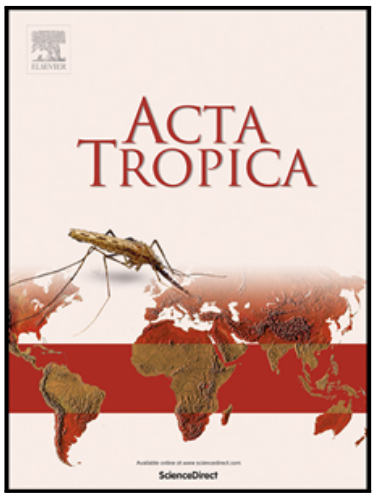

Analysis of the Costs Incurred by Patients with Chagas Disease: The Experience in Endemic Municipalities in Colombia

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Highlights

- Chagas disease mainly affects the most vulnerable populations, perpetuating the cycle of poverty.
- Healthcare for Chagas disease is mainly provided by specialists, rather than via primary healthcare, which increases costs for the health system and patients.
- Early diagnosis and treatment of CD has a substantial impact on the quality of life of patients.
- When health systems guarantee availability of care near where affected people live, adherence and compliance with treatment can be improved.

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Analysis of the Costs Incurred by Patients with Chagas Disease: The Experience in Endemic Municipalities in Colombia

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Summary

Background

Out-of-pocket expenditure (OOP) are key costs (medical and non-medical) that many individuals incur to receive health services. They have been identified as a key access barrier for vulnerable populations, in particular for populations affected by neglected diseases with a chronic progression, such as Chagas disease. It is important to understand the costs of accessing healthcare services that are borne by patients with *T. cruzi* infection.

Methodology

We prepared a structured survey for patients with *T. cruzi* infection/Chagas disease who were all treated by the healthcare system in endemic municipalities in Colombia. The results were analyzed according to three categories: 1. The socioeconomic profiling of the patients; 2. The costs of accommodation, food and transportation, in addition to the time spent commuting; and 3. the opportunity costs (money that was not earned due to absence from work) related to treatment at the local primary care hospital or at the high-complexity reference hospital.

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Main findings

Ninety-one patients answered the survey voluntarily. The data revealed that, when treated at the specialized reference hospital, patients spent 5.5 times more on food and accommodation, transportation costs were five times higher, and the loss of earnings was three times higher than when they were treated at the local primary care hospital. Moreover, the amount of time spent on transportation was 4 times higher at the reference hospital.

Conclusions

Providing comprehensive healthcare services for Chagas management at local primary healthcare hospitals would allow the most vulnerable patients to save on expenses related to medical and non-medical costs, in turn leading to higher adhesion to treatment thus benefiting the health system as a whole. These findings are in alignment with the WHO's World Health Assembly 2010 Resolution on the importance of treating Chagas at local primary care hospitals, thereby saving patients time and money, allowing for timely care, and promoting access to healthcare.

1. Introduction

Out-of-pocket expenditure can be defined as the direct payments made by an individual to healthcare providers at the time of provision of a service, these costs include medical and non-medical expenditure (Organización Panamericana de la Salud., 1999; Hernández-Vásquez A et al., 2020; Memirie et al., 2023). Naturally, the associated non-medical costs connected to the provision of such services, for instance, the cost of transportation and food, the loss of earnings caused by medical visits and especially the loss of time, which is particularly important when the service must be provided outside of the locality where the patients live. Non-medical costs are decisive in terms of access to healthcare, as they can be higher for some households and, in some cases, may lead to lack of adherence to treatment (Sauerborn R et al., 1996). Many specialists believe that a broader concept of out-of-pocket expenditure is more useful, as it better reflects what happens in practice (McIntyre D et al., 2006; Organización Panamericana de la Salud., 2021; Memirie et al., 2023).

When OOP is required for the provision of healthcare, they become an access barrier. Even when minimal, they just need to be high enough in relation to the paying capacity of a household to be relevant. They are, therefore, a determinant factor in the management of chronic diseases, as they contribute to the impoverishment of people and the unequal provision of healthcare. OOP (medical and non-medical costs) may negatively affect the level of wellbeing of the households concerned and their consumption of other basic goods and services, such as food, rent, or educational fees (Cid C et al., 2021).

