



Sociocultural dynamics that influence Chagas disease health care in Colombia

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ABSTRACT

Chagas disease (CD) is a Latin America endemic and neglected tropical disease that affects primarily poor people living in rural areas. Its current low profile leads to many diagnostic, treatment, and control challenges. This study aimed to identify and characterize the sociocultural dynamics that influence CD health care in Colombia.

Data for our ethnographic study was collected in 2013 and included participant observation in two main endemic areas in Colombia. In addition, 81 people belonging to four groups (patients and family members; health care workers; researchers; and officers) were recruited through snowball sampling technique and participated in informal and semi-structured interviews. People from the first two groups also participated in social cartography exercises.

Data analysis resulted in the identification of three main sociocultural dynamics. *Local Understandings*: Patients reported confusions around disease transmission, treatment effectiveness and development of future complications. *Providers' Knowledge and Training*: Failures in professional's knowledge and training mostly affect the primary level of care in rural areas. Professionals undergo minimal training during medical school and lack access to continuous education. In contrast, clinicians working at tertiary university hospitals or at the CD unit of the Colombian National Institute of Health (NIH) exhibited great knowledge and competency. *Health Care System Barriers*: The Colombian market-based health care reform augmented access barriers, which impacted CD care greatly. We identified geographic and bureaucratic itineraries that depended on type of insurance plan, insurance contracts with service providing institutions, and levels of care.

This study shows that people's experience of these sociocultural dynamics vary depending on their mobility from rural to urban contexts. It unveils the importance of analyzing the structure of the health care system. In the Colombian case, its for-profit orientation has become one of the most important obstacles for comprehensive, integrated, and timely health care responses.

1. Introduction

Chagas Disease (CD) is a vector borne disease (VBD) endemic to Latin America. In this region, the triatomine bug and zoonotic foci carry the causative parasite *Trypanosoma Cruzi*. The estimated prevalence is 1 infection per 100 habitants for a total of 5.7 million in the region (World Health Organization, (WHO), 2015). CD affects primarily poor people living in rural areas whose household and job conditions are precarious. Usually, the infection occurs at a young age and then a silent period of decades ends when clinical manifestations develop. Around 30% of infected people develop cardiac disease or, less frequently, digestive and neurological alterations (WHO, 2015).

Etiological treatment effectiveness and the physiopathology of cardiac alterations as a result of the infection remain controversial (Morillo et al., 2015). In adults without advanced heart disease, etiologic treatment could reduce the parasite load and control disease progression (Lescure et al., 2010). Notwithstanding current debates, clinical guidelines recommend etiologic treatment with Benznidazole or Nifurtimox in people younger than 19, acute infections and to prevent congenital transmission. All infected people who have not yet developed clinical manifestations should be offered antiparasitic treatment (Dias et al., 2016; Lescure et al., 2010; Rassi et al., 2017). In its chronic form, the recommended treatment follows specific organ complications. The most important public health strategies to control CD are vector

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control interventions, community education and engagement, and blood bank and prenatal screening (Lescure et al., 2010). Given the challenge of lack of health infrastructure in remote areas, strategies such as housing improvement, community participation, and health education have shown promising results (Santana Rangel et al., 2016; Sartor et al., 2017).

CD transmission rates, the specificities of prevention control campaigns and diagnosis and treatment procedures have changed according to historical, political, and cultural dynamics (Briceño-León and Méndez Galván, 2007; WHO, 2015; Zabala, 2009). The progress of national and international parasite and vector control programs faced the challenge of infected patients migrating to urban areas and non-endemic places around the world (Nunes et al., 2013), where they faced stigmatization and difficulties finding jobs and getting adequate health care (Dib, 2011; Minneman et al., 2012; Sanmartino, 2009; Storino et al., 2002; Ventura-García et al., 2013). During this period, limited availability of resources, lack of political will, and significant barriers to diagnosis, treatment, and control in both endemic countries and around the world led the WHO to include Chagas disease in the list of 18 “neglected diseases” (Hotez et al., 2007, 2008) or Neglected Tropical Diseases (NTDs) (Manderson et al., 2009; WHO, 2015). Hence, clinicians and scholars working on CD argued for increasing funding and elevating CD as “an international health priority” (Ventura-García et al., 2013, p. 1; WHO, 2013).

