Targeted screening and health education for Chagas disease tailored to at-risk migrants in Spain, 2007 to 2010

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Chagas disease is endemic in Latin America, but migration has expanded the disease's geographical limits. Spain is the most affected country in Europe. From 2007, a specific Chagas disease programme aimed at at-risk migrants was developed in three Spanish cities (Madrid, Jerez de la Frontera and Alicante). The objectives of the programme were to increase participants' knowledge and decrease their fears about the disease and to encourage them to undergo screening for *Trypanosoma cruzi* infection. The programme was specially focused on migrants from Bolivia and Latin American women of childbearing age. Culturally tailored interventions were carried out in non-clinical settings. A total of 276 migrants were screened using a rapid immunochromatographic test following talks on the disease: the results were then later confirmed by standard serological tests. Of those tested, 44 (15.9%) were confirmed cases of Chagas disease. All of them came from Bolivia and a quarter were pregnant women. Of the 44 cases, 31 were later followed up at a specialised Chagas disease clinic. We consider that the adaptation of the programme to the target population's needs and collaboration with non-governmental organisations and migrants' associations contributed to the acceptance of the programme and the increasing number of patients seen at a specialised clinic

Background

Chagas disease, caused by the parasite *Trypanosoma cruzi*, is naturally transmitted in endemic areas by triatomine vectors. Between 8 and 10 million people are estimated to be infected worldwide [1]. In Latin America, where it is endemic, it is the leading cause of cardiomyopathy [1]. After the 1990s, migration from Latin America resulted in an expansion of the disease's geographical limits, to include non-endemic regions, where other modes of transmission (blood and organ donation and mother-to-child transmission) may spread the infection [2].

Among European countries, Spain has the largest number of migrants from Latin America, globally ranking second to the United States [3]. There is evidence that Chagas disease is a serious challenge to public health in European countries, with being Spain the most affected country: in 2009, it was estimated that between 39,985 and 65,258 migrants were infected in Spain, mostly people from Bolivia [4]. After the first cases of the disease due to blood transfusion were diagnosed [5,6], the Spanish Government implemented in 2005 a law regulating the screening of blood donors from endemic areas [7]. To tackle health issues related to *T. cruzi*-infection of migrants, in 2007 the Tropical Medicine Unit at the Ramón y Cajal Hospital in Madrid developed a holistic approach to the management of Chagas disease.

All clinical and non-clinical activities described in this analysis were provided free of charge for every patient. The study was approved by the Ramón y Cajal Hospital's ethics committee.

Chagas disease clinic, Ramón y Cajal Hospital

The Tropical Medicine Unit at the Ramón y Cajal Hospital is a referral centre for tropical diseases and parasitology within the national health system. In addition to providing assistance to migrants [8], a specialised clinic was set up four years ago for the diagnosis, evaluation, follow-up and treatment of patients with Chagas disease, according to a specific protocol [9]. There is also a telephone consultation service, to facilitate patients' access to the doctors even if they cannot attend the clinic. This clinic offers the patients free access to healthcare (without the need for prior referral by a physician) and free-of-charge assistance, including antiparasitic treatment with benznidazole, even if they are not legal residents.

Building up a Chagas disease programme

'*New citizens, new patients*', a culturally tailored community-based health education programme for migrants settled in Spain, was set up in 2007. The programme is run by a multidisciplinary team of physicians, intercultural mediators and a psychologist. A Chagas disease-specific programme was developed, focused primarily on migrants from Bolivia and Latin American women of childbearing age. Its objectives were to improve migrants' knowledge and decrease their fears regarding the disease and to encourage them to undergo screening for *T. cruzi* infection, particularly Latin American women of childbearing age. Staff of non-governmental organisations (NGOs) and migrants' associations promoted talks on the disease to migrants using their services and used a variety of approaches to encourage them to participate, such as placing advertisements on the walls of their premises and talking to people in person or by telephone.

In an initial phase, we obtained background information on migrants' knowledge and beliefs about Chagas disease in order to tailor our planned activities to the target population. First, from May to July 2007, we carried out qualitative research consisting of nine in-depth interviews with migrants in Madrid (seven women and two men) from different areas of Bolivia (Cochabamba, Santa Cruz, Potosí, Oruro and La Paz) [10]. This research revealed a general lack of knowledge about the disease, as well as many fears and false beliefs. In addition, the questionnaires demonstrated a lack of knowledge regarding vertical transmission and symptoms of the disease [10].

Second, in June to November 2007, the data obtained through the qualitiative research were used to design a questionnaire and to tailor educational material to the target population. The questionnaire comprised two sets of questions: one regarding social and demographic characteristics and the other on knowledge and beliefs about the disease.

