

Chagas Disease in a Non-endemic Country: A Multidisciplinary Research, Bologna, Italy

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Abstract Global processes have brought about a substantial change in the epidemiological landscape of Chagas disease, spreading it to non-endemic areas. Italy is the second country in Europe in terms of Latin American migrants and expected infection rate. Given that scenario, the Bologna University Teaching Hospital undertaken a study aimed at providing preliminary data on the prevalence and investigating the knowledge and the subjective perceptions of Chagas disease, migration pathways and other relevant ill-health experiences. A cross-sectional study was undertaken in association with an ethnographic research. Between November 2010 and May 2013 Chagas disease testing was offered to people who attended the hospital and data were collected to investigate the broader socio-demographic and cultural factors. 151 individuals were screened for anti *T. cruzi* antibodies; 12 of them, 10 Bolivians and 2 Argentinians, were seroreactive, resulting in an overall prevalence of 7.94 %. Both the quantitative and the qualitative analysis revealed a degree of heterogeneity

in terms of knowledge and perceptions of the disease as well as of migration pathways. The results are comparable with those reported by previous studies with similar characteristics and highlight the relevance of such public health issue in a non-endemic context. Moreover, the interdisciplinary approach has greatly helped to unveil the complex social and cultural implications of Chagas disease, to explain the subjective ill-health experiences, and to understand the ways in which the broader socio-economic and cultural context affects an intervention and its potential for success or failure.

Keywords Chagas disease · International migration · Italy · Multidisciplinary

Introduction

Listed by the World Health Organization (WHO) among the neglected tropical diseases, the Human American Trypanosomiasis, widely known as Chagas disease, affects seven to eight million people worldwide [1].

In the majority of infected people, the disease remains clinically silent; however, 30–40 % of the cases develop organ damage, mainly cardiomyopathy, arrhythmias and megaviscera [2].

In the Latin American context, Chagas disease has been defined as “a reflex of the regional history, particularly in terms of equity and production dealings” [3]. It has historically been linked to poverty, marginalisation and social disadvantage [4], and still disproportionately affects forgotten populations—such as rural farmers and internal and transnational migrants, whose economic and political voice is weak—often far from health services, diagnosis or

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treatment [5]. Furthermore, Chagas disease has often been burdened by a stigma, related to poverty and rurality, which entails social consequences such as discrimination in the labour market [6].

The global processes of the last decades, increasing the migration of poor people looking for better life conditions [7], have brought about a substantial change in the epidemiological landscape of Chagas disease, spreading it out of the traditional boundaries to non-endemic areas such as North America, Europe and the Western Pacific Region.

With regard to the number of Latin American migrants and the expected infection rate, Italy is the second country in Europe, with around 390,000 people proceeding from endemic areas and an estimated prevalence rate ranging between 1.7 and 3.1 % [8]. Among Italian regions, Emilia-Romagna ranks third in terms of migrants as a share of the total population, with 11.1 % of foreign-born residents [9]. At the beginning of 2013, the number of Latin American migrants proceeding from areas endemic for Chagas disease reached 16,000 units (approximately the 3 % of the foreign-born population) [10].

Despite this demographic and epidemiological scenario, and the WHO call “to reinforce efforts to strengthen and consolidate national control programmes especially in areas where Chagas disease has re-emerged, in disease-endemic and non-endemic countries and to establish them where there are none” [11], medical professionals are not trained to suspect and diagnose the disease and national public health policies have not yet been adopted [12]. However, as a result of an awareness effort led by tropical medicine doctors national-wide, two screening programmes for congenital Chagas disease control have been put in place and other few specialised centres across the country offer screening programmes targeted to the at risk population [13, 14]. Despite these recent initiatives, the current scenario still entails an index of underdiagnosis estimated between 98.3 and 99 % [8]. Little is also known about the subjective perception of Chagas disease among those who are potentially infected, their attitudes towards a screening service and their fears about being positive in a foreign country [15] while—as migrants—they often face challenging life conditions, experience other more urgent health needs, and encounter multiple barriers in accessing healthcare services [16].

On the basis of the epidemiological estimates and the lack of data at regional level, the objectives of the present study, the first one to be carried out in the Emilia-Romagna region, were to provide preliminary data on Chagas disease prevalence in the local context, and to investigate the knowledge and the subjective perceptions of Chagas disease, together with migration pathways and other relevant ill-health experiences.

Methods

Design and Setting

A descriptive cross-sectional study was undertaken in association with an ethnographic research at the Bologna University Teaching Hospital, a reference centre for the diagnosis and management of Chagas disease in the Emilia-Romagna region. The working team included physicians (infectious disease specialists, gynaecologists, cardiologists, paediatricians), microbiologists, public health doctors and medical anthropologists.

