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Elise Rapp

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Chagas Congenital Screening in Switzerland: Processes of Recognition and Knowledge-Sharing

Elise Rapp ^{a,b}

^aHESAV School of Health Sciences, HES-SO University of Applied Sciences and Arts Western Switzerland, Delémont, Switzerland; ^bInstitute of Humanities in Medicine, Faculty of Biology and Medicine, University of Lausanne (UNIL), CH-1015 Lausanne, Switzerland

ABSTRACT

Disparities in control mechanisms to prevent the spread of Chagas disease in Switzerland raise questions about the process of its recognition as a public health problem, particularly as it concerns migrant populations. With a focus on congenital screening practices, I explore the way in which health care providers experience, problematize and respond to the disease, acting as key agents not only in the provision of care but also in the recognition of Chagas disease as a problem that needs to be addressed. Such an approach contributes to the understanding of processes of public health agenda creation around neglected tropical diseases in non-endemic countries.

RÉSUMÉ

Les disparités dans les mécanismes de prévention de la transmission de la maladie de Chagas en Suisse soulèvent des questions sur les processus de sa reconnaissance en tant que problème de santé publique, en particulier lorsque le risque concerne les populations migrantes. En portant une attention particulière sur les pratiques de dépistage congénital, j'explore la manière dont les professionnels de la santé perçoivent, problématisent et répondent à la maladie, agissant comme des acteurs clés non seulement dans l'attribution des soins mais aussi dans la reconnaissance de la maladie de Chagas comme un problème qui requiert d'être considéré. Une telle approche contribue à la compréhension des processus de création de programmes de santé publique autour des maladies tropicales négligées dans les pays non endémiques.

KEYWORDS

Switzerland; Chagas disease; congenital screening; migration; neglected tropical diseases; public health

Since the end of the 20th century, Chagas disease (CD) – which can only be spread in non-endemic countries through congenital transmission, blood transfusions, and organ transplants – has been considered “an emerging public health problem” in Europe (Requena-Méndez et al. 2014). In Switzerland, an estimated 2000 to 4000 people are infected, but most of them are not diagnosed. Indeed, in 2011, the under-diagnosis index of Chagas-infected people in Switzerland was estimated to be between 89 and 95% (Basile et al. 2011), and, although major screening efforts have since been made in the cities of Geneva and Lausanne, the under-diagnosis index remains high.

Measures to protect the population from transmission via blood transfusions have been in place since 2013, and the control of potential transmission through organ donations is also carried out on a national scale despite a lack of official recommendations from national public health institutions.¹ Congenital screenings of CD have only been institutionalized in two university hospitals in the city of Geneva since 2008, and in Lausanne since 2011. The situation in Switzerland reflects a trend observed

CONTACT Elise Rapp  elise.rapp@hesav.ch  HESAV, Avenue De Beaumont 21, Lausanne 1011, Switzerland

Media teaser: What drives attention and recognition of neglected tropical diseases in non-endemic countries? I explore the case study of congenital Chagas disease in Switzerland.

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in other countries, namely that health policies designed to control the transmission of CD during pregnancy are generally underdeveloped in non-endemic countries (Requena-Méndez et al. 2014).

CD is characterized by a chronic infection that can remain silent for decades and in about one-third of cases lead to serious health problems. Drugs are effective in eradicating the parasite during a recent infection, such as in children born infected, but their effectiveness decreases significantly over the years. Screening pregnant women for this silent disease provides an opportunity to monitor potential transmission early enough to permanently cure infected children.

As congenital transmission takes place between pregnant migrant women and their children, there is almost no chance that this disease can spread to other groups of the population. Hence, while in Switzerland all are protected from the risk of contamination via organ transplants and blood transfusions, congenital transmission still poses a risk for infected Latin American migrants and their children. Further, studies have shown that CD is more prevalent among migrants experiencing layers of marginalization: socioeconomic disadvantage, absence of legal residency status, and barriers in access to quality medical care, such as unfamiliarity with the Swiss health care system and lack of communication proficiency (Jackson et al. 2009a; Jackson and Chappuis 2011). In Switzerland the number of undocumented migrants from Latin American countries is estimated around 32,600 people (Morlok et al. 2015).

There are questions to be asked about how CD is recognized as a public health problem in Switzerland, given the absence of national recommendations and guidelines for congenital screening of CD, and the disparities in efforts to address all of the multiple modes of transmission of the disease. Health policy regulation in Switzerland is a decentralized system. Cantons enjoy a large degree of autonomy over care provision, hospital organization, and the training of health professionals. Some aspects of health policy are regulated at the federal level, such as the prevention of communicable diseases (Rossini and Legrand-Germanier 2010). Although national recommendations and guidelines are not legally binding they provide guidance for the implementation of care and health care providers' practices. However, even if for the insured Chagas congenital screening costs can be claimed and reimbursed there are no national recommendations or guideline for the control of congenital CD, such as screening at risk pregnant women and treating infected newborns.