In Colombia, health expenditures are primarily covered by public funds. According to data from 2019, this amounts to 1,276 USD per capita (OECD., 2021), 989 USD (or 77%) of which are absorbed by government entities. Out-of-pocket expenditure, amounting to 190 USD per capita and equivalent to 20.6% of health expenditure, are among the lowest in the region (Chang AY et al., 2019).

Research conducted with Chagas patients in Colombia in 2017 has shown that the amount of direct non-medical costs reached 1.5 million USD, corresponding to 20.4% of the total direct costs related to the disease in that year (Olivera and Buitrago., 2020). It has been noted that more than half of the total out-of-pocket expenditure were related to food, transportation, and accommodation during the treatment. It is estimated that society pays 4,226 USD a year for the treatment of each

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patient with chronic *T. cruzi* infection/Chagas disease (Cid C et al., 2021).

In 2016, Colombia published resolution 3202 concerning the adoption of a manual on the development and implementation of Comprehensive Healthcare Roadmaps for the management of different diseases (*Rutas Integrales de Atención en Salud*, RIAS). Consequently, a number of RIAS were created, including one for Chagas, to use as tools within the Comprehensive Healthcare Model (*Modelo Integral de Salud*, MIAS) and to ensure the population can enjoy the right to health. With their focus on the patient, the RIAS mitigate the costs inherent in a fragmented healthcare model, as well as having other positive aspects (Ministerio de Salud y Protección Social., 2016).

It is necessary to identify and analyze the costs that patients incur during a long treatment if we want to ensure that they adhere to the treatment and, consequently, experience fewer complications. Mitigation of these complications would lead to a favorable economic impact not only for the patient but also for society as whole, decreasing the burden of the disease in terms of both individual and public health. Moreover, alternative mechanisms that can tackle such costs are urgently needed, so that appropriate health polices can be developed to improve access to essential healthcare services and, ultimately, so that the vicious cycle of poverty and disease can be broken.

This analysis is a key element in the development of public policies that can mitigate the payment of out-of-pocket expenditure (medical and non-medical) by patients with *T. cruzi* infection/ Chagas disease, facilitating the diagnosis, etiological treatment, and provision of comprehensive care that are part of the goal of eliminating Chagas disease as a public health problem in Colombia.

The goal of this study is to understand from the patients' perspective the costs they incur in gaining access to diagnosis and etiological treatment of *T. cruzi* infection/Chagas disease. The primary question was what the out-of-pocket expense is derived from the care of Chagas disease in patients from two endemic municipalities. A secondary question was to identify the difference between the out-of-pocket expenses among patients treated in different healthcare levels: those who are treated in the primary healthcare level versus those who are referred to a healthcare facility of greater complexity.

2. Material and Methods

2.1. Type of Study

This is a cross-sectional costing analysis based on data from a survey completed by 91 patients with Chagas disease who received care between 2019 and 2020.

Data analysis was organized in three categories: 1. the socioeconomic profiling of the patients; 2. the costs of and time spent on transportation, accommodation, and food; and 3. the opportunity costs (money that was not earned due to absence from work) related to treatment at the local primary care hospital or at the high-complexity reference hospital.

The results of the analysis of the variables were presented as the mean and its standard deviation for the quantitative variables and as percentages for the qualitative variables. Depending on the type of variables, the differences between the groups were evaluated using the t-test and chi-squared test. All expenses were expressed in Colombian pesos (COP) and US dollars taking into account the average of the representative market rate for the year 2020. The conversion rate was:

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1 USD [US$] = 3,693.36 COP (range: 3,253.89 - 4,153.91) (Banco de la República de Colombia., 2020). As a reference, in 2020 the minimum wage in Colombia was 877,802 COP equivalent in dollars to US$ 237.67 (Ministerio de Trabajo de Colombia, 2019).

We calculate total Out-of-pocket (OOP) expenses as the sum of direct medical and non-medical expenses. For medical expenses we include payments made for medical consultation, laboratory tests and medicines. For non-medical expenses, we add OOP expenses related to transportation, food, and accommodation related solely to access to medical care. On the other hand, we calculate income lost from time spent seeking care (Memirie et al., 2023).