The Ethical Committee of the Bologna University Teaching Hospital approved the study protocol in October 2010 and all participants signed a written informed consent; when participants were aged under 18, parents or guardians were requested to sign it.

An illustrated multilingual (Spanish and Portuguese) leaflet, aimed at disseminating the information about the disease and the diagnosis and management service, was conceived and designed through a participative process involving Latin American migrants in a preliminary phase [17]. The information strategy was extensively negotiated in order to find the most appropriate language and prevent causing alarm in the population. The leaflet was thus distributed to all the family counselings of the Bologna Local Health Authority, the clinics for undocumented migrants, and the trade union offices. It was also directly handed out during informal talks about the available service that took place in churches, municipal social centres and other meeting points for migrant associations.

Participants and Procedures

Between November 2010 and May 2013 the Bologna University Teaching Hospital offered Chagas disease testing free of charge to at-risk people who attended the service for any clinical reasons and to those who asked for it after being reached by the above-mentioned information campaign. Test scheduling was flexible in order to meet people's needs and availability.

In a context where data about prevalence were completely lacking, a target enrolment of at least 150 people was set in order to gather preliminary information that would possibly justify further focused public health strategies.

Inclusion criteria for screening were: being born in an endemic country for Chagas, or having spent three months or more in endemic areas, or being born from a mother born in an endemic country.

Socio-demographic and clinical data, as well as a sampling of 5 ml of venous blood, were collected after informed consent.

For all the individuals enrolled in the study, physicians reported clinical and demographic data on a clinical record form; in addition, foreign adolescents and adults with a history of migration were asked to fill in a questionnaire (translated into Spanish and Portuguese and available for readers upon request) to investigate socio-demographic conditions, migration pathways, relevant ill-health experiences, and specific knowledge of Chagas disease. Medical anthropologists were on-site and, if the clinical conditions allowed, they invited the person to a private talk aimed at better exploring the issues addressed in the questionnaire. All the information collected was reported on a research diary. The same topics were further investigated with the participants who accepted to undergo an in-depth interview.

Serum samples were tested in order to determine the qualitative presence of anti *Trypanosoma cruzi* specific antibodies, using a combination of three tests: (a) immunochromatographic card test (SD Chagas Ab Rapid-BioLINE), (b) ELISAs test based on recombinant antigens (BioELISA Chagas-Biokit), (c) *T. cruzi* lysate test (Test ELISA Chagas III, GrupoBios S.A.-BiosChile). In accordance with WHO diagnosis criteria [18], *T. cruzi* infection was diagnosed when at least two tests were positive.

All the individuals with a confirmed *T. cruzi* infection were invited to access the Infectious Disease outpatient unit, where the test result was communicated and focused counseling on Chagas disease was offered. At the same time, they received a preliminary clinical evaluation consisting of a general physical examination, a 12-lead electrocardiogram (ECG), and an echocardiogram.

In addition, a five-day hospital admission was proposed in order to completely stage the disease, to evaluate the need for treatment, to possibly start it and to monitor its potential early adverse effects. During admission, patients underwent a complete epidemiological and clinical assessment, a cardiologic reassessment if needed, a chest X-ray and a gastro-intestinal tract barium exam according to the Rezende method [19].

Following the available recommendations, treatment with benznidazole (5–7 mg/kg/day for 60 days) was offered to all seropositive eligible patients [20, 21].

Data Analysis

A descriptive analysis of the quantitative variables (presence of anti *T. cruzi* antibodies, risk factors and Chagas disease knowledge) was performed. The qualitative data analysis had been conducted as an ongoing process throughout the study. This allowed adjustments of the data

collection process to be introduced when additional concepts needed to be investigated, or new relationships to be explored. Analysis was refined at the end of the field work when meaningful contents were examined and interpreted.

Results

151 individuals were screened for anti *T. cruzi* antibodies. The mean age was 37.5 [standard deviation (SD) 13.1, range 1–68]; women represented the 62.91 % of the sample (N = 95).

143 individuals were adult Latin American migrants proceeding from endemic areas (94.7 %), 6 were adopted children (3.97 %) and only 2 were Italian travellers (1.32 %); the countries of origin are detailed in Table 1.

12 individuals were seroreactive for *T. cruzi*, resulting in an overall prevalence of 7.94 %, with all the cases being adult Latin American migrants (10 Bolivians and 2 Argentinians).

All the seropositive individuals underwent the preliminary clinical evaluation; among them, two refused hospital admission and did not receive any gastrointestinal assessment nor treatment so far.