Of special interest for our study is the research on the sociocultural dynamics and people's experiences and interpretations of CD (Dell’Arciprete et al., 2014; Forsyth, 2015; Manderson et al., 2009; Ventura-García et al., 2013). Studies report that people have difficulties understanding the specific etiological, clinical and therapeutic aspects of different VBDs (Ávila Montes et al., 1998; Azogue, 1993; Magnani et al., 2007; Parker and Allen, 2014; Pinto Dias and Borges Dias, 1985). People may or may not associate household bug infestations with the infection or with cardiac alterations that develop later in life (Dib, 2011; Sanmartino, 2009; Ventura-García et al., 2013). Prevention and control programs, including those geared to improving household conditions, face rejection from some communities, in part because these programs lack cultural sensitivity and health care personnel are poorly trained (Dell’Arciprete et al., 2014; Magnani et al., 2007; Manderson et al., 2009). Notwithstanding the importance of these studies, social scientists claim that we need more research on the sociocultural dynamics of NTDs (Bardosh, 2014; Ventura-García et al., 2013). Bardosh (2014), for example, argues that we still need to understand how globalization, policy, and the institutional characteristics and organization of health care systems influence NTD programs and interventions. He also argues that we still do not know how class, gender, race, age, and livelihoods create differences between how groups get sick, access health care, or challenge community based programs. Furthermore, more studies are needed to understand how war, migration, and the global distribution of research funds and drug development impact the effectiveness of interventions that tackle NTDs (Bardosh, 2014; Manderson et al., 2009), and whether or not the interventions address the structural determinants of NTDs or depoliticize local efforts to address them (Parker and Allen, 2014).

Our research focuses on Colombia, where estimates indicate that 437,960 people are infected with *T. cruzi* and 4,813,543 are at risk of infection (WHO, 2015). Chagas disease is concentrated in two main areas of the country: the east, comprised of seven departments (the Colombian designation for province or state), and the northern Sierra Nevada highland (Guhl et al., 2007). In these regions, there are 25 triatomine species, with *Rhodnius prolixus* and *Triatoma dimidiata* being implicated as the main species transmitting *Trypanosoma Cruzi* (Guhl, 2005). Improvements in case reporting strategies and blood bank screening have resulted in higher reported prevalence in recent decades (Guhl, 2007). We could identify only two studies that report sociocultural aspects of CD in Colombia, both of which were limited to the disease's perception by indigenous communities (Dib, 2011; Ríos-

Osorio et al., 2012).

It is significant that in 1993 Colombia underwent a drastic market-based health care reform that introduced a mandatory and universal individual insurance scheme and for-profit insurers as administrators of the system (Hernández, 2002; Iriart et al., 2001; Yepes et al., 2010). One of the main structural problems of the system was the establishment of two different clinical packages and costs of premium/capitation unit called subsidiary or contributory regimes, which depend on people's payment capabilities. Furthermore, the insurance companies receive all the system's resources but refuse to pay providers' bills, a practice that has driven the system to a major functioning crisis (Molina Marín et al., 2010). In addition, patients experience a lengthy process of authorizations as insurance companies deny treatments, medications and procedures, even those covered, which resulted in the largest number of cases of health care judicialization in the world (Abadía-Barrero and Oviedo Manrique, 2009; Lamprea, 2017). Against the law, insurance companies established vertical integration with clinics owned by the same financial and commercial groups, establishing highly inefficient and unequal monopolies and oligopolies that provide poor quality health care (Bejarano-Daza and Hernández-Losada, 2017). Moreover, most insurers have been accused of illegal use of resources and embezzlement, many of them being forced to close down as patients have been transferred to other insurers.

Furthermore, public health programs, including infectious disease programs, were decentralized and defunded (Borrero et al., 2012; Hernández, 2002). Local health authorities did not have the level of expertise that officers from the former centralized programs had. In addition, decentralization did not come with resources allocated to run specific programs and the importance given to each program depended on local politics, which often resulted in programs being totally abandoned or reduced to a handful of ineffective activities (Borrero et al., 2012; Hernández and Obregón, 2002; Ministerio de la Protección social et al., n.d.). Over time, a restructuring of specific programs and population-level interventions started to take place either as part of individual insurance plans or as special programs run by local and national public health authorities. The Ministry of Health recognizes that there are failures in detecting acute cases of CD, problems in intra-household control, and barriers to accessing diagnosis and treatment (Ministerio de la Protección social et al., n.d.). In 2008, the Ministry of Health set up a national program aimed at controlling, preventing and treating CD. In 2011, the Ministry offered recommendations for diagnostic and treatment pathways that align with the current market-based structure of the system (Cucunubá et al., 2017). Therefore, in Colombia, we highlight a context characterized by 1) minimal knowledge around the sociocultural dynamics of CD, and 2) a radical transformation of the country's health care system that hindered infectious disease control programs and clinical care of affected populations. In this study, we aim to identify and characterize the sociocultural dynamics that influence CD health care in Colombia.

Our study is part of a larger scientific effort to assess the status of CD in Colombia. Importantly, the network has already published one study to explore how the health care system serves those suffering from CD (Cucunubá et al., 2017). This published study focuses on the macro-components of the supply side of the health care system (i.e. a macro-policy model) and the authors do recognize that the demand side and social values are potentially undermined (Cucunubá et al., 2017). Nonetheless, their results offer important information for our purposes, such as estimating that the coverage of screening is only 1.2% and etiological treatment coverage reaches barely between 0.3 and 0.4% of the 437,960 cases estimated to be in need of such treatment. It also provides some important information about how four domains of the supply-side of the health care system (financing, payment, regulation, and organization) influence diagnosis and treatment of CD, which stand as crucial explanations to the alarmingly minimal coverage of screening and etiological treatment. Hence, our study complements their results by offering an on-the-ground and ethnographic look at the experiences

of those affected by the disease and exploring the sociocultural dynamics that surround their relationship with the health care system.

