

Chagas disease at the crossroad of international migration and public health policies: why a national screening might not be enough

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Since the year 2000, Chagas disease, traditionally known as a rural Latin American affliction, has been rising in the ranking of international health priorities due to the growing migration flows from endemic areas to non-endemic ones. Using the example of Italy and reporting preliminary results of a study carried out in the district of Bologna, the paper will argue that a disease-centred public health approach might be inadequate when dealing with complex and uncertain situations, in which complete statistical data are not available or not reliable, and in which the involved actors, health professionals on the one side, migrants on the other, appear to be unaware of the issue, or might even be denying it. In such a context, an effective public health approach should be capable of crossing disciplinary boundaries and bridging the gap between health services and communities, as well as between health and social issues.

Chagas disease: still a silent affliction?

Traditionally known as a rural Latin American affliction, Chagas disease is still, more than 100 years after its discovery, affecting between 8 and 10 million people worldwide, with an incidence of more than 40,000 new cases per year [1].

This parasitic illness caused by *Trypanosoma cruzi*, transmitted by a vector in endemic areas and through non-vectorial transmission routes in non-endemic countries, is listed by the World Health Organization (WHO) among the so-called 'neglected tropical diseases'. Such conditions, close companions of poverty, are tightly linked to marginalisation and social disadvantage. Nationally as well as internationally, they are of low public health priority, they do not raise much scientific interest nor do they attract research investments. Suffice it to say that the only two current treatment options for Chagas disease, which are poorly effective in the chronic phase and have significant toxic side effects, were developed in the 1960s, and

that since then, in over 35 years, not a single new drug has been approved [2].

Since the year 2000, due to the growing migration flows from endemic areas in Latin America, the scientific literature has increasingly reported imported as well as autochthonous cases of Chagas disease in many European countries [3]. Significantly, since it began to be perceived as a potential threat for most developed countries, the condition has been rising in the ranking of international health priorities. Articles are being published by the most influential medical journals; initiatives from non-governmental organisations and public-private partnerships are thriving [4]; Chagas disease has been addressed, during the 63rd World Health Assembly, in a resolution concerning control and elimination in endemic and non-endemic countries [5]. Although the recent WHO initiative for non-endemic countries calls for a broad approach and for the foundation of inter-disciplinary reference centres in all non-endemic countries [6], the strategies adopted until now to address the new potential public health challenge have missed to acknowledge the complexity of the relations between a long-forgotten disease, international migration and public health legislation and policies.

Using the example of Italy, this paper will argue that a disease-centred public health approach might be inadequate when dealing with complex and uncertain situations, in which complete statistical data are not available (i.e. for undocumented migrants) or not reliable (i.e. estimates of infection prevalence in non-endemic areas), and in which the involved actors, health professionals on the one side, migrants on the other, appear to be unaware of the issue, or might even be denying it. The considerations we raise here for public discussion are based on a review of the literature and on the preliminary results of a study that is being carried out by the authors in the district of

Bologna (Emilia-Romagna region) in collaboration with S.Orsola-Malpighi Teaching Hospital.

The research, aimed at evaluating the presence and impact of Chagas disease among Latin American migrants living in the area, adopts a multidisciplinary, multi-method and participative action research approach and promotes the active engagement of all involved stakeholders. Medical doctors work in close collaboration with anthropologists, and the data collection and analysis combine epidemiological tools with qualitative research methodologies (i.e. ethnography, in-depth interviews and focus groups).

Chagas disease in Italy: a complex emerging public health challenge

Since the late 1990s, after migration flows between Europe and Latin America reversed their former westbound direction, the number of Latin American migrants living in Europe has more than doubled. In 2005, nearly 2 million people born in Latin America were living in western European countries, mostly in Spain, Italy and Portugal. In the period from 2004 to 2009, in Italy, the number of Latin American migrants has doubled from 169,000 to 343,000; estimates say the figure in 2010 could be close to 600,000 when including undocumented migrants [7]. Worried about the increase in imported cases of Chagas disease, and fearing a domestic spread of the infection through blood transfusions and organ transplantation, Spain, France and the United Kingdom have implemented control or exclusion measures to address what was perceived as an emerging public health threat [6,8]. Italy has yet to adopt specific health policies and the related scientific debate is still nascent [9]. Several reasons might lie behind this difference, as illustrated in the following paragraphs.