Screening for CD depends on local initiatives. This is the case in Geneva and Lausanne, where health professionals have mobilized locally to implement CD control in collaboration with hospital authorities, political decision-makers, and community associations. Protocol for congenital CD control consists in systematically offering screening to all pregnant women of Latin-American origin. In case of a positive diagnosis, her newborn is medically followed up during the first year of their life and treated with medication if they turn out to be infected. Drug treatment is also proposed to the mother after the breastfeeding period.

CD is classified as a rare disease by the European information portal Orphan (Orphanet n.d.), as it affects fewer than 5 in 10,000 people in a given region. This may not be the case everywhere, for example in Spain prevalence can be high. It is now well documented that not all diseases classified as rare are given the same attention, and this varies with the commitment of actors (often patient associations) and the success of their mobilization (Nouguez 2014). Viewed from a sociological lens, the recognition of a "public problem" is not inevitable, but arises from mobilization processes. Since Chagas disease is embedded in profound mechanisms of invisibility, it is through dynamics of recognition that it emerges as a public health problem. It requires the engagement of actors who work creatively to circulate the problem between different arenas (scientific, political, clinical, economic) to maximize its visibility. This research illustrates that the implementation of a congenital screening apparatus is the result of the mobilization of a local network of health professionals. I define apparatus in the Foucauldian sense, as a heterogeneous ensemble of discursive and non-discursive elements, consisting of discourses, institutions, technologies, scientific statements, moral propositions, etc. as well as of relations that can be established between these elements (Foucault 1980).

Health care professional activists are not the only actors who undertake to make CD more visible in Switzerland. They are part of a broader network that includes the Aswisschagas association, NGOs

such as DnDi and Mundo Sano, the Swiss Tropical and Public Health Institute and the World Health Organization (WHO). Far from an exception, this kind of mobilization can also be observed in other non-endemic countries, such as Spain, France, and Italy (Requena-Méndez et al. 2014; Soriano-Arandes et al. 2016).

By focusing on the process of recognition of CD in a non-endemic country, I explore how a neglected disease can be transformed into a public health problem, and the reasons why little attention is paid to it. Through an understanding of how medical practitioners conceive and manage CD in a non-endemic context, this study can contribute to a more nuanced understanding of the complexities of health and migration in the design and implementation of public health procedures.

In this article, I focus on how the attention devoted by some local health care providers has led to the implementation of congenital screening at two university hospitals. Examining the mobilization patterns of these health professionals helps reveal conditions for the recognition of CD as a public health problem as well as the dynamics of its invisibility, which leaves people exposed to risk. I first explore how a group of health care providers identified CD as a public health problem, the actions they undertook to address it, and the drivers of their commitment. Then, I examine the production and circulation of knowledge as strategies to build awareness of the disease within the medical community, and evaluate its impact on clinical practice by investigating how the congenital screening of CD is conducted and sustained in two districts of Switzerland.

Methodology

This research is based on two sets of complementary data – first, a qualitative analysis of semi-structured interviews with health care providers conducted in Geneva and Lausanne in 2019, and, second, a critical review of the Swiss medical literature on CD – in order to provide greater insight into the production and circulation of knowledge about CD, as well as the history of its clinical and public health trajectory in Switzerland.

The analysis of Swiss medical publications reveals the network of actors involved in the management of CD at the clinical level. With snowball sampling from the initially interviewed actors, a more detailed picture of the network of actors and their role emerged. I conducted interviews with the heads of two maternity units in Geneva and Lausanne, and midwives carrying out the screening at these locations. A total of 16 health care professionals – eight medical doctors and eight midwives – were interviewed. Nine of these were based in Geneva, and seven in Lausanne.

The roles of these actors fall into two categories:

- (i) Nine health care professional activists (*central actors*) who are part of a network playing an active role in the recognition of CD through the implementation and operationalization of screening apparatuses within hospitals (and also out of hospital) as well as knowledge sharing among health care providers. This category includes midwives and doctors, many of whom are involved in the clinical follow-up of pregnant women positive for CD. They are specialized in tropical diseases, migrant care, pediatrics, or gynecology.
- (ii) Seven *clinicians* conducting screening and care in maternity cases or in charge of units where congenital screenings are realized, *but* who are not initiators of those practices.

In line with actor-network theory, I consider the establishment of a new practice as resulting from the actions of central actors (Mahil and Tremblay 2015) who identify a problem and implement a response to it. In this perspective, the conception and implementation of a practice is gradually transformed and supported by an ever-increasing number of actors (Akrich 1993) who participate in defining the situation. In this sense, the distinction between “central actors” and “clinicians” identifies facilitators, obstacles, and translational discrepancies between screening implementation, awareness production, and concrete clinical practice.

In order to understand the positions of these actors and their power relationships, I have specified their hierarchical position, but, since they are part of a small network of easily identifiable specialists, their identities remain deliberately vague in order to respect their anonymity. The precise location of the actors, their characteristics, and the sites of care are, nevertheless, fully integrated into the analysis.

In conjunction with the interviews, I compiled a body of empirical data based on an exhaustive literature review of 62 articles that address CD according to the following inclusion criteria:

i) treating CD as a primary or secondary subject and ii) published in Swiss medical journals, or authored by health professionals who played a role in the implementation of screening systems in Switzerland.