Delivering information about Chagas disease

Development of a leaflet about Chagas disease

A culturally tailored leaflet about the disease was designed following the qualitative research. Healthcare staff and intercultural mediators participated in its design. It was fully illustrated in order to make it understandable, regardless of the reader's educational level. It was used to illustrate talks that were given and was also distributed during social events. The material is freely available on the Internet, from the Tropical Medicine Unit, Ramón y Cajal Hospital [11]: information about Chagas disease and specialised centres is provided in Spanish, English and French, so that patients, professionals in both health and social fields and the general population may benefit from it.

Talks to groups of migrants in non-clinical settings

From December 2007 to July 2010, we organised talks on Chagas disease to groups of migrants in Madrid, Jerez de la Frontera (Cádiz) and Alicante. These cities were chosen because of the proportion of resident at-risk migrants, the absence of any similar ongoing public health activities related to the disease and the availability of specific consultations for Chagas disease in the cities. A total of 487 migrants from Latin America were informed about Chagas disease through 44 talks, organised in collaboration with five NGOs and migrants' associations in Madrid (42 talks), Jerez de la Frontera, Cádiz (one talk) and Alicante (one talk). Of the participants, 350 (72%) were from Bolivia and 299 (61%) were women) (Table 1). The above-mentioned questionnaire was filled out by participants just before the talks took place. On the basis of the completed questionnaires, the speakers were able to adapt their talk accordingly. The speakers were experienced healthcare workers, who were assisted by a Latin American intercultural mediator (specifically trained for this purpose). The NGOs and migrants' associations involved have considerable influence over Bolivians living in Madrid, Cádiz and Alicante. Another organisation is focused on pregnant women and young mothers at risk of social exclusion. Staff of the organisations encouraged migrants to attend the talks and informed them when they would be held.

Spreading information through the media and social events

General information about Chagas disease and information regarding the ongoing programme was also spread through media (press and radio) targeting migrants and social events for people from Latin

Table 1

Characteristics of participants attending talks on Chagas disease, Spain, December 2007–July 2010 (n=487)

Item	Number (%)[a]
Talks	44
Participants	
Total	**487**
Mean per talk	11
Median age in years (range)	32 (1–68)
Sex	
Female	299 (61.4)
Male	188 (38.6)
Women of childbearing age[b]	257 (52.8)
Country of origin	
Bolivia	350 (71.9)
Ecuador	60 (12.3)
Peru	31 (6.4)
Other	46 (9.4)

[a] Unless otherwise indicated.
[b] 15–45 years.

America, such as the Bolivian National Day celebrations in Madrid in 2008 and 2009. The leaflet was also distributed at such social events. Participants were encouraged to share the information they had received in this kind of event (as well as in the talks) with their friends and relatives.

Targeted screening for *T. cruzi* infection

During 2008 and 2009, a rapid immunochromatographic test (ICT) (Simple Chagas WB, Operon) was offered to participants after the talks. A finger-prick blood sample was also collected on filter paper and sent to the reference laboratory (the National Microbiology Centre) for confirmation, using both indirect fluorescent antibody technique and enzyme-linked immunosorbent assay.

Each screened participant (or parent, if a young child was tested) was informed of the result immediately after the ICT (confidentiality was maintained). Pre- and post-test counselling were provided for all who participated. Once the results of the serological tests from blood samples on filter paper had been obtained, every patient was informed by telephone. Those found to be positive for *T. cruzi* were given an appointment at the specialised clinic. Psychological support was provided if requested.

From May 2008 to December 2009, 276 (78.4%) of participants attending the talks were screened (Table 2). Among the 76 who chose not to be tested, 15 had been previously screened: 13 in Spain and two in Argentina (six were *T. cruzi* positive and nine were negative).

Table 2

Targeted screening for *Trypanosoma cruzi* infection: results and characteristics of participants, Spain, May 2008–December 2009 (n=276)

Item	Number/total (%)[a]
Participants in talks	352
Participants who were tested by rapid immunochromatographic test	276/352 (78.4)
Country of origin of tested participants	
Bolivia	211/276 (76.4)
Ecuador	29/276 (10.5)
Peru	16/276 (5.8)
Other	20/276 (7.2)
Sex of tested participants	
Female	179/276 (64.9)
Male	97 /276 (35.1)
Confirmed positive cases	
Total	**44/276 (15.9)**
From Bolivia	44/44
Pregnant women	11/44
Confirmed *T. cruzi*-positive patients who later attended the Chagas disease clinic	31/44

[a] Where appropriate.

The ICT yielded six false-negative (2.2%) and 13 false-positive (4.7%) results, giving a sensitivity of 86.3%. A total of 44 (15.9%) participants were confirmed cases of Chagas disease. All of them came from Bolivia and 33 were from the regions of Cochabamba and Santa Cruz. The seroprevalence rate in the Bolivians who were screened was 20.9% (44/211). Of the 44 infected with *T. cruzi*, 30 were women of childbearing age. Of these 30 women, 11 were pregnant.