A first consideration relates to the fact that, compared to other European countries, Italy is a relatively new migration country, in which migratory processes have greatly changed over a short period of time and migrants come from a wide variety of nations. Notably, Italy started registering positive net migration balances in the mid 1970s, but has since 1990 seen a ten-fold increase in its migrant population. Today, almost 5 million foreign nationals live in Italy, originating from 190 countries and representing 7% of the whole population. The majority of them traditionally come from eastern Europe and northern Africa, while migrants from Latin America, who arrived mainly in the past decade from Peru, Ecuador and Brazil, account today for less than 10% of the total migrant population [7], representing a new and relatively small community. Preliminary results from our research conducted in the district of Bologna show that compared with migrants originating from other areas, such as North Africa or eastern Europe, Latin American migrants tend to be perceived as more similar to the local population and less associated with the stigma of poverty, ignorance and criminality. Overall, there is little awareness of

their presence, despite the fact that, at the regional level, their number in Emilia-Romagna has increased by 34% from 2005 to 2008 [10].

A second challenge that might have delayed addressing the issue of Chagas disease is the difficulty in estimating the epidemiological burden of the condition. Part of the reason is that the prevalence rates for *T. cruzi* infection in the countries of origin, commonly used to calculate the expected prevalence in migration countries, are estimates resulting from different and heterogeneous data sources and also differ within those countries, being much higher in rural areas [8,11]. Moreover, such uncertainty is associated with the difficulty in collecting data about migrant populations, particularly undocumented residents. In this respect, current legislation in Italy requires migrants to be employed in order to be eligible for a residence permit. Therefore, due to the instability of occupational conditions worsened by the economic crisis [12], more and more people periodically drop from the status of legal to that of illegal migrant and become invisible for official statistics [7]. In our study, in order to trace the presence of this hidden population, we retrospectively analysed the registers of two out-patient clinics run by non-profit organisations that, in agreement with the regional health system, offer primary care to undocumented migrants. Both clinics had undocumented Latin American migrants among their patients [10].

A third characteristic of the Italian context is that, compared to other European countries and possibly related to its weaker colonial history, there has never been a strong tradition of tropical medicine [13]. To date, only a few referral centres, dedicated to tropical infectious disease and travel medicine, are equipped to routinely diagnose and treat Chagas disease, and there are no standardised protocols to be followed [14,15]. Since the majority of Italian health personnel is not trained to suspect the condition and search for it among the resident population (of both Italian and foreign origin), and diagnostic and therapeutic tools are de facto not available or not promptly accessible, underdiagnosis is likely to occur.

Finally, the complex socio-political and cultural implications of Chagas disease, which impact on its distribution in endemic countries, and on the access to healthcare in endemic as well as non-endemic ones, need to be mentioned. As previous research, conducted by the authors in endemic areas (Buenos Aires and Chaco region, Argentina) showed [16], and as reported in the international literature, Chagas disease is a complex phenomenon whose roots lie in historical, socio-political and economic processes that strongly link endemic with non-endemic countries [17]. In most endemic countries the disease has not been considered for decades as a public health priority, with the effect of substantially excluding from information and diagnosis the majority of the people, particularly those living in remote rural areas. As a consequence, many

migrants travel without being aware of their serological status. Furthermore, in endemic countries Chagas disease is a stigmatised condition that can lead to the exclusion from the labour market, stereotypically associated with rural poverty, ignorance and marginalisation [18]. The ethnographic research conducted in the district of Bologna confirmed these perceptions and revealed that also among Latin American migrants, mentioning Chagas disease often evokes a denial reaction related to those stigmas which may hamper access to further information and service [10].