Out of the ten patients who were admitted to the hospital and completed the clinical assessment, seven were in the indeterminate phase. In 1 case a gastrointestinal involvement (megacolon) was diagnosed while cardiac involvement was suggested in one patient who presented a first-degree atrioventricular block. Since none of them had severe cardiomyopathy, all were treated with benznidazole. Nine patients concluded the treatment (60–80 days totally) and one patient interrupted the therapy and was lost to follow-up; four of the treated individuals presented cutaneous rash treated with antihistamine therapy.

50 % of seropositive patients had already received a diagnosis of Chagas disease in their country of origin; in 1 case the diagnosis was made in another Italian hospital. None of them was receiving any treatment or undergoing a clinical follow up at the time of testing. When asked for the missing clinical management of the infection, people gave different reasons. While someone reported that the *T. cruzi* infection was not perceived as a relevant health problem compared to other urgent daily life needs, others thought that the Italian healthcare system would not have been equipped to manage the disease. Another common reason that prevented people from seeking care was the conviction that accessing healthcare services would have been as costly as it was in their countries of origin.

Due to substantial differences in terms of migration history and risk factor patterns between Latin American migrants on the one hand, and Italian travellers and adopted children on the other, the descriptive analyses that

follow were performed only on the first subgroup (N = 143), using the information collected through the clinical record form as well as the questionnaire and the interviews.

Table 2 summarizes information related to socio-demographic status, history of migration, of transfusions in the country of origin and of Chagas disease within the family in Latin American migrants.

In this subgroup, the prevalence was 8.39 %, the mean age was 39.11 (standard deviation (SD) 11.25, range 12–68) and women represented the 64.34 % of the population. When only Bolivians were considered, the prevalence rose to 30.3 %.

Among the women, six were pregnant at the time of test and 61 had one or more children. Furthermore, 19.58 % of the subjects declared that they had donated blood or organs (in the case of the organ donation, it was a kidney) in their country of origin while 2.8 % of them had donated blood in Italy. Specifically, among the seropositive patients, three received blood transfusions and two donated blood in their countries of origin; none of them donated any organ.

Table 3 shows data about previous knowledge of Chagas disease, including the source of information, as well as the opinion about a broad information campaign on Chagas disease and its control. Both the quantitative and the qualitative analysis revealed a degree of heterogeneity in

Table 1 Countries of origin and population groups (absolute numbers and percentages)

Country of origin	Latin American migrants	Adopted children	Travellers	Total
Argentina	13 (9.09 %)			13 (8.61 %)
Bolivia	33 (23.08 %)			33 (21.85 %)
Brazil	9 (6.29 %)			9 (5.96 %)
Chile	1 (0.7 %)			1 (0.66 %)
Colombia	6 (4.2 %)	3 (50 %)		9 (5.96 %)
Ecuador	20 (13.99 %)			20 (13.25 %)
Italy	3 (2.1 %)		2 (100 %)	5 (3.31 %)
Mexico	2 (1.4 %)			2 (1.32 %)
Paraguay	1 (0.7 %)			1 (0.66 %)
Peru	54 (37.76 %)	2 (33.33 %)		56 (37.09 %)
Venezuela	1 (0.7 %)			1 (0.66 %)
Not known		1 (16.67 %)		1 (0.66 %)
Total	143 (94.7 %)	6 (3.97 %)	2 (1.33 %)	151

Table 2 Distribution of demographic characteristics and risk factors for Chagas disease (absolute numbers and percentages)

	Individuals with <i>T. cruzi</i> infection (N = 12)	Individuals without <i>T. cruzi</i> infection (N = 131)	Total (N = 143)
Sex			
Female	9 (75 %)	83 (63 %)	92 (64 %)
Male	3 (25 %)	48 (37 %)	51 (36 %)
Age			
≤35	1 (8 %)	56 (40 %)	57 (40 %)
>35	11 (92 %)	75 (60 %)	86 (60 %)
Country of origin			
Bolivia	10 (83 %)	23 (18 %)	33 (23 %)
Other than Bolivia	2 (27 %)	108 (82 %)	110 (77 %)
Residence area			
Rural	7 (58 %)	38 (29 %)	45 (31 %)
Urban	5 (42 %)	93 (71 %)	98 (69 %)
Cases of disease among family members			
Yes	5 (42 %)	6 (5 %)	11 (8 %)
No	7 (58 %)	125 (95 %)	132 (92 %)
Blood transfusion in the country of origin			
Yes	4 (33 %)	8 (6 %)	12 (8 %)
No	8 (67 %)	123 (94 %)	131 (92 %)