2.2. Population and Sample

Ninety-one people with a confirmed diagnosis of *T. cruzi* infection and living in the municipalities of Mogotes and Soatá, located in the departments of Santander and Boyacá, respectively, were selected for this study.

The municipality of Soatá is located in the northwest of the Boyacá department. By 2020, the municipality had 9,195 people, where 27.8% lived in a non-urban area (Dane, 2018). 59.6% of the population were insured under the subsidized health regime (Departamento Nacional de Planeación, 2021) and were treated mainly at the San Antonio de Soata Hospital, a medium-complexity care unit, and on multiple occasions patients must scroll for assessments that are not available at the local hospital. In 2020, 145 health care services were registered for the migrant population, all from Venezuela (0.7% of care at the departmental level) (ESE Hospital San Antonio de Soata., 2021). Soatá is part of the 596 endemic municipalities for Chagas disease in Colombia and in 2013 received certification for the interruption of intradomiciliary vector transmission of *Trypanosoma cruzi*, by *R. prolixus* (Organización Panamericana de la Salud, 2013). A seroprevalence of 3% is registered in pregnant women for 2017 (Suescún-Carrero et al., 2017).

On the other hand, the Municipality of Mogotes is located in the southeast of Santander department (Municipio de Mogotes., 2021). For 2020, a population were 10,665 people, 59.7% lived in non-urban areas (Dane, 2018). The majority of the population is insured under the subsidized regime (86.4%), this municipality has only one public hospital (ESE Hospital San Pedro Claver de Mogotes) with low-complexity care (Municipio de Mogotes, 2021). Mogotes is one of the municipalities with the highest burden of CD in Colombia, with a report of seropositivity in pregnant women of 18% (Castellanos-Domínguez et al., 2016). Mogotes Municipality has been certificated for the interruption of the intradomiciliary vector transmission of *Trypanosoma Trypanosoma cruzi*, by *R. prolixus* (Ministerio de Salud y Protección Social, 2017). Both municipalities were included in the pilot project for the implementation of the CD care route developed during the years 2017 to 2020, where the post-implementation results demonstrated an increase in access to diagnosis and treatment (Herazo, et al., 2022).

Patients were identified in the databases of hospitals of the two municipalities considered for the project and those with a confirmed diagnosis of Chagas disease were selected. They were then invited to participate in the survey freely. Only patients with confirmed Chagas disease were selected and those who agreed to participate and were treated at the two municipal hospitals through deliberate (non-probabilistic) sampling. There was no sample-specific calculation.

These two municipalities were part of the Chagas Care Pathway implementation project, which had the goal of reducing access barriers to the diagnostic and treatment of the *Trypanosoma cruzi* infection. The general objective of the pilot project was to validate the implementation of the Chagas Care Pathway established by the Ministry of Health and Social Protection in 2016. This project was initially carried out in five municipalities in the departments of Arauca, Boyacá, Casanare and Santander. Four specific objectives were established related to increasing access to diagnosis and treatment, increasing the availability of health centers with installed capacity for the

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care of people with CD, improving the quality of care and managing intersectoral articulation. (Ministerio de Salud y Protección Social, 2016; Herazo et al., 2022).

During the interviews, two healthcare scenarios were considered for patients with *T. cruzi* infection/ Chagas disease: the first was treatment at the local primary healthcare hospital, defined as a healthcare center located in the area (municipality) where the interviewee lived and which they visited; the second was treatment at a specialized reference hospital, defined as a specialized healthcare center (internal medicine, cardiology, almost others) to which the interviewee was referred, and which was located outside of the area where they lived. Patients were asked about the two scenarios according to their experience during CD healthcare. The questionnaire considered questions on costs derived from healthcare in the two scenarios (primary or specialized levels).

Patients are referred from the primary healthcare level to another of greater complexity on an outpatient basis mainly based on the need for evaluation and treatment of complications. However, several referrals might be unnecessary, mainly for patients in the indeterminate phase of CD. The hospital care network is defined by the patient's Health Insurance (paid by the patient).

2.2.1 Questionnaire

A structured questionnaire was used with 38 questions in Spanish written in simple language (variables) organized into three sections: general characterization, care and expenses incurred by patients in the local health service, and care and expenses incurred by patients in a higher complexity health service. The questionnaire was completed face to face.