2. Methods

Our ethnographic research is grounded in critical medical anthropology (Singer, 2015; Singer and Baer, 2012), meaning an ethnography that pays particular attention to the merging of critical political economy with health outcomes. The study was approved by NIH's ethics committee (FOR-R03.0000–005) and pseudonyms are used to protect the identity of participants. Data were collected in 2013 through participant observation, formal and informal semi-structured interviews (Tashakkori and Teddlie, 2003), and social cartography (Delgado and Gutiérrez, 1994) in several municipalities of two departments. At the department of Casanare, we collected data at all 8 municipalities of the piedmont of the eastern Andean mountain chain, which are considered endemic areas for CD. At the department of Cundinamarca, we collected data at two municipalities located at the same piedmont area where one of the investigators had access to known CD cases and health care institutions. We also collected data in Bogotá, given that the main referral units are in the capital and we could find experts, researchers, and patients. In particular, we collected data at the country's NIH where CD patients are referred to from other regions of the country or where people who test positive in blood banks are first directed to. In addition, we interviewed people at three tertiary hospitals in Bogotá that have cardiologists who specialize in treating CD patients. Ethnographic data were contextualized with secondary sources that included the history of CD in the country and the specific geographical, cultural, economic and political contexts of both departments.

Social cartography took into consideration the Latin American construct called social determination of health-disease-treatment process (Breilh, 2003). A geographer and an environmental manager led the social cartography aspects of the research and helped trained the team of researchers. Two different groups participated in the elaboration of social cartographies. Cartographies with technicians from VBD's programs dealt with the most important economic activities of the region and the location of the vector and of CD patients. Cartographies with people living with CD and family members centered on education, living conditions, health, work, recreation, nature surroundings, utilities, nutrition, social participation and health care access routes. Figures or images aided the exercise. Each person created his/her own map and discussed it in groups, which helped bridge the social cartographies with the larger ethnographic study.

For the interviews and social cartography, 81 people were recruited through snow ball and convenience sampling techniques (Miles and Huberman, 1994). Participants belonged to four groups: 1) 38 patients and family members; 2) 20 workers from health care secretaries and VBD units; 3) 8 CD researchers; and 4) 15 health care providers including general practitioners, specialists, registered nurses, and nursing assistants from endemic areas. The last two groups participated in interviews only.

Three experienced field research assistants participated in an intense training on the specificities of CD, the structure of the health care system, and the different methodologies. Data collection and analysis was conducted in consecutive moments as follows: 1) one month of data collection, 2) one month of group data analysis, 3) one month of additional data collection, and 4) final group data analysis. Field researchers wrote initial reports of each of the two departments, which were commented and expanded in several sessions. Material for final analyses consisted of the initial reports of the two departments, field notes, interview transcriptions, social cartographies, notes on group discussions, and secondary sources. Photographic archives also aided in the data reporting and analysis process. Threats to validity (i.e. different viewpoints among researchers, contrasting or contradictory information, and whether or not analytical categories encapsulated adequately some or the whole data) were considered both in the data

collection process and in the final qualitative analysis (Maxwell, 1996), which was conducted in different sessions by the whole team. The different sources and different view points of the interdisciplinary team of researchers served to triangulate the information. A content analysis approach as described by Flick (2007) resulted in the themes presented in the results section.

3. Results

The results section is divided into three main themes that derive from the data analyses: Local Understandings, Providers' Knowledge and Training, and Health Care System Barriers. Each section starts with a short patient narrative, exemplar of the main theme. Data from clinicians, program officers/researchers, social cartography and field notes are added to help in the interpretation and contextualization of each theme. Even though each region is imbued with specific characteristics, we did not identify regional differences with respect to the disease's sociocultural construction or the experience of illness. Initially, we had thought that each region would yield important information about the country's sociocultural variability. However, we found that there were not drastic differences between the two studied departments and many CD patients did not remain confined to rural areas but, rather, it was frequent that out of economic needs or family dynamics, they moved to semi-urban and urban locations. Hence, the larger sense of mobility reported in the literature (Nunes et al., 2013; Ventura-Garcia et al., 2013) challenged the initial regional division between rural/highly endemic areas and urban centers and forced us to think of themes that could connect both departments with different histories of mobility.

3.1. Local Understandings

About eight years ago, I started feeling very tired. The doctors didn't know what I had. Then, I was referred to Bogotá and the doctors said that my only chance was a heart transplant. I got the transplant three years ago and since then, I don't think about Chagas anymore. The doctors said that if after ten years I am fine, then I won't have Chagas anymore Now I know what Chagas disease is, because of the things I learned at the hospital: that the female pito [triatomite bug] affects men and the male pito affects women. Before, in Tauramena [a small town in the department of Casanare], I got a pamphlet that had all the information on the pito, but it didn't explain well which one affected men and which one affected women.