Why, in Italy, national screening might not be enough

In the absence of regulated interventions and official guidelines, the few referral centres in Italy that are presently equipped to diagnose and treat Chagas disease have taken laudable initiatives to set up screening services and programmes targeted to Latin American migrants [14,15]. Even if these initiatives, often based on the good will and voluntary action of committed professionals, are to be welcomed also for their coordination effort, they are geographically limited to a few areas of the country and cannot reach the whole target population. Since they are hospital-based interventions, they concentrate on the serological and clinical aspects of the disease, often overlooking the broader determinants mentioned above. The gap between implemented practices and needed national plans could become a fruitful space for discussion in order to draw on the experience already gained and to develop comprehensive, harmonised and effective public health policies at the country level.

Indeed, acknowledging the complexity of the Italian scenario, a biomedical, disease-centred rather than people-centred approach could be ineffective in protecting individuals' and community health, and might even become harmful if used as a control measure rather than as a health promotion strategy. This is not meant to disregard the importance of effective biomedical tools in managing the disease, which remain crucial in several aspects, but rather to raise awareness about the risk in relying exclusively on them.

Communicable diseases have, at different times in history, given rise to responses such as the forced expulsion of suspected carriers, quarantine and, in the contemporary setting, health screening [19,20]. Chagas disease is therefore but a recent case in a long tradition of real and perceived public health threats linked to the movement of people. However, with the globalisation of communication, commerce and travel, and migration being a structural and growing component of such processes, prevention and containment policies which rely mainly on control measures are likely to become increasingly costly and ultimately ineffective [21,22].

Furthermore, public health approaches targeted to a specific condition tend to hinder the development of more comprehensive strategies [23]. Failing

to acknowledge and address the wider determinants of health and disease, and to take into account and respond to people's perceived needs, these approaches are likely to be unsuccessful when facing conditions which are multi-causal and have many interdependencies on the socioeconomic, cultural and political side, such as Chagas disease has proved to have.

Moving from these broad considerations to analysing the practical implementation of measures such as a screening protocol for at-risk populations, a crucial issue to be addressed is the different pattern of accessibility and utilisation of health services by foreign communities and individuals. An abundant literature examines the barriers which impair migrants' access to health services, particularly to prevention programmes, compared to national populations, considering factors such as linguistic difficulties, lack of information, time and job constraints, or fear [24]. A low social status is in itself a determinant of poor interaction with the healthcare system, in quantity and quality. This is not an issue specific for migrants, rather a general disadvantage of lower socioeconomic groups, in which however migrants are over-represented [25]. In this context, screening protocols built on existing services might be unable to reach at-risk populations and therefore ineffective as a control or prevention measure. This is particularly relevant considering that Chagas disease is predominantly an asymptomatic condition and many infected individuals will not seek healthcare.

Further issues need to be raised when analysing the distinctive features of the current Italian socioeconomic and political context, in which the described access barriers for migrants appear increasingly difficult to overcome [26]. The immigration law approved in 2002 strictly bound the legal status of migrants to the needs of the labour market and made irregular immigration an endemic feature in Italy [27], which is worsening in the current context of economic distress. Further legal developments, adopted in 2009 under the name of 'security package' [28], introduced, among other norms, the criminalisation of irregular entry and stay in Italy. After the adoption of the law, non-profit organisations that run clinics for undocumented migrants reported a decrease of up to 50% in patients' access. Even though it was soon after clarified that access to health facilities could not lead to any kind of alert or registration (except in those cases where a report is mandatory by law, on an equal footing with Italian citizens), these legal developments still spark fear and confusion among migrants [29].