2.3. Ethical Considerations

Both the study and the tools used for analysis were reviewed and approved by the Research Ethics Committee of the Medical School of the University of Los Andes (protocol number 201909243).

The survey was conducted in person and all participants signed an informed consent form before taking part.

The data was manually collected for each interview and later tabulated and analyzed in Excel.

3. Results

3.1. Social and economic profile of the patients

A total of 91 patients with *T. cruzi* infection completed the survey. The majority of the patients surveyed were women (64.8%). The mean age was 55.5 ±14.1 years and ages ranged from 19 to 80 years. 56% of the patients lived in rural zones (Table 1).

Table 1. General profile of the patients surveyed

VARIABLE		SURVEYED PEOPLE (N=91)	
		N	%
LOCATION			
	Mogotes	30	33
	Soatá	61	67
GENDER			
	Female	59	64.8
	Male	32	35.2
AGE GROUP (years)			
	<20	1	1.1
	20 – 39	14	15.4
	40 – 59	30	33
	>60	44	48.3
	No data	2	2.2
PLACE OF RESIDENCE			
	Rural	51	56
	Urban	40	44

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EDUCATION LEVEL		
None	12	13
Elementary	58	64
Secondary	15	17
Technical/Trade	2	2
Professional	1	1
Other	2	2
No data	1	1
HEALTH INSURANCE REGIMEN		
Subsidized	83	91
Contribution	8	9
HEAD OF FAMILY		
Yes	64	70
No	27	30
COMORBIDITIES[a]		
None	45	49
High blood pressure	25	27
Diabetes	11	12
Lung problems	12	13
Kidney failure	2	2
Other	11	12
More than 1 comorbidity	17	19
OCCUPATION		
Housewife	47	51.6
Agriculture	21	23.1
Other	8	8.8
No data	15	16.5
DAILY INCOME[•]		
None	50	55
1000-5,999 [0.27 – 1.62]	15	16.5
6,000-14,999 [1.62 – 4.06]	5	5.5
15,000-49,999 [4.06 – 13.54]	8	8.8
50,000-100,000 [13.54 – 27.08]	3	3.3
No data	10	10.9

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[a] 19% of patients have more than 1 comorbidities. Others: (Cancer, Parkinson's disease, anemia, heart disease and others not specified)
[*] COP: colombian pesos [US$]

The majority of the patients (58/91; 64%) only had an elementary education. There is no statistically significant difference in the educational levels of women and men. 36/58 (62%) of the women reported that they did not work (table 2).

Among patients interviewed, 45/91 (49%) did not report suffering from a clinical condition other than *T. cruzi* infection. Of those who had comorbidity, 17/91 (19%) said they had two or more pathologies.

All respondents were affiliated to the health system, 83/91 (91%) of whom were in the subsidized regimen.

50/91 (55%) of the patients did not have a daily income: 55% of the men compared to 65.4% of the women. The average daily income for the women was 2,772 ±5,175 Colombian pesos (COP) [<US $ 1], while for the men it was 14,091 ±28,727 COP [US $ 3.82] (*p=0.006*).

The highest reported incomes were reported by men. 8/29 (27.6%) of the men had a daily income of >15,000 COP [>US $ 4.06], compared to 3/52 (5.8%) of the women.

Table 2 Education Level, daily income, and employment status according to gender

VARIABLE[a]	GENDER		P value[b]
	Male (%)	Female (%)	
EDUCATIONAL LEVEL			*0.934*
None	5 (16.1)	7 (11.9)	
Elementary	20 (64.5)	38 (64.4)	
Secondary	5 (16.1)	10 (16.9)	
Technical/Trade	1 (3.3)	1 (1.7)	
Professional	0	1 (1.7)	
Other	0	2 (3.4)	
Total	**31**	**59**	
EMPLOYMENT STATUS			*0.333*
Without a job	13 (48.2)	36 (62.1)	
Informal	12 (44.4)	18 (31)	
Salaried	0	2 (3.5)	
Retired	0	1 (1.7)	
Other	2 (7.4)	1 (1.7)	
Total	**27**	**58**	
DAILY INCOME*			*0.027*
None	16 (55.2)	34 (65.4)	
1000-5,999 [0.27 - 1.62]	5 (17.2)	10 (19.2)	
6,000-14,999 [1.62 - 4.06]	0	5 (9.6)	
15,000-49,999 [4.06 - 13.54]	5 (17.2)	3 (5.8)	
50,000-100,000 [13.54 - 27.08]	3 (10.4)	0	
Total	**29**	**52**	