Alirio, 63 years old, interviewed in Bogotá. May 9, 2013.

Alirio's narrative illustrates the many difficulties that people have understanding the etiology and physiopathology of CD. This misunderstanding is usual for other VBDs given that it is difficult to understand that “inside” a bug there is another microorganism that causes a disease. Myths and other cultural explanations add to the disconnect between the medical and local narratives (Asavarut et al., 2016; Bardosh et al., 2014; Forsyth, 2015; Manderson et al., 2009). Interestingly, people may re-evaluate the importance of the diagnosis and the infection compared to cardiac complications, if the latter develop. Several family members were adamant in ruling out a CD diagnosis given that they knew that “it kills people.” However, the data illustrated that once people develop cardiac complications, all the efforts of patients, family members, and health care networks concentrated on the cardiologic treatment. Patients who developed cardiac disease and their relatives did not refer to their condition as a result of CD but rather as “heart problems” that required “controls,” “pacemakers,” or “transplants.” Other patients mention “thrombosis,” “fatigue,” or “my legs are not working right.”

As it has been reported in other studies, many patients commented that it was very hard to associate an early childhood infection that nobody even noticed with the development of heart disease later in life (Dell'Arciprete et al., 2014; Ventura-Garcia et al., 2013). As Alirio's case

illustrates, educational materials and campaigns and even the advice of clinicians seemed to be ineffective in transmitting clear messages around the disease (Forsyth, 2015).

People who were diagnosed as children through screening research protocols that aimed to establish the disease seroprevalence in endemic areas and benefited from etiologic treatment seem to not care anymore about CD. Even a VBD program technician who had been infected was not willing to accept the idea that he needed to have yearly medical exams and denied that he had any health problems. Rather, he said, “diseases are psychological, just like feeling old. There are true diseases that lower your defenses. Fortunately, that is not my case and that is why I don't pay too much attention to it [CD].” Some patients who developed side effects to the etiologic treatment were more adamant to the idea that there was nothing wrong with them.

In contrast, young adults who were diagnosed through blood banks and we met at the National Institutes of Health shared the biomedical knowledge and refer to their condition as “having been infected by Chagas” and “being in control to prevent complications of Chagas disease” or to “assess the progress of Chagas disease.” In informal conversations during the ethnography, they reported that they kept their yearly follow-up appointments, mostly because they liked the care they received by the doctors and the unit proactively called the patients to schedule the appointments. Hence, the range of experiences indicate that whether people develop organ complications paired with the kind of program one has access to and people's age, migration history, and educational level influence their knowledge about CD and their approaches to treatment and control.

3.2. Providers' knowledge and training

My left eye swelled and I had such a headache. The doctor said it was acute sinusitis, and she prescribed antibiotics and pain medication. Since I didn't get better, she referred me to an ENT doctor way over in Yopal (capital city of Casanare Department), but he didn't change the sinusitis diagnosis; he just changed the treatment. Days later I started to feel tightness in my chest and I couldn't breathe. I ended up at the hospital and an internal medicine specialist told me that what I had was acute Chagas disease and that I could be having a heart attack. I ended up hospitalized for 20 days ... Nowadays I prefer to go to the city for medical care and even better if I can get a direct appointment with the specialist because the doctors in my town don't know anything.

Amanda, 19-year-old college student, interviewed in Casanare June 7, 2013.

Amanda's case reflects clinicians' lack of knowledge of CD. One physician affirms Amanda's interpretation when, she said, “you cannot diagnose what you don't know.” Another recent graduate in the mandatory social service commented “I do remember I learned something about VTD perhaps in fourth semester, but we did not review that ever again. To tell you the truth, you really learn about those diseases here.” This physician argued that she has learned quite a bit about Dengue but that she had not seen a CD case. She suggested that we talked to another physician who had been working in several CD endemic regions for over twenty years. Surprisingly, he pulled out a medical textbook from his library to check the specificities of CD while he told us that “I am yet to see a Chagas patient.” According to our data, both recent graduates and experienced clinicians working in endemic areas may not be aware of the disease or be prone to include it in their differential diagnosis.

One of the national experts on CD and a health care professional working at the health care secretariat in one of the endemic areas agreed that health care personnel in endemic areas showed knowledge deficiencies and lack of training. One experienced clinician added that “in these regions it is very difficult to get any sort of training.” Her explanation reaffirms calls by experts to improve training/capacity-building of health care personnel at the primary care level (Marchiol et al., 2017). Health care officers from the Ministry of Health and the Colombian NIH commented that they do provide training about CD and

other vector borne diseases in endemic areas or in Bogotá. They acknowledged, however, that the effectiveness of training sessions is compromised by the high turnover of health care personnel and the inability of key clinical personnel to attend, given the time and financial constraints faced by local health care institutions. Despite the efforts conveyed by specific health care personnel in directorship positions, all the interviewees pointed to three main obstacles to effective training of health care personnel in endemic areas: 1) there is a high rotation of personnel given that in endemic areas most clinicians are fulfilling their mandatory social service with appointments lasting between 6 months and 1 year, 2) the entities (both health care institutions and insurance companies) decide what is priority in terms of training and resources and there are no consequences for lack of training, and 3) even the contract of physicians who have finished their mandatory social service are temporary and include only clinical tasks. The few personnel with permanent positions or with contracts that include administrative tasks are not the ones providing clinical work and are forced to attend these trainings. Fieldwork notes and group discussions among the research team confirmed that the existing efforts are ineffective in reaching the physicians who are providing the first level of care for CD patients.