Construction of Chagas disease as a public health issue

From clinical invisibility to the recognition of a public health problem

The identification of a public problem is often characterized by the occurrence of unusual events that upset ordinary landmarks (Neveu 2015). Although a few case studies were published in Switzerland in the 1990s about CD (Liechti et al. 1990; Sztajzel et al. 1996), it was not until the early 2000s a few central actors identified it as a health problem that needed to be addressed through the institutionalization of treatment and screening protocols. This identification was closely associated with the appearance of clinical cases that increased the visibility of CD. Indeed, a large wave of migrants from Latin America arrived in Europe in the early 2000s.² A few years later, several clinical cases of CD were identified at Geneva University Hospitals, most of which were characterized by pronounced cardiac symptoms. In 2001, a significant placental malformation was discovered in a Bolivian patient after she gave birth at that same hospital (Jackson et al 2009b). This generated considerable interest among health professionals who faced difficulties making a diagnosis. An initial incorrect diagnosis was made, but a young doctor persisted in the inquiry because something seemed inconsistent: “I started from there, and I didn’t give up” (Louis, *central actor*, pediatrician). After several months of investigations surrounded by controversy among professionals, the placental malformation was identified as being related to an infection of *Trypanosoma cruzi* – the parasite that causes CD. As Louis explained, this unexpected disease created tensions between health care providers, leaving a first “emotional imprint” of CD:

It is Chagas disease. All of a sudden, it was not my story anymore. It had become the history of pediatricians in the department: “Oh my God, Chagas disease in Geneva!” It’s not like, all of a sudden, we say “ok we follow the recommendations.” I don’t know how to explain it, sometimes, in the medical field, you have an emotional imprint that makes us remember things better. So a little bit [...] the collective mind was imprinted in Geneva.

In 2006, a second placental malformation resulting from CD was found in the same maternity ward (Jackson et al. 2009b). In 2007, a patient died following a heart transplant that had fatally reactivated an unidentified *T. cruzi* infection. These cases, although few in number, led to the identification of an emerging pathology for which knowledge and management strategies were lacking. As one of the interviewees recounted, it was “an alert call for a public health and clinical landscape that was absolutely not prepared to deal with it” (Daniel *central actor*, doctor in a leadership position).

From identifying the scope of the situation to building scientific credibility

The occurrence of clinical cases, their emotional imprint, and a lack of means to respond to them acted as factors in raising the visibility of CD. This led health care providers to re-imagine how to approach the diagnosis and care of CD within at-risk communities of often undocumented migrants facing constraints related to health perceptions, health-seeking behavior, and their relationship with medical institutions. A few central actors took on this task and formed a local network of organized health professionals. This series of local, contextual, and singular events evolved into a problem requiring cooperation at different levels, and expanded into a network that included practitioners, researchers,

community actors, and political actors, such as the WHO and EuroTravNet, a network of clinical experts in tropical and travel medicine founded in 2008 by the International Society of Travel Medicine (Perez-Molina et al. 2011).

Since 2007, in order to identify the scope of the Chagas health problem and its possible solutions, a few health care providers initiated scientific research in Geneva. This included work to estimate the prevalence of CD, evaluate bio-psycho-socioeconomic and behavioral characteristics in adult patients diagnosed with CD, and assess diagnostic technologies and treatment practice. Considering that “a key factor of success is the mobilization of the community itself” (Bruno, *central actor*, doctor in a leadership position), they collaborated with migrant associations and organized “recruitment sessions” within the community to reach individuals at risk. In 2009, under a WHO initiative, several international experts conducted epidemiological studies in order to document the CD situation in non-endemic countries (Basile et al. 2011).

One doctor claimed during one of the interviews that the epidemiological research was not only useful for realizing the scope of the situation but also provided scientific credibility. Central actors used this knowledge to inform public health decision-makers and clinicians.

It is interesting to note that for health institutions to recognize CD as a public health issue, it was necessary that a panel of international experts shed light on the problem. This highlights the hierarchy of knowledge in which certain organizations and actors are more legitimate and powerful in bringing something into existence. Indeed, the recognition of the presence of CD in Switzerland has mainly stemmed from biomedical expertise, with social science expertise playing a limited role in both endemic and non-endemic countries, despite its importance in understanding the complex socio-cultural and socio-economic contexts of the disease (Ventura-Garcia et al. 2013). Further, in the case of Switzerland, in spite of important collaboration with community actors, directly affected minority groups have been largely absent in the publicization of CD among health institutions. As Kreimer and Zabala (2008) hypothesize, the absence of patient mobilization could be related to the often silent nature of the infection, a desire to avoid discrimination, and the fact that not all groups are equal in terms of power, influence and authority in defining the reality of a public problem (Gusfield 1984). Thus, as CD affects invisible and precarious groups of migrants in Switzerland, its recognition depends largely on the commitment of more established actors who become their spokespersons.