*COP: Colombian pesos [US$]
[a] The table shows some missing records from the dependent variables, so the data summatory is not equal to the total of N (91)
[b] Estimation with Chi^2 (Fisher's exact)

1. 3.2. Place, time, and costs related to healthcare

Analysis of the time and costs related to transportation showed a dependence on the level of care at which the patient was seen. Of the 91 patients who participated, 64 (70%) said they were sent to

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a specialized reference hospital.

53/91 (58%) of the patients spent less than one hour traveling to the local primary care hospital while 30/91 (33%) said they did not spend money on travel. In contrast, the need for transport to the specialized reference hospital impacted patients, as 40/64 (62.5%) of them spent more than 40,000 COP [US $ 10.83].

36/64 patients (56.2%) that were referred to the specialized reference hospital spent more than 40,000 COP [US $ 10.83] on other costs, such as accommodation, transportation and food. In comparison, 32/91 (35%) of the patients attending a local primary care hospital did not need to pay for accommodation or food and, of those who did, 54/91 (59.3%) spent less than 40,000 COP [US $ 10.83].

The average cost of transportation to the local primary care hospital was 12,986 ±17,817 COP [US $ 3.52]., compared to an average cost of 68,453 ±55,239 COP [US $ 18.53] (*p<0.001)* for transportation to the high-complexity reference hospital. The average cost for accommodation and food for the local primary care hospital was 10,626 ±12,343 COP [US $ 2.88]., while the average for the reference hospital was 57,991 ±58,338 COP [US $ 15.70]. (*p<0.001*). The cost of transportation, accommodation, and food is significantly higher when patients are referred to find healthcare in a high-complexity reference hospital.

Table 3. Differences in out-of-pocket expenses (medical and non-medical) between the two healthcare scenarios

VARIABLE[a]	Local primary care hospital (%) (n=91)	Specialized reference hospital (%) (n=64)	P value[b]
TRAVEL TIME TO THE CARE CENTER			*<0.001*
< 1hr	53 (58.2)	5 (7.8)	
1-2 hrs	21 (23.1)	5 (7.8)	
2-4 hrs	7 (7.7)	11 (17.2)	
> 4 hrs	10 (11)	43 (67.2)	
TYPE OF TRANSPORT USED[c]			*<0.001*
Walking	54 (60)	1 (1.6)	
Motorcycle	15 (16.7)	0	
Car	12 (13.3)	10 (15.6)	
Bus	3 (3.3)	53 (82.8)	
Other	6 (6.7)	0	
TRANSPORTATION COSTS *			*<0.001*
None	30 (33)	0	
<10,000 [<2.71]	13 (14.3)	8 (12.5)	
10,000 – 39,999 [2.71 - 10.83]	25 (27.5)	16 (25)	
40,000 – 69,999 [10.83 - 18.95]	5 (5.5)	14 (21.9)	
70,000 – 99,999 [18.95 - 27.08]	0	7 (10.9)	
>100,000 [>27.08]	1 (1)	19 (29.7)	
No data	17 (18.7)	0	
OTHER COSTS (food and accommodation)*			*<0.001*
None	32 (35.1)	1 (1.6)	
<10,000 [<2.71]	14 (15.4)	2 (3.1)	
10,000 – 39,999 [2.71 - 10.83]	40 (44)	22 (34.4)	
40,000 – 69,999 [10.83 - 18.95]	5 (5.5)	21 (32.8)	
70,000 – 99,999 [18.95 - 27.08]	0	3 (4.7)	
100,000 – 199,999 [27.08 – 54.15]	0	9 (14)	
>200,000 [>54.15]	0	3 (4.7)	
No data	0	3 (4.7)	