In light of the clinicians' minimal knowledge and training difficulties, these data raise serious concerns about failures to diagnose infected people in endemic areas, even with distinctive manifestations such as in Amanda's pathognomonic Romana sign. This worrisome scenario adds to research reports that denounce the deterioration of training and working conditions of physicians in Colombia (Molina et al., 2009).

We found a drastic difference between the knowledge of the disease's manifestations and treatment protocols between clinicians working in endemic areas and those of the CD unit of the Colombian NIH in Bogotá. Cardiologists working in tertiary university hospitals also exhibited up to date knowledge, rapidly linked clinical symptoms with the patient's social history, and ordered appropriate tests to rule out the infection. These data suggest that this disjunctive knowledge between endemic areas and referral centers is behind the challenges that patients face in rural areas to receiving accurate diagnoses and prompt medical care (Azogue, 1993; Dell'Arciprete et al., 2014; Manne et al., 2013). While it might be argued that the differences in knowledge between levels of care (primary health care centers versus referral units) or between rural versus urban centers is logical, the data indicate that health care personnel working in primary health care centers do not have the basic knowledge they should according to the 2014 revisions to the national guidelines to be more relevant for primary health care settings (Marchiol et al., 2017). At the very least, they should be able to include acute and chronic CD in their differential diagnosis, order initial tests, and, if positive, order confirmatory testing (currently unavailable at the primary health care level) and follow up with etiological treatment and further assessments, as has been recently recommended (Marchiol et al., 2017).

3.3. Health Care System Barriers

Months ago I felt sick, I couldn't breathe. The doctor from my town (Medina, department of Cundinamarca) said that I had bronchitis. After my mom insisted, the doctor sent me for a special test in Villavicencio (capital of the bordering department of Meta). I had to go there three times until they finally told me that I had Chagas. Then, I was referred to Bogotá to get some heart tests but it took them two weeks to schedule them. Fortunately, a sister of mine lives in Chía [a town close to Bogotá] and I stayed with her. Then, I had to go back to Villavicencio for another test, for which I had to pay in full [63,000 Colombian pesos, around \$25 USD] ... To get my heart medications I have to go all the way to Villavicencio every month, which is difficult because I don't have a job. But let me tell you that for each appointment or test I have to first request an authorization at the EPS [insurance company] and they take like two months for each authorization.

Patricia, 42 years old, interviewed in Bogotá. August 13, 2013.

Besides reinforcing the previous data that indicate lack of adequate physician's training, Patricia's case illustrates the fragmentation dynamics created by Colombia's market-based health care reform of the 1990s (Abadía-Barrero and Oviedo Manrique, 2009; Hernández, 2002; Yepes et al., 2010). We interviewed some patients that were suffering from cardiac complications but given their level of poverty they were unable to continue with medical care. When asked why she had stopped treatment, Alcira, who had developed cardiac complications said: "[because I didn't have any money to be traveling to Bogotá all the time. It was almost a year that I didn't take any [medication]. Only when I felt very sick again, I went back to the doctor." Importantly, the interviews and social cartographies showed a correspondence between poverty, rurality and lack of care. As families moved to semi-urban or urban areas in search of better economic opportunities or as a result of forced violence, they gained economic resources and social capital and were able to handle geographic, economic and bureaucratic barriers more effectively.

One health professional in clinical pathology from the Department of Casanare explains: "for families coming rural areas, it is a whole nightmare. Imagine, they have to come at 4 a.m., stand in line, ask for the appointment. Many [insurance companies] have online appointment systems. First access barrier. Then, if they managed to get the appointment, the doctor listens to them very quickly [out of time constraints]. If they are lucky enough, they meet a physician who knows about Chagas and orders the test. Second access barrier. If the doctor orders the ELISA [for confirmatory testing] adequately, that is a test done at the secondary level, so the patient has to go to Bogotá and to the insurance for authorization. The insurance starts to screw them around, pardon my French." She concludes with the image of a peasant dealing with the enormous bureaucracy that the insurance companies have instituted in the city in order to depict the absurdity of rural patients with CD, the great majority belonging to the subsidiary regime, trying to circumvent the access barriers imposed by the system. Years of accumulated frustration were evident in the kind of language she used. Importantly, her explanation connects the three sociocultural dynamics we are explaining.