In January 2008, a few of these central actors succeeded in developing and implementing screening and care strategies, such as systematic congenital screenings of pregnant Latin American women at the Geneva University Hospitals. A few years later, in 2011, a small group of health professionals from the University Hospital of the neighboring city of Lausanne (Lausanne University Hospital) implemented diagnostic procedures at several health care centers (Da Costa-Demaurex et al. 2019).

This period marked the beginning of a long process of mobilization to implement health measures to manage CD across Switzerland. Indeed, these health professionals deployed several strategies: i) establishing local and international networks; ii) conducting research on CD; iii) providing care to patients and implementing screening measures at the university hospitals of Geneva and Lausanne, as well as occasionally within the community; and iv) communicating in order to educate at-risk individuals, share knowledge of the disease with fellow health care professionals, and create awareness among authorities and policymakers.

Moral values and interests as vectors of commitment and action

As Quéré and Gusfield point out, moral feelings such as indignation “play an essential role in the institution of a public problem” (Quéré 2012:26) by qualifying a situation as distressing and making it desirable to address the problem (Gusfield 1984). Thus, facing problematic situations is a prerequisite for recognizing a problem, but there is still a need for actors to lead actions. In this section, I explore how key actors frame the issue, specifically how they construct the risk of congenital CD transmission as a public health problem and justify a commitment to address it. I show that the reasons for their commitment go beyond clinical and public health imperatives, and are rooted at the crossroads of

professional ethical duty, emotions often linked to personal proximities to Latin Americans, political values regarding migration policies, and economic and academic interests.

An ethical duty

CD often lies undetected due to ignorance within the health system and decades of asymptomatic infection. Taking this with the knowledge that the disease is potentially preventable and treatable, central actors feel they have a professional responsibility and moral duty to intervene:

From a point of view, I would say ethical, [...] because it is a potentially preventable disease, [...] we have an ethical duty to intervene in this respect (Daniel, *central actor*, doctor in a leadership position).

Screenings for CD should be carried out early, because effective treatments for early stage CD are available. These treatments are less efficacious at the chronic phase of the disease. Furthermore, as CD often goes undetected, the central actors are advocating for proactive screenings organized and structured through the public health system.

If there is a pregnancy with Chagas and we don't do the test, it's horrible, because your child will have Chagas because there's a gynecologist who hasn't paid attention. (Miguel, *central actor*, family doctor).

While there is a considerable focus on controlling transplacental transmission, and thus on monitoring the health of the future child, actors also emphasize the benefits for the mother and the community. Indeed, although a proportion of “individuals with an undetermined form of CD will never develop the disease,” identifying and treating infected women in the chronic stage helps prevent the occurrence of late complications and often enables doctors to “identify other infections” among family members, especially siblings (Wagner et al. 2015:22).

Social justice for marginalized communities

Addressing the problem is not only a case of curing people by reducing the biological impact of an infection. Aside from this clinical framing of Chagas as a health problem, central actors also frame the issue from a social justice perspective. They advocate that care should consider the social vulnerability of populations and ensure that migrants without documents have access to health care (Basile et al. 2011; Jackson and Chappuis 2011; Velarde-Rodríguez et al. 2009).

Under Swiss law, all people residing in Switzerland, regardless of legal residency status, are required to take out health insurance which ensures access to care. Although the transfer of information between the health services and the immigration authorities is prohibited, several studies (Bilger et al. 2011; Jackson and Chappuis 2011) highlight the many barriers that migrants face in accessing health insurance. These include fear of denunciation to the immigration authorities, affordability of insurance, lack of knowledge about the system or lack of awareness among insurers regarding their obligation to insure undocumented people willing to be insured. Consequently, many undocumented migrants do not have health insurance. Even though the law stipulates that every person residing in Switzerland has the right to “assistance when in need including all essential resources to lead a dignified human existence” (Bilger et al. 2011:25), cantons have a degree of autonomy in the interpretation and regulation of this legislation. While undocumented migrants without insurance have access to emergency care in every canton, in Geneva and Lausanne, they can benefit from a broader range of services. Special units at the university hospitals in both cities provide undocumented migrants with “basic” care in emergency and non-emergency cases for which they pay according to their ability (Bilger et al. 2011). This decentralized structure provides an insight into why the implementation of screening and treatment for CD is a complicated issue in Switzerland, and how disparities in care organization can foster inequalities.

Solidarity with disadvantaged social groups

Various actors report that cases of congenital infections are under-diagnosed due to a lack of public health attention, which is supposedly due to a rarity of cases and the fact that it concerns a minority group in Switzerland. There is, therefore, a striking contrast between “a health system that is very generalist and does not care much for minorities” (Bruno, doctor in a leadership position), and the commitment of actors motivated by solidarity with disadvantaged social groups. In addition to a commitment to social justice, actors have also expressed the motivating value of reciprocity, acknowledging that the (often domestic sector) labor that migrants provide benefits the host society which then has a responsibility to provide quality care in return.

The neglected characteristic of the disease is another factor that drives their commitment. It motivates them to develop research projects aimed at reducing material inequalities, and building scientific knowledge in order to compensate for the disparities in research on CD. As Daniel emphasized:

They have, like other human carriers of disease [...] the right that someone is interested in their fate and to be offered effective tools. Currently, it is not the case.