Table 3 Knowledge of Chagas disease (absolute numbers and percentages)

	Individuals with <i>T. cruzi</i> infection (N = 12)		Total (N = 143)	
	Yes	No	Yes	No
Knowledge of Chagas disease	12 (100 %)	0	65 (45 %)	78 (55 %)
Source of knowledge				
Family or direct experience	6 (50 %)		11 (17 %)	
Media	3 (25 %)		14 (22 %)	
Doctor	1 (8 %)		2 (3 %)	
School	0		15 (23 %)	
Other sources	0		18 (28 %)	
Do not remember	2 (17 %)		5 (8 %)	
In favour of a broad information campaign about Chagas disease	11 (91.6 %)	1 (8.4 %)	131 (92 %)	12 (8 %)

the knowledge and perceptions of the disease among Latin American migrants.

While being aware of the risks of generalisation, it appeared that on the one hand Peruvian and Ecuadorians—who represent 40 % of the sample—along with people coming from Central America, Colombia and Venezuela had no or limited knowledge about the disease. On the other hand, migrants originating from Argentina and Brazil, as well as those from Bolivia, were more aware of the disease. A similar difference emerged as well in relation to the attitude towards the disease originating from its social meaning and individual perception. While the majority of Peruvians and Ecuadorians did not perceive Chagas disease as a worrisome condition, Argentinians and—to some extent—Brazilians often showed different reactions, from refusal to detachment, accompanied by discrimination attitudes towards those possibly affected by the condition. This can be explained recalling the stigma referred to earlier that associates Chagas disease with poverty and rurality in their countries of origin.

Moreover, positive individuals, the majority of whom were Bolivians, were particularly worried by the possibility of being stigmatised by the host community. Upon receiving the diagnosis, they frequently asked health professionals not to mention the Infectious Disease department in their external communications, and not to send test results to their employees as they were afraid to lose their job. They also asked to directly explain the results to family members, relatives or employees specifying that the infection would not represent a danger or a limitation to work.

The ethnographic research also revealed a rather mixed scenario in terms of migration patterns and their impact on ill-health experiences. A small group of migrants coming mainly from Brazil, Argentina, Colombia and Chile moved to Italy for political and security reasons; the majority of them were women married to Italians and this status was

linked to better integration, better social position and easier access to healthcare and social resources when needed. Conversely, the largest group, mainly made by Ecuadorians, Peruvians and Bolivians, generally left their homeland for economic reasons and often experienced challenging life and working conditions such as illegal work, unemployment, exploitation, and weak social networks. They frequently perceived their health status as being vulnerable and reported significant barriers to accessing and utilizing the Italian healthcare services. Common complaints were psychological suffering, feeling of loneliness and homesickness as well as physical symptoms such as osteoarticular pain and gastrointestinal or sleeping disorders, frequently seen as a consequence of hard working and challenging life conditions.

Discussion

In the subgroup of adult Latin American migrants the overall prevalence of Chagas disease was 8.39 %, a finding that is comparable with those reported by previous studies with similar characteristics carried out in Switzerland [22] and elsewhere in Italy [13], but lower than those found in Barcelona [23]. In line with previous reports from other non-endemic countries [22, 24], and due to the heterogeneous distribution of Chagas disease in Latin American countries [25], Bolivians appear to be the most affected group. Only two cases were diagnosed in people coming from Argentina, while no cases were diagnosed among Peruvians and Ecuadorians.

While these findings shed some light on an unrecognized public health issue, they cannot be generalised to the wider Latin American population living in Emilia-Romagna region because of limitations of the sample strategy.

Indeed, although a representative sample would have been the ideal choice, logistical and feasibility constraints

led to a different approach in selecting the study participants.

On the one hand, the Latin American community was highly fragmented and hard-to-reach given the absence of defined meeting points, leading associations or identifiable community leaders. On the other hand, the stigma related to the disease in certain contexts might have possibly hampered the willingness to participate to the proposed screening in those who got information about the service. These characteristics posed a significant challenge in complying with sample representativeness requirements; at the same time, the urgent need for a preliminary assessment of the serological prevalence among Latin American migrants led to choose an opportunity sample with the aim of obtaining exploratory findings. Despite of this methodological limitation, the study suggested that Chagas disease is an issue in the local contest and contributed to confirm what found in previous researches in non-endemic countries in terms of risk factors and behaviors associated with the affliction.

The distribution of those characteristics that are widely acknowledged as Chagas disease risk factors showed a predictable pattern, being often more prevalent among the cases.

