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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Abstract

Background

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

Methodology

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

Principal Findings

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

Introduction

89

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 priorization of their migratory goals in the process of care seeking behavior are

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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

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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

Ethic statements

This study received the approval of the ethics committee of Institute of Tropical

Medicine (NEKKEN) of Nagasaki University with the approval number 18031188.

Informed written consent was obtained from all participants. All the data collected

during the quantitative and qualitative part was anonymized by code number and

privacy was protected.

219

Results

Description of the participants

A total of 75 participants were recruited into the study. The participants age ranged

between 20 and 70 years old, with a mean of 44.5 ± 13.2 years old. There were slightly

more women than men, 54,1% and 45.8%, respectively. Almost 95% of the women had

children. Most of the participants had secondary education (62.1%). The Bolivian

migrant population represents 95.5% of the participants. More than half of the

responders (57,6%) came from endemic areas for CD. The most common city of origin

was Santa Cruz in Bolivia (44%), followed by Riberalta (22%). Most of the participants

have been living in Japan for more than 10 years (81.1%). Mie prefecture and

Kanagawa prefecture had the highest number of participants (Fig. 1). In addition, 9.6%

of the participants came from other prefectures including Tokyo (n=8,8 %) and

Ishikawa (1.6%) (Table 1).

233

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	

1

- 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 diseas**e. 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 $\leq$

1

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 7	FEMALE 8	MALE 26	FEMALE 31	0.942			
Education	1 0	2 8	3 6	1 3	2 33	3 16	0.991			
Area of origin	HE 5	LE 3	NE 6	HE 24	LE 1	NE 20	0.9168			
Time in Japan	<5 4	5-10 1	>10 10	<5 5	5-10 3	>10 46	0.1971	>10 8.42	>10 1.56-48.62	>10 0.0130
Lived in rural area	YES 10	NO 4	YES 28	NO 21	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.

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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

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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**

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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).

1

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

1

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.

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

Acknowledgements

540

541

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Identify CD as a problem and assign the real magnitude

- Think that CD is a problem in the country of origin — n= 60 — 85,7
- Think that if you have CD can affect children (women answer) — n= 28 — 84,8
- Think that CD has serious symptoms — n= 54 — 79,4
- Existence of treatment for CD — n= 53 — 79,1
- Think that CD is a problem in the LA migrants living in Japan — n= 48 — 71,6

Stigmatization of the disease

- If have CD and the posibility of being treated, want to be treat — n= 69 — 97,2
- If have the opportunity ot be tested for CD, would like to be tested — n= 68 — 94,4
- In the case of having CD, been worried that others will know it — n= 21 — 29,6

Access to the Health System in Japan

- Satisfied with the care received in Health Centers in Japan — n= 65 — 95,6
- Have health insurance in Japan — n= 61 — 88,4

Risk factors of CD

- Heard about CD — n= 60 — 82,2
- Had been lived in rural area — n= 38 — 60,3
- Have ever seen the triatomine — n= 27 — 36,5
- Had lived in an adobe house in LA — n= 19 — 31,6
- Have any relative affected by CD — n= 15 — 22,7
- Have you ever seen it at home — n= 12 — 16,2
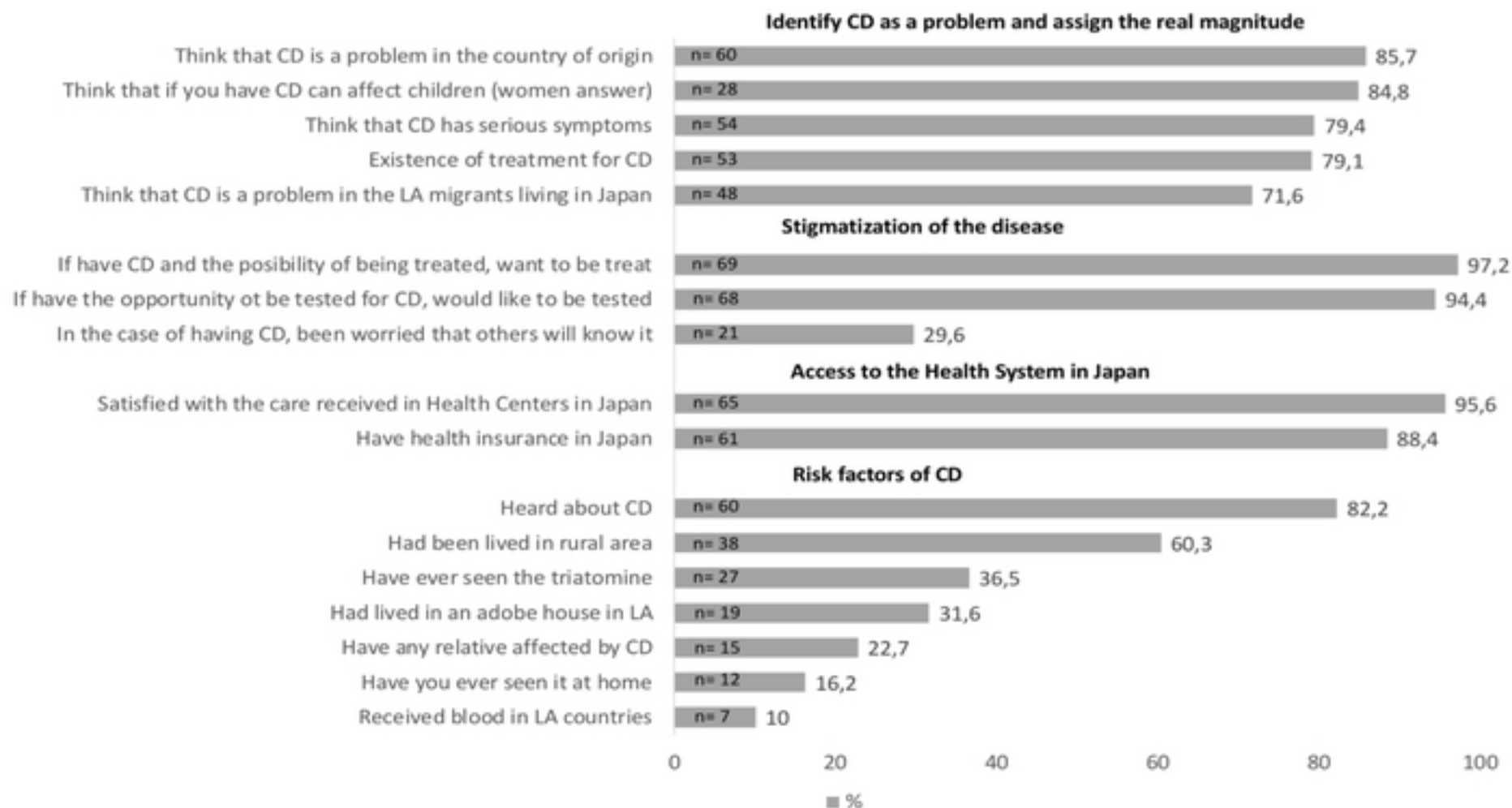- Received blood in LA countries — n= 7 — 10