A migrant-friendly landscape

The local context in which these actors operate is key: the Swiss health system consists of 26 coexisting cantonal systems whose functioning depends largely on local decision-making and cantonal political trends (Rossini and Legrand-Germanier 2010). In Geneva and Lausanne, the health care landscape is particularly migrant-friendly in comparison to the rest of Switzerland (Bilger et al. 2011). Indeed, these cities are the only places where integrated care units in a public hospital that are dedicated to the care of undocumented populations exist. In other Swiss cantons, these services are provided by NGOs, the private sector, or there is no specific infrastructure. Antonio (doctor in a leadership position), also pointed out that the attention paid to CD and at-risk populations is favored by the intersection of interest in tropical medicine and migrant medicine at these institutions, although most of them would like for CD to leave the sphere of specialists to be treated as a general medical problem. This reveals a complex process of making and categorizing of a “new” etiology within a non-endemic context, which becomes more complex as the process concerns the development of health issues that affect particularly migrant populations.

The cost-saving benefit of a cheap intervention

Actors were able to emphasize the cost-saving benefit of congenital screenings. They insist that these screenings are inexpensive, noninvasive, and simple to carry out, as it is a simple “rapid test,” which is then confirmed by a laboratory test in the case of a positive result (Chappuis et al. 2010). “We nevertheless have a luxury medicine, we treat anything, even untreatable things; so, I think we can still treat CD [...] it is nothing at all; compared to the mass of one billion and some of the financial budget [of the hospital], [...] there is no equipment, there is nothing.” (Aurélien, *central actor*, doctor in a leadership position).

Seven of the health care providers argued during the interviews that “even with very low prevalence, it remains advantageous to perform the screening [because] if we leave them without follow-up and care, it will cost us much more” (Jeanine, *central actor*, midwife). According to them, it is in the general interest of public health, as well as the economic benefit of the host society, to address the problem. They base their arguments on research that highlights the cost-effectiveness of screening all pregnant Latin American women and their infants in a non-endemic area (Sicuri et al. 2011). According to this research, it is not only less costly for the health system but also beneficial in terms of QALYs for patients. However, determining the population to be screened has to address both technical and

political tensions, for instance the choice between universal and targeted approaches and factors such as feasibility (Requena-Méndez et al. 2017). The definition of the screening population remains under discussion and controversial.

Academic opportunism

These findings show that the engagement of these health professionals is motivated by the need to address a problem that extends far beyond the local level and the implementation of screening systems within their institutions. However, this goes hand-in-hand with a certain academic opportunism, in which doctor-researchers transform the moral and medical challenge of managing CD into research projects likely to provide “a little scientific novelty” (Daniel, *central actor*, doctor in a leadership position), which is a key lever in academic careers. As one doctor explained: “After all, don’t forget that, in a dynamic where you create something, we still have other interests that you can imagine, namely publication interests” (Bruno, *central actor*, doctor in a leadership position). At the same time, the production and circulation of knowledge plays an important role in raising awareness of CD and contributing to its visibility and emergence as a public issue. This topic will be explored in the following section.

Knowledge circulation and awareness production among health care providers

Central actors are engaging in several initiatives aimed at the circulation and accessibility of scientifically validated data on Chagas in order to produce a stabilized, shared conception of the problem that extends beyond the group that developed it and involves their peers in a strategy for the detection and management of new cases. Figure 1 shows the increase in medical literature which has been published in Swiss journals or written by central actors involved in the recognition of Chagas in Switzerland since 2008.

An increase in Chagas-related publications does not always result in knowledge that can help to effectively solve socio-medical problems (Kreimer 2016). Understanding the success and constraints of knowledge circulation in clinical practice is useful for identifying factors that contribute to the recognition or lack of attention to CD. Here, I explore the point of view of both the central actors and caregivers who carry out the screening. We will see that the attention to CD is driven by contextual factors: the committed network and accessibility of written information, emotional experience related to cases encountered versus the rarity of cases, cognitive overload, and health care turnover. It is also strongly dependent on whether a health problem affecting migrants stays within a limited area of specialists, or becomes a widely shared problem.

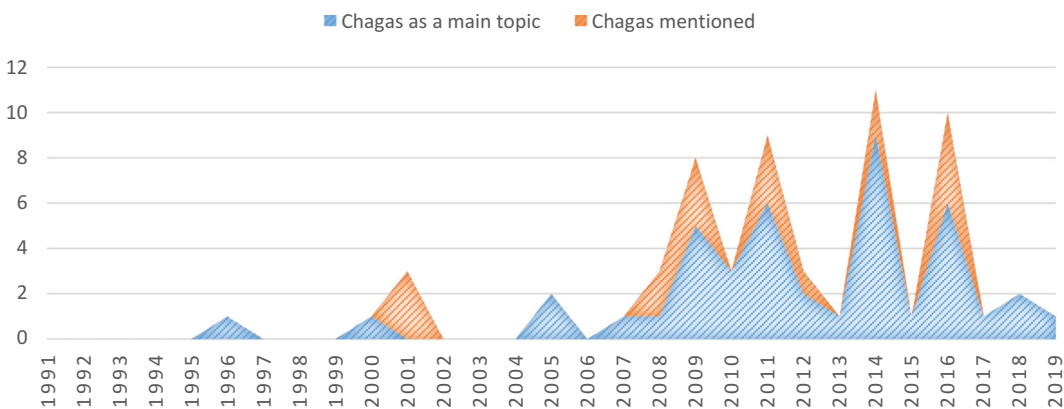


Figure 1. Swiss medical literature on Chagas disease.