Social cartography aided in reconstructing these itineraries and helped us illustrate how the different fragmentations forced patients to manage several appointments and maneuver different authorizations. These data corroborated the clinical pathologist assessment: people's economic resources and social support networks influenced how successful they were in facing the many obstacles imposed by the health care system (Arrivillaga et al., 2009; Ewig and Hernández, 2009).

Health care system's problems, however, also affect the cities. A cardiologist working at a University hospital and expert in heart failure indicated that she had "lost" some CD patients. In her case, Rosita, a patient from the subsidiary regime, had been transferred to a lower level hospital that could not perform the transplant she needed. The cardiologist commented that both she and the patient were crying. "She needed a transplant. She was young and she would tell me 'don't let them take me.'" She explained that while the insurer had a contract with the hospital for cardiac care that included transplants, it did not have a contract for "chagas" care, reason why the patient was not authorized to continue the treatment with her. She also remembered Víctor, a patient from the contributory regime that she also "lost." "The contributory regime also fails me," she said. The problem with Víctor was the same as with Rosita, the insurer did have a contract with the hospital for "heart transplants" but not for "chagas." The difference was that Víctor was transferred to another facility that *could* do the transplant.

Patients are well aware of the problems of the system. Miguel, a middle-age man who had already received the transplant said that "controls are a real problem. You have to start like a month and a half in advance to ask for the appointment. So much paperwork and so little money." In his case, he was living in Medellín where he took heart

medication for five years until he was told he needed a transplant. He was sent to several institutions without contract or installed capacity for his level of care. He learned how to sue the insurance company and he said proudly, "I did it myself." The judge granted him integral care, which allowed him to be transferred to Bogotá and have the required test and the transplant performed.

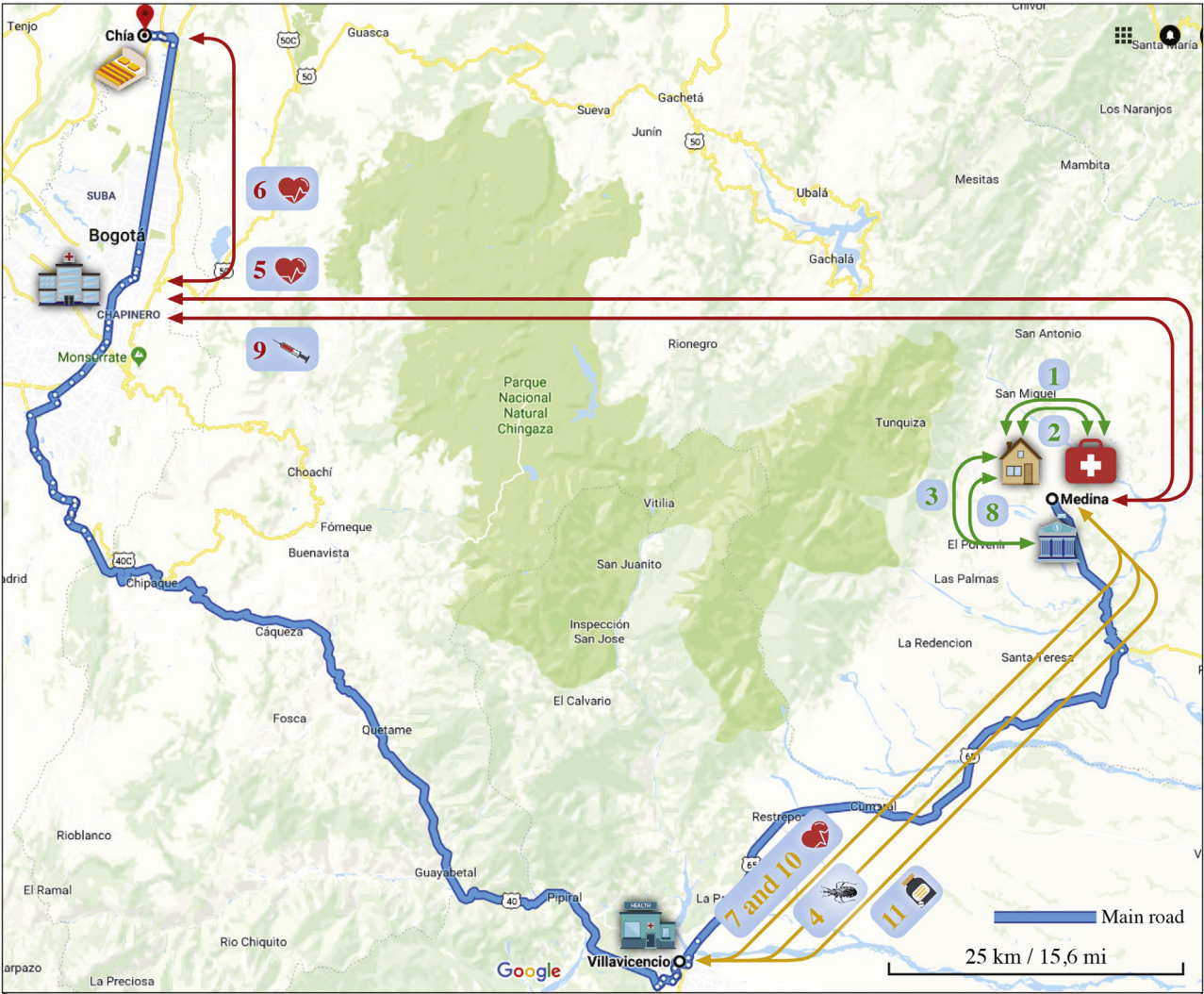
Several analyses sessions allowed us to postulate that the fragmentations of the health care system that affects CD care depend on: 1) *Insurance Plans*. The specifics of the individual health insurance plan whether subsidiary or contributory affect patients' level of difficulty in navigating the administrative complexities of the system, bureaucratic itineraries (Abadía-Barrero and Oviedo Manrique, 2009), and associated out-of-pocket costs. Patricia, Miguel and Rosita have "subsidized" insurance plan, which is known to have more barriers to access and fewer participating health care networks; hence, less de facto coverage (Arrivillaga et al., 2009; Ewig and Hernández, 2009). These differences could explain why Rosita did not have the same referral as Víctor and why people like Miguel are forced to resort to the judiciary. 2) *Insurance Contracts with Service-providing Institutions*. Insurance companies contract services with different health care institutions, and patients such as Patricia find themselves in situations where different institutions handle different aspects of their care (certain appointments, laboratory tests, or medications). Social cartography and interviews demonstrated that this fragmentation is experienced differently in urban contexts and rural areas. In cities, it can be exhausting and expensive to get around on public transportation between insurance companies' authorization centers and different health care facilities. In rural contexts, a handful of institutions manage all the contracts with insurance companies for both regimes and provide most services. As has been discussed in other studies (Molina Marín et al., 2010), however, we also identified cases in which patient care was affected because insurance companies suspended contracts with health-providing institutions or contracted out services based on cost rather than proximity. This was true in both rural and urban contexts. 3) *Levels of Care*. Different aspects of CD diagnosis and treatment are included in the system's different levels of care, which results in many trips to different centers. For example, the echocardiogram and Holter, which are considered secondary level of care according to the system's decrees, are usually available in semi-urban or urban centers.

