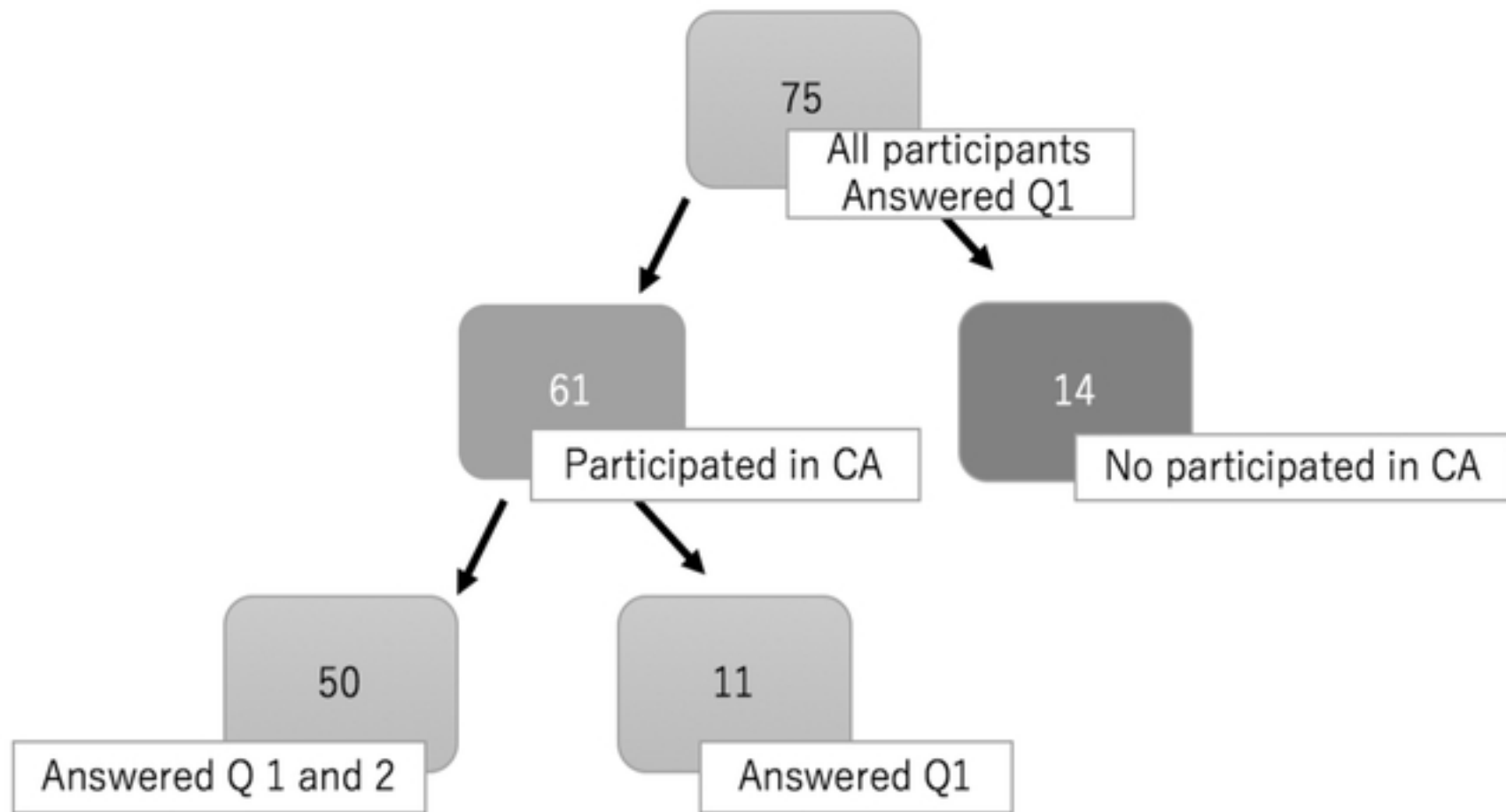


Fig 5. Flow chart of the participants included in Community Activity and participants who answered Questionnaire 1 and Questionnaire 2.

Q1, Questionnaire 1; Q2, Questionnaire 2; CA, Community Activity.