Communication spread

According to central actors, health professionals do not intentionally neglect the Chagas problem. The lack of attention is because there is no awareness strategy, particularly in the academic field. As one doctor explained, “it is the lack of information [that explains the lack of awareness]. It is very rare for a health professional to intend not to inform [a patient of the congenital risk] [...] We really have a duty to inform, but we can only inform based on what we know” (Louis, *central actor*, pediatrician). To counteract this lack of knowledge, several central actors have targeted their peers by publishing articles, and training students and medical interns in hospitals, and family doctors in cities where they work as well as at national conferences and meetings.

These communications take various forms: they can be included among other topics at conferences, or through specific communication on CD. One doctor emphasized that the strategy is not only to raise awareness, but also to maintain attention on CD by engaging health care professionals in the issue during professional training. Sometimes, more informal approaches are adopted, such as interpersonal communication in non-institutional spaces. One doctor recounted: “I did something I was very happy to have done: [...] [I] ate with [...] a gynecologist, and I told him about Chagas, because I was motivated [...] and so I made him aware. A year later, he found a case of Chagas and [...] wow, I was very happy” (Miguel *central actor*, family doctor).

Several actors point out that these initiatives have had an impact on the local health care network, with out-of-hospital health professionals now contacting them for advice as to what clinical approaches to adopt with a child of Latin American origin, for example. Thus, the recognition of CD as a health issue that needs to be addressed now extends beyond the context in which screening is carried out, particularly in anamnesis practices: young practitioners who are aware of the issue refer pregnant women to hospitals with the note “to screen for Chagas” on the transfer report. Finally, most midwives working at maternity units in Geneva and Lausanne stated in their interviews that the implementation of screening has been a success, considering the number of women of Latin American origin tested during prenatal consultations: “There is a good follow-up; I frankly believe it is established. [...] It has become a mandatory systematic screening” (Hélène, *clinician*, midwife in a leadership position).

The influence of a network on clinical awareness

According to the actors, one of the central factors of their success is the existence of professional networks characterized by the presence of program managers and the establishment of working groups that meet once a year. The maintenance of databases and the coordination between different services (gynecology, pediatrics, tropical medicine, or adult medicine) is also important to ensure that no cases are “lost.” Indeed one of the main issues that occurs internationally is the loss of patients between screening and treatment due to economic constraints (e.g. fear of losing work because of absence or earning less money if salaries are on an on-time basis), and rumors about the treatment among the community (Blasco-Hernández et al. 2016; Da Costa-Demaurex et al. 2019; Ventura-Garcia et al. 2013).

The production and circulation of information among professionals and services plays an important role in maintaining attention on Chagas in this specific context. This is well-expressed by one doctor: “I think that if there are three people involved [...], it is not that complicated to do. It is just necessary to avoid that [the responsibility] rests on a single person” (Dominique, *central actor*, pediatrician).

On the other hand, screening implementation can suffer if the network is weak. In one of the regions studied, only one doctor is formally and effectively in charge of the Chagas program, and, although it is well received by the institution’s managers, the success of its implementation with the entire professional network remains unstable, particularly among gynecologists and pediatricians. According to the manager of the program, this situation remains strongly linked to a lack of

resources and time to promote, disseminate, and optimize screenings. He expressed this with regret, but also a bit of guilt: “I feel a little angry because I wish I could do more [. . .] We procrastinate a little” (Antonio, *central actor*, doctor in a leadership position). This again illustrates the way in which the process of knowledge circulation within the medical environment sometimes depends on particular individuals and their ability (in terms of time, power, and circumstances) to promote an issue.

Disseminating written materials

Mobilization also involves the implementation and dissemination of written materials – including flyers, posters, and guidelines – in health care facilities. Such materials remind health care professionals about CD and increase overall awareness. They also serve as a guide in the absence of national protocols by communicating technical information related to the management of cases and foster professional referral networks in a health system that is compartmentalized into specialties. Speaking about how awareness is linked to written materials, a midwife explained the use of posters to remind practitioners of protocols: “we knew very well because it was posted everywhere in the wards, so a very good visibility in relation to all this; we couldn’t miss it” (Hélène, *clinician*, midwife in a leadership position).

The production and distribution of written documents also played a role in motivating physicians to engage. For example, after reading a flyer a family doctor working outside the hospital decided to contact the central actors and even launch an awareness-raising campaign with fellow family doctors. It is worth noting that this doctor is an immigrant, as are many of the health care providers who pay particular attention to CD. Having a personal history of migration can play a role in motivating health care providers to engage, particularly those who speak Spanish.