Fig. 1 illustrates Patricia's geographical barriers, bureaucratic itineraries, and time demands that the fragmentations of the health care system impose on patients.

As others have reported, the gap between rural and urban areas in relationship to human resources and health care institutions creates further challenges for timely and adequate diagnosis and treatment of CD in Latin America (Santana Rangel et al., 2016; Sartor et al., 2017). Rural areas are characterized by sparse health care services and poor transportation systems, which adds to the time needed to seek health care services, specially for more complex procedures or levels of care (Santana Rangel et al., 2016; Sartor et al., 2017). While the system stipulates that transportation costs in remote areas should be covered by the system, patients need to fit several requirements and, if eligible, fight for it. In Colombia, in addition, private health care institutions took over the market of health care services in the five most populated areas and offer the great majority of higher level health care services. Most semi-urban and rural areas have predominantly public health care centers (many have only one) that provide a very reduced number of services of low and medium complexity that are insufficient to provide a first level of care (Amaya et al., 2013; Banco de la República, 2014). This is true for both subsidiary and contributory regime.

4. Discussion

Our results support the argument that CD should be a health care priority given the many significant problems that continue to exist in terms of people's understanding of the disease, lack of awareness, poor



Medina - Villavicencio: 75 km / 46 mi, approx 2 hr*
Medina - Bogotá: 196 km / 122 mi, approx 5 hr*
Bogotá - Chía: 38 km / 23 mi, approx 1:30 hr*
*average trip time on public transportation

#	SERVICE TYPE	PLACE WHERE IT IS PERFORMED	TIME THE PROCESS TAKES
1	First appointment	Medina	
2	Pneumonia diagnosis/treatment	Medina	1 month
3	Authorization for diagnostic test	Medina	2 months
4	Chagas diagnostic test	Villavicencio	
5	Scheduling of holer and echocardiogram	Bogotá	15 days
6	Holer and echocardiogram	Bogotá - Chía	
7	Cardiologist appointment	Villavicencio	
8	Laboratory test authotization	Medina	2 months
9	Laboratory test	Bogotá	
10	Cardiologist control appointment	Villavicencio	Every 3 months
11	Pharmacy/medications	Villavicencio	Every month



Fig. 1. Access barriers imposed by the health care system, Patricia's case.

training of health care personnel, and access barriers to diagnosis and treatment. Our results confirm that people living in rural areas face greater access barriers to Chagas disease's diagnosis and treatment (Forsyth, 2015; Santana Rangel et al., 2016; Sartor et al., 2017). We also found, however, that people's understanding of CD and health care options change depending on their location: rural, semi-urban, and urban centers (Sanmartino, 2009; Sanmartino et al., 2015; Ventura-García et al., 2013).