Older age as well a history of Chagas among family members (out of 12 seropositive patients, seven had cases of Chagas within their families) were more frequently reported by seropositive individuals. It is widely recognised that older Latin American migrants have been exposed to higher risk of infection than younger people, mainly due to the progressive implementation of control programmes in endemic countries [26]. Similarly, having a relative diagnosed with Chagas disease was more common among those who tested positive possibly due to the sharing of the risky environment or the vertical transmission.

Furthermore, a history of dwelling in rural areas—generally the poorest and the most isolated areas in the Latin American continent—was another shared risk factor among infected individuals, as previously argued by other authors [16]. However, some doubts arise regarding the reliability of such an indicator: the qualitative analysis pointed out that people may report urban dwelling if they lived in urban context for a significant amount of time, or if they want to hide a rural background associated with poverty and stigma in endemic countries [27].

In terms of risk connected to transfusion, a substantial proportion (33 %) of seropositive subjects received blood products in their proceeding countries although a causal relationship could not be established.

Furthermore, across the whole study sample, a small percentage of subjects (19.58 %) donated blood (in one case an organ) in their country of origin as well as in Italy (2.8 %). This finding, though encouraging as a sign of

possible integration, raises concerns over blood-borne transmission and demands the implementation of adequate control measures for both blood and organ safety [22].

The level of knowledge and awareness around Chagas disease, including its transmission pathways and clinical implications, was rather mixed among Latin American migrants who participated in the study. While among the whole sample only less than half had some information, all the positive individuals knew about the affliction, mainly through family or direct experience and through media campaigns carried out in their country of origin. Accordingly, previous knowledge of the disease should be regarded as a red flag in the epidemiological assessment, indirectly reflecting the presence of the affliction in one person's ecological and social environment [16].

Despite this scenario, the majority of people who took part in the screening programme affirmed that an information campaign on the disease and the related risks would be very relevant in order to enhance the awareness among at-risk population and the access to the test.

While investigating the social and subjective dimensions of Chagas disease, the interdisciplinary approach, crossing methodological boundaries and unveiling the correlations between a proposed health programme and its meaning and impact on people's lives, has greatly helped in identifying aspects that would have remained obscure if only quantitative tools were adopted.

The ethnographic research has shown that, in our context, the diverse levels of awareness and the divergent attitudes towards Chagas disease might lead to distinct attitudes to a screening programme.

On the one side, the Bolivians—though complaining about a broad range of health problems often related to the challenging life and work conditions they experience—might welcome a programme aimed at specifically managing the disease, acknowledging its epidemiological importance in their context of origin.

On the opposite side stands the broad spectrum of people coming from other endemic countries, with their own social and cultural representations of Chagas disease and their different histories as migrants in a foreign country. Among them, those who consider Chagas disease as an unlikely but epidemiologically plausible infection might show interest and adhere to a dedicated screening programme, if available, also because it represents a possibility to access the broader health system, overcoming the multiple barriers that migrants experience often resulting in unmet health needs [28].

For others, conversely, Chagas disease might evoke a denial reaction which may hamper their participation to a dedicated screening programme, either because they do not perceive the condition as a threat or due to the associated stigma.

The need to ensure access to diagnosis and treatment for Chagas disease to all potentially infected people should not overlook these standpoints, which may negatively or positively influence the adherence to a proposed screening programme. The challenge is to turn such perspectives into strengths and opportunities for those who might benefit from such an action.

Moving from these considerations, it can be argued that Chagas disease is a public health issue also in the Emilia-Romagna region, in particular when considering the burden among migrants coming from Bolivia. At the same time, in dealing with the disease in a non endemic context, it sounds strategic take into account the well-known risk factors along with the awareness and the social and subjective dimensions of the disease.

Recalling suggestions from other studies [29], a possible way forward might be to integrate Chagas disease screening for the at-risk population into mainstream prevention programmes, thus avoiding a vertical and potentially stigmatizing strategy while increasing the test availability and coverage at the local level.

At the same time, it would be strategic to equip primary care facilities and train general practitioners to suspect, identify and manage Chagas disease. Such an approach might increase Chagas disease visibility and detection in the midst of more compelling health conditions among which this silent affliction tends to fade away. On the other hand, it avoids essentializing Chagas disease through a vertical strategy that makes all those other conditions disappear.

Furthermore, an interdisciplinary approach that constructively challenges the limits of biomedical reductionism should be encouraged, as it may be particularly helpful to unveil the complex social and cultural implications of Chagas disease, explain the subjective ill-health experiences, as well as understand the ways in which the broader socio-economic and cultural context affects an intervention and its potential for success or failure.

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Conflict of interest The authors declare that they do not have any conflict of interests.

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