However, it can be seen that the inclusion of CD screenings in protocols should not be taken for granted. For example, a central actor reported the decision of a senior physician not to include CD in a protocol document that listed screenings according to patient category, arguing that “the protocol would be too busy.” This situation reflects the large number of screenings for different conditions that physicians have to deal with, but also the threshold effect related to the clinical rarity of the cases encountered, which can mean that CD is ranked as a low-priority disease.

Erosion of the emotional imprint

One factor that determines actors’ attention toward CD is the social proximity between health professionals and at-risk populations, as encountering clinical cases leaves an emotional imprint. As expressed by one midwife: “Sometimes knowledge is lost because we don’t reactivate it [. . .], sometimes memory is due to the events that have marked us” (Laura, *clinician*, midwife conducting screening). We can see that direct encounters with Chagas are one of the main drivers of professional involvement, as illustrated by one doctor’s narrative: “I think if one day I was confronted [with an infected patient], then there would be no problem. I think in a half day I would review the literature, but, as I have never seen positive cases, I have never looked into the problem; but that’s normal” (Isabelle, *clinician*, doctor in a leadership position).

Five actors stated that the majority of practitioners have heard of Chagas disease, but are not familiar with its specificities (symptoms, available treatments, populations concerned, etc.) or recommendations for management. This situation is characterized by two determining elements: the amount of knowledge required for professionals to practice and the rarity of cases encountered in clinics. “For one part, there is a lack of knowledge: they don’t even know the indications. I’m not critical because they have to know a hundred thousand things [. . .] It is said that there are 6,000 possible diagnoses; it is tremendous” (Louis, *central actor*, pediatrician). According to one doctor (Aurélien, *central actor*, doctor, in a leadership position), if Chagas arouses the interest of professionals, e.g., during continuing education, this interest is often ephemeral and limited because of their low exposure to cases. In this context the flow of new information about competing diseases takes over.

Besides, the turnover of caregivers who have been familiarized with screenings make it difficult to maintain attention on CD in units, as there is a continuous need to update the following caregivers.

Securitized perspective versus global health inequality

In the maternity units of Geneva and Lausanne University hospitals, it is protocol to screen all pregnant women of Latin American origin. In practice, this means that midwives rely on administrative identity, physical appearance, and anamnesis, during which the question of time spent abroad is raised, in order to identify women of Latin American origin. This *modus operandi* has been strongly rooted in health care practices, not only with regard to CD, but since the outbreak of the Zika virus in 2015, which is also characterized by a risk of congenital transmission. As one midwife conducting screening explained, because the Zika outbreak was highly publicized in the media, and given the visible and debilitating consequences of the disease on children (microcephaly), Zika gained significant attention within the health system.

According to several of my informants, this difference in the treatment of the Chagas parasite and the Zika virus is also linked to the fact that sexual transmission of the Zika potentially puts non-migrant populations at risk. This raises an important political, health, and moral question: to what extent is attention paid to NTDs in non-endemic countries modulated by a securitized perspective that “focuses on the ‘risk’ posed by NTDs to populations in non-endemic countries [rather than the opinion that NTDs] are an avoidable, unnecessary, and unfair component of global health inequality” (De Maio et al. 2014:373–377).

Making Chagas a more visible and shared issue

Finally, according to a few actors, the circulation of information about CD should not be limited to the specialized research literature that professionals can consult, but should also reach the general population so that society as a whole is aware of CD. This opinion was shared by a doctor who carries out screenings: “I think that, for a better impact, it is preferable to talk about Chagas in *20 Minutes* [a free daily newspaper with a large circulation] rather than in medical journals, because information for the general public spreads” (Isabelle, *clinician*, doctor in a leadership position). This argument is based on the assumption that the strategic mobilization of public opinion would generate recognition of the problem, which would have an impact on the attention paid to it by health professionals.

Further, a few interviewees emphasize that screening should be carried out not only by specialized professionals, but also by a variety of health care providers. The latter should be brought closer to at-risk populations so that medical practice, moral commitment, and emotional experience create and maintain awareness. They spoke of involving medical interns and midwife students in screening procedures, so they can then bring their knowledge of CD to their future practices, especially outside of hospitals: “Medical interns must be involved so that they are aware and [...] that they continue to do [screening], because, otherwise, it will remain a specialist and not a general medicine thing” (Antonio, *central actor*, doctor in a leadership position); “they will work all over Switzerland, and I think they will be the driving force for the future” (Hélène, *clinician*, midwife in a leadership position).

Chagas therefore appears to be an entity whose existence is inseparable from the moral and political mobilization of committed professionals who hope that a national recommendation shared between clinics and public health would transform the disease into a more visible and shared problem.