This study also illustrates several of the challenges that control, prevention, and treatment efforts face in terms of people's interpretations of the disease (Dib, 2011; Sanmartino et al., 2015; Uchôa et al., 2002). Confusions about disease transmission, treatment effectiveness, and the development of complications as a result of the infection may result from differences between the biomedical understanding of the disease and people's lived experiences and explanatory models (Forsyth, 2015). If the control of CD is important to biomedicine, for the majority of the people in our study the disease is only important when and if cardiac complications develop. In contrast, Bolivians offer structural explanations to their conditions and have incorporated the idea that CD can be controlled but can never be cured (Forsyth, 2015). People's confusions about CD, both in our study and elsewhere, might also parallel the current status of the debates around the pathophysiology and effectiveness of etiologic management of CD (Viotti et al., 2014).

While we also identified the social dynamics of visibility/invisibility of CD (Auger, 2012), we did not register strong discriminatory attitudes towards people with CD (Auger, 2012; Bardosh, 2014; Moretti, 2012; Nulu, 2016; Zabala, 2012). We did identify, however, that poor clinical training and knowledge deficits of health care practitioners in endemic areas affect the disease progression (Bardosh, 2014; Nulu, 2016). Importantly, our results indicate that the primary health care level in endemic areas is failing to offer adequate care as a result of lack of adequate medical training in medical schools, deficiencies in continuous education programs in endemic areas, and the health care system infrastructure that harm clinical time and the possibility of physicians to attend training. In contrast, specialized centers do offer better standards of care. Nonetheless, even at tertiary levels, physicians and patients experience the effects of the fragmentation of the health care system and its for-profit logic.

The results presented here advance our understanding of the ways in which health care system's structures facilitate or impose barriers to diagnosis and treatment of CD. Our ethnographic results complement the few existing studies that have examined this relationship through a macro-policy approach. These studies report problems related to insurance coverage, referrals, supply of etiological treatment, and awareness of providers in Colombia (Cucunubá et al., 2017), Mexico (Manne et al., 2013) and the United States (Manne-Goehler et al., 2015). Interestingly, these three countries have fragmented health care systems with important individual insurance schemes, raising questions about how other types of health care systems facilitate or make it more difficult to provide adequate CD care. Some studies recognize that the remoteness that characterize rural areas challenge access to CD prevention and care (Santana Rangel et al., 2016; Sartor et al., 2017). The authors of these studies, however, argue that this challenge can be confronted through community participation, a strengthened primary health care approach, and comprehensive rather than vertical programs (Santana Rangel et al., 2016; Sartor et al., 2017), all of which have been considered as key components of publicly oriented health care systems in Latin America.

In particular, our data suggest that people who have migrated to urban centers, develop cardiac complications, and have contributory regime policies have easier access to treatment and receive higher quality of care in comparison to those who have remained in rural areas who usually have subsidiary regime. In the Colombian case, our data indicate that the fragmentations introduced or augmented by the market-based health care reform negatively affect access to timely and

comprehensive diagnosis and care. As has been shown previously in relation to other diseases, the market orientation of the Colombian health care system degrades clinical outcomes and reinforces social inequalities in health (Abadía-Barrero and Oviedo Manrique, 2009; Arrivillaga et al., 2009). While our study did not take a historical approach and we cannot compare these results with the situation prior to the reform, historical studies do show that the 1993 market-based health care reform did away with previous efforts to think about regional approaches to population health care needs, based on primary health care and integrated networks. The reform also defunded and destabilized specific national health programs as they entered into administrative conflict with the logics of individual insurance schemes (Hernández and Obregón, 2002). Hence, our results offer empirical information and additional conceptual tools to understand the alarmingly low estimates of coverage of diagnosis and treatment for CD in Colombia (Cucunubá et al., 2017), with ethnographic data collected five years after the new national program for the control, prevention and treatment for CD was launched in 2008. Hence, our results support other analysis about the meager progress of the national program (Cucunubá et al., 2017; Marchiol et al., 2017), which seems to be ineffective at confronting the market-based structure of the system. Importantly, this study complements the macro-level understanding of how the financing, payment, regulation and organization of the Colombian health care system impose additional administrative, economic, and geographic barriers to diagnosis and treatment (Cucunubá et al., 2017).

5. Conclusions

This ethnographic study showed that the sociocultural dynamics that influence CD health care relate to people's mobility from rural to urban contexts. Failures in professional's knowledge and training mostly affect the primary level of care in rural areas. This study unveiled the importance of analyzing the structure of the health care system for timely access to high quality health care services. In Colombia, the market-based structure of the health care system has created or augmented health care access barriers and has become one of the most important obstacles for comprehensive, integrated, and timely health care responses. Patients and physicians from both rural/primary health care areas and cities/tertiary health care units face enormous problems navigating the complex bureaucracy and fragmentations of the health care system. Importantly, this research indicates that the structure of the health care system also creates obstacles to initiatives that aim to train health care professionals in endemic areas. This study supports the idea that CD, as one of the NTDs, continue to face enormous challenges that require robust efforts to eliminate economic, geographic, administrative, technical, and cultural barriers to access prevention, diagnosis and treatment.

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