Despite our efforts to contact all infected patients, 13 of the 44 confirmed cases did not attend the Chagas disease clinic. Eight of these patients were contacted by telephone after they failed to attend their scheduled appointment: five of them stated they did not attend because they had been working and the other three had moved to other cities. All eight indicated that they had intended to request an alternative appointment. It was impossible to reach the five remaining patients who did not attend their appointment.

Consultations for Chagas disease

We have seen an increasing number of consultations for Chagas disease since 2003. The most remarkable increase took place between 2007 and 2008, after the Chagas disease programme has been established: twice as many patients were seen in 2008 compared with 2007 (394 versus 191) [10].

Discussion and conclusion

The establishment of Chagas disease – a neglected tropical disease – in countries of the European Union (EU) – represents a challenge for public health. The strength of the Chagas disease-specific programme described here was that it was accessible and tailored to at-risk migrants. This was mainly thanks to the cultural adaptation of all the activities and the adaptation of the team according to the migrants' circumstances and needs. The programme consisted of practical interventions, such as talks, delivering of information and targeted screening, to detect infected people in order to offer them clinical follow-up and treatment. It could also help to avoid new infections. Its weakness is that it relies on the need for financial support and an enthusiastic and dynamic group willing to adapt to the target population's needs. This is especially hard in the current economic crisis. A clinical centre for referral is also necessary.

Our background qualitative research showed a lack of knowledge about vertical transmission of the parasite [10]. Congenital transmission rates up to 7% have been documented in Spain [12]: it is important to note that 30 of the 44 confirmed cases of Chagas described in this study were women of childbearing age.

Migrants from Latin America are often not aware of Chagas disease. Particularly if they are asymptomatic, they may be less likely to access healthcare facilities to request screening [10]. In addition, it may be difficult for them to attend for screening, due to their working

hours. Collaboration with NGOs and migrants' associations enabled us to bring the programme closer to these groups. We also adapted our working hours to meet the needs of the target population.

Probably due to this flexibility, there was a good uptake of the rapid test: more than 78% of participants at the talks were screened. Unfortunately, the ICT used did not prove to be sufficiently sensitive to allow its use as a screening tool without performing an additional test to confirm all results. Consequently, since January 2010 it has no longer been used. However, if a highly sensitive rapid test using peripheral blood samples were available, it would be an ideal method for screening at-risk populations in the EU.

The prevalence of the disease may vary according to the screened population and the recruitment scenario. It is expected that the prevalence among those recruited in primary healthcare or in non-clinical settings will be lower than that found in referral clinical settings [9,13]. Among those screened in our study, the prevalence was 15.9%. This figure is greater than the 12.8% recently found in a Swiss cohort [14], but less than the 23.6% found in another similar study in France following a public information campaign [15]. The mean prevalence of these three series combined was 15.2% (234/1,542), rising to 24.6% (226/918; range: 20.9–26.2%) among participants who were from Bolivia.

According to studies performed in specialised centres, many patients with Chagas disease in Spain are female Bolivian migrants aged 30–40 years who may transmit the parasite vertically or horizontally through blood or organ donation [9]. Although screening for *T. cruzi* is currently performed for at-risk blood and solid organ donors in Spain, there are no official national guidelines for screening pregnant women in the country. In our study, 11 infected pregnant women were detected: all the mothers and their babies were followed up in the clinic. No newborns were infected in this cohort.

Not all patients with confirmed infection later attended the Chagas disease clinic. Their failure to attend may have been due to work-related problems or because they were no longer in Spain (more than 22,000 Bolivians in Spain migrated to another country during 2009) [16]. This highlights the need to increase efforts to adapt the intervention programme to the target population.

As migrants usually do not know about the existence of specialised centres for tropical diseases in the host country, we consider it crucial to provide information about where people should go for diagnosis, follow-up and treatment of Chagas disease. We included this information in the talks, which may have contributed to the high percentage of *T. cruzi*-positive participants who later attended the Chagas disease clinic.

An increasing number of consultations for Chagas disease was observed, which may be a result of the programme. Information on the disease was also delivered through media specifically targeting migrant groups. This initiative had a great impact: for example, a 50% increase in the number of patients attending the Chagas disease clinic was seen (unpublished data) after an article on healthcare resources for the disease in Spain was published in 2008 in a newspaper aimed at people from Latin America [17].

In conclusion, the holistic approach described in this article can help to reduce the public health problem of Chagas disease in non-endemic countries. Moreover, referral of *T. cruzi*-infected people to a specialised clinic with free access, follow-up and treatment should also contribute to it success. Early diagnosis can also lead to an improvement in the quality of life and prognosis of patients with the infection.

Our programme is currently ongoing, delivering information in non-clinical settings and offering management of patients with the disease at a specialised unit. As Spain is the country in Europe most affected by the disease, our programme may not be directly relevant to some European countries. Nevertheless, we believe this programme could help to guide the implementation of prevention and control strategies in other countries in Europe affected by the disease.

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