The double burden of a neglected and rare disease

Knowledge circulation can play an important role in the process of transformation of an “emerging” and “rare” disease into a public health problem, in an environment where its endemic components are absent and medical knowledge and procedures are lacking. We have seen that the facilitating factors

for the circulation of CD knowledge, and thus its recognition by health professionals, includes, for example, the establishment of a network and the writing and implementation of protocols. Inversely, the clinical invisibility of CD, competition between diseases, and an overload of medical knowledge have reduced its visibility and awareness among health professionals. The low prevalence of cases that health care professionals encounter during their clinical practice is another key factor contributing to its invisibility.

However, the rarity of cases as a factor causing this lack of awareness can be regarded differently. Indeed, the majority of the issues encountered in the case study of Geneva and Lausanne are not exclusive to non-endemic countries. For example, the lack of CD knowledge among health workers can also appear in endemic countries (Martínez-Parra et al. 2018; Ventura-Garcia et al. 2013), and for interventions to be successful, a number of challenges must be addressed, such as the maintenance of awareness due to limited human resources, high staff turnover, and implementing close follow-up by personnel (Pinazo et al. 2020).

Further, despite the increased coverage and capacities of the diagnosis and treatment of congenital cases of CD in Latin America (PAHO 2017), the prevalence of its vertical transmission remains high (Santana et al. 2020). Yet, since CD affects an estimated six to seven million people, we might expect this prevalence to be reflected in the research agenda or public health priorities (Manderson 2012), but this neglected disease remains “under-diagnosed, under-studied and under-treated” due to poverty and lack of political will (De Maio et al. 2014). These aspects, along with the lack of training on CD in many educational settings, contribute to a lack of awareness and inadequate clinical mastery.

In an article published in 2014, in which the sociopolitical framing of NTDs is compared with that of emerging infectious diseases, the authors underline that these two “disease groups” are the result of a sociopolitical construction serving different interests. They highlight that the term NTD invokes diseases neglected by people and institutions, and refers to “processes, structures and systems of neglect and the politics behind it” (Jackson and Stephenson 2014:997). NTDs are often described as “orphans of profitability.” They overwhelmingly affect people of low socioeconomic status, and their prevention and treatment are often neglected, notably in terms of the development of pharmaceutical drugs (Crompton et al. 2011; Villa et al. 2009).

The question of how the disease is perceived and classified is important because words carry political weight and repercussions. The label “neglected” influences how NTDs are addressed (Jackson and Stephenson 2014; Vanderslott 2017). Thus, even in non-endemic areas, CD must be considered less as a rare disease than as undergoing a complex dynamic of negligence while affecting millions of people. In these contexts, CD carries the double burden of being a neglected disease and a rare disease overwhelmingly affecting migrants. This means, once CD is identified as a public health problem, it is not sufficient to develop and implement medical protocols. Additionally, the hard work is overcoming the health barriers that plague migrant communities. Most at-risk migrants are already in precarious situations, and located in a socio-political context where being a migrant is a disadvantage.

Conclusion

In this article I focus on the implementation of congenital screening in two hospitals of Geneva and Lausanne, so as to explore how attention to health risks that affect migrant populations in a non-endemic country can be generated. Since CD is a NTD embedded in profound mechanisms of invisibility, its recognition as a public health problem requiring medical screening implementation is particularly dependent on the mobilization of actors located within a migrant-friendly structural context. Such commitments are based on medical but also political and moral reasons related to the precariousness to which migrant population may be exposed and an imperative to reduce social inequalities.

Focusing on the clinical aspects of Chagas recognition, and based on the comments of actors involved in the implementation of screenings, I have discussed the integration of Chagas in the agenda of public health at the local level as well as among health professionals. My research will later be

complemented with the analysis of other key actors' viewpoints, including political decision-makers and community associations, in an effort to continue exploring the socio-political determinants that influence policy regarding the prevention of Chagas transmission in Switzerland. Correlatively, it will be extremely important to understand the perspectives and experiences of pregnant migrant women infected with Chagas and undergoing congenital screening.

Thus, in conducting this research, I aim to uncover linkages that go beyond the case of Chagas disease in Switzerland and help us to better understand processes of public health agenda creation around NTDs in non-endemic countries. An understanding of how public health policies are produced can also help to provide the tools needed to build a more equitable and fairer public health system for all, regardless of nationality, citizenship status, ethnicity or gender.

Notes

1. Personal communication with a representative of Swisstransplant.
2. Due to a lack of data, information about Latin American immigration to Europe in the early 2000s is limited (Pellegrino 2004). According to the statistics, from 1990 to 2005 the number of Latin American residents in Switzerland has increased from 13,920 to 38,464. These numbers do not take into account undocumented people (Bolzman et al. 2007).

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Notes on contributor

Elise Rapp is currently a doctoral assistant at the School of Health Sciences (Haute Ecole de Santé Vaud - HESAV), University of Applied Sciences and Arts Western Switzerland (Haute Ecole Spécialisée de Suisse Occidentale - HES-SO) and a doctoral candidate at the University of Lausanne, Switzerland (UNIL). Her work explores the management of neglected tropical diseases in Switzerland through a sociological lens. She is also a nurse specialized in tropical medicine, and a biologist with a master's degree in evolutionary parasitology.

ORCID

Elise Rapp  <http://orcid.org/0000-0002-4100-6164>

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