Our preliminary results confirm that significant barriers to health services exist also for Latin American migrants living in the district of Bologna. These barriers relate mainly to a lack of information on migrants' rights and available services, as well as to language difficulties. Financial barriers were mentioned as a factor delaying care for the unemployed and those who rely on temporary jobs and below-standard incomes.

Geographical accessibility was cited as particularly relevant for migrants living outside the city, while fear and insecurity in using public services were pointed out as the main existing barriers specifically for undocumented migrants [10]. Moreover, the local representatives of the main Latin American nationalities, whom we reached through qualitative interviews, have remarked that people could distance themselves from interventions explicitly targeted to Chagas disease, in order to avoid the prejudices that accompany the condition in their countries of origin (rural poverty and ignorance). Some of them also objected to the public disclosure of a direct link between their origin as migrants and the disease, fearing the possibility of a political use of such information to promote anti-immigration policies (unpublished results).

A possible way forward: crossing boundaries and bridging gaps

An effective public health approach should start by acknowledging that assessing merely the quantitative side of the problem is not enough. This is due to extrinsic limitations (unavailability and/or unreliability of data) as well as to the intrinsic biomedical bias which still affects mainstream epidemiology [30]. As recently recommended by, among others, the WHO Commission on Social Determinants of Health, a rich and diverse evidence base should be developed in order to adequately address the bio-psycho-social dimensions of public health challenges, and to evaluate interventions, including evidence from multiple disciplines and methodological traditions as well as knowledge and experience from key stakeholders [31]. In this respect, social and human sciences, particularly sociology, political science and anthropology, can provide theoretical insights and methodological tools which can be applied in public health to help translating research into effective policy and practice [32]. In fact, qualitative data, on which these disciplines greatly rely, are crucial in order to explain the subjective experience of a problem or its impact on people's lives, as well as to understand the ways in which context affects an intervention and its potential for success or failure.

The issue of Chagas disease in Italy should therefore be assessed, and addressed, by multidisciplinary teams in which public health professionals, clinicians and social and human sciences professionals work together in close collaboration, adopting quantitative as well as qualitative research methods. In our experience, this approach has greatly helped in identifying aspects of the issue that would have remained obscure to conventional epidemiology, such as the perceived needs and priorities of Latin American migrants, their problems and fears in accessing the health services, as well as the perceptions of health professionals towards their presence in our country.

The results of such analysis should be used to inform a national plan aimed at expanding the availability of diagnostic and therapeutic tools for Chagas disease

within the health services according to the assessed needs, and at setting standardised protocols for screening and treatment. They should further be used to remove the identified access barriers to services in order to reduce inequalities in the utilisation of health services which can impair the effectiveness of any intervention. Finally, they should inform adequate training programmes for health personnel to increase their capacity to deal with the biological as well as psycho-social and cultural aspects of the new condition. Physicians should be able to consider and collect in a medical history all those factors that affect the health status and play a major role in the development of the disease.

A further step would be to complement the disease-centred with a multi-method approach and participatory, community-based action research programmes aimed at a broad promotion of the right to health. Evidence from the literature shows that working in partnership with relevant stakeholders and involving the community are effective practices for successful health interventions [33]. Such practices can also trigger participation and empowerment of community members, particularly those in marginalised groups, allowing them to take part in decisions related to the improvement of the conditions that affect their well-being. Moreover, the action research strategy allows to progressively tailor the interventions to the local context, a good example of proactive medicine that can improve the responsiveness of health services to population needs.

Working together with Latin American migrants living in the district of Bologna has allowed us to understand that, in order to effectively act on Chagas disease, the issue has to be framed within a broader action aimed at making health and social services more open, integrated and equity-oriented, and more broadly at promoting the right to health and healthcare through the promotion of all related human rights. This applies to endemic as well as to non-endemic countries.

Dealing with Chagas disease therefore offers a strategic opportunity for experimenting with innovative public health approaches, capable of crossing disciplinary boundaries and bridging the gap between health services and communities, as well as between health and social issues.

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