■ %

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.
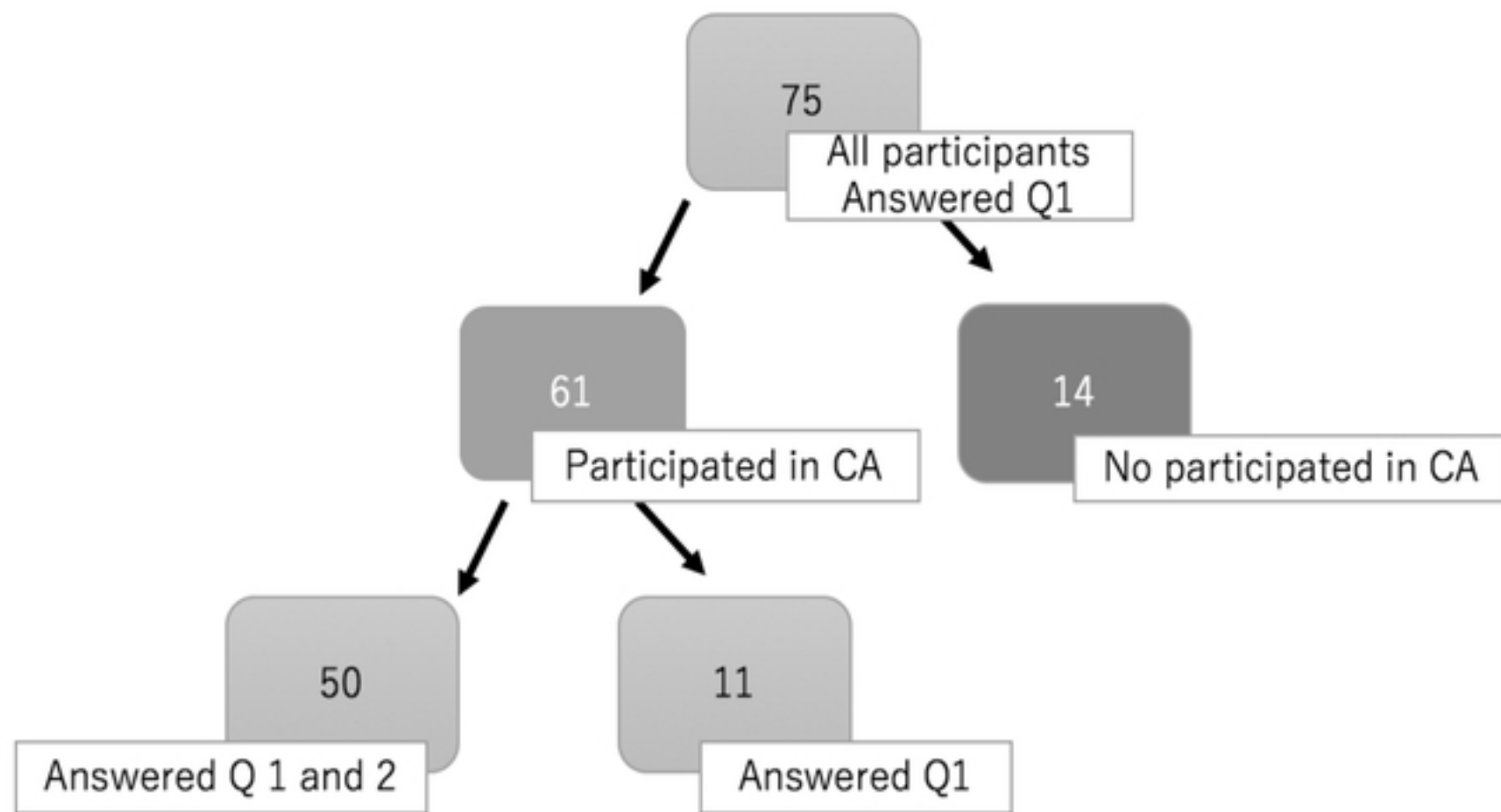
CD, Chagas Disease; LA, Latin America

Figure 2

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.

Figure 3

Figure 1