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OTHER COSTS (material used for paperwork)			
Patients that paid	83 (91.21)		
Average cost*	2,961 [<US $ 1]		
MEDICAL COSTS			
PAID FOR TESTS/EXAMS (ECG, ECO, LAB, etc.) [d]			
Patients that paid	7 (7.7)	5 (7.8)	
Average cost*	167,666 [US $ 45.40]	415,400 [US $ 112.47]	*0.307*
PAYMENT FOR TRYPANOCIDE TREATMENT (benznidazole or nifurtimox)			
Patients that paid	2 (2.2)		
Average cost*	86,500 [US $ 23.42]		

[a] The table shows some missing records from the dependent variables, so the data summatory is not equal to the total of N (91)

[b] Estimation with Chi^2 (Fisher's exact)

[c] Data is missing in the local primary care hospital group

[d] ECG: electrocardiogram, ECO: echocardiogram and LAB: laboratory test)

* COP: Colombian pesos [US$]

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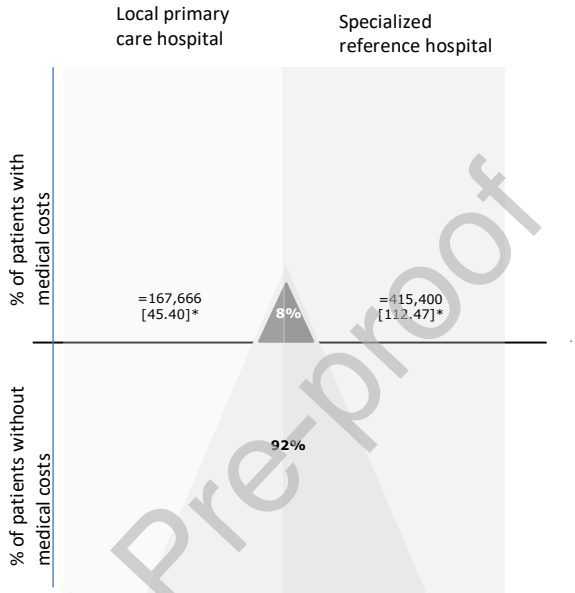
Almost 8% (7/91) of the patients paid for exams such as electrocardiograms, lab tests, and echocardiograms during their period in the healthcare system, both at local primary healthcare facilities and at specialized reference hospitals (Table 3) (Chart 1). Two patients reported that they paid for their antiparasitic medication, which averaged 86,500 COP [US $ 23.42]. This points to the broad coverage of the benefits plan included in the Chagas RIAS (Table 3).

Chart 1. Medical costs per healthcare level



* COP: Colombian pesos [US$]. The values correspond to average of medical cost (paid per test/exams) per healthcare level.

70/91 (76.9%) of the respondents had lab tests carried out at the local primary care hospital, 14/91 (15.4%) had them done outside of their municipality, and the remaining 7/91 (7.7%) somewhere else in their community (a park, school, or other), which probably coincided with collective actions promoted by the program for vector-borne diseases. 62/91 (68%) of the electrocardiograms were done at the local primary care hospital and 84/91 (92.3%) of the respondents did not have to pay for them.

2. 3.3. Opportunity costs (money that was not earned)

Of the total number of patients, 42/91 (46.1%) said they lost income every time they had to go to a doctor's appointment at the local primary care hospital. The percentage increased to 33/64 (51.6%) when the doctor's appointment was at the specialized reference hospital. Although these percentages were close, the range of lost income for each level of healthcare was very different.

Income lost in both healthcare scenarios was concentrated around the 10,000 COP - 39,999 COP [US $ 2,71 - 10,83] range. In general, the proportion of people in each monetary range was the same in both scenarios. (Table 4)

Table 4. Differences in lost income between the two healthcare scenarios

VARIABLE	Local primary care hospital (%) n=42/91 (46.1)	Specialized reference hospital (%) n=33/64 (51.5)	P value[a]

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Lost income*			*0.259*
<5,000 [<1.35]	3 (7.1)	0	
5,000 – 9,999 [1.35 2.71]	2 (4.8)	1 (3)	
10,000 – 39,999 [2.71 – 10.83]	20 (47.6)	12 (36.4)	
40,000 – 99,999 [10.83 – 27.08]	3 (7.1)	3 (9.1)	
>100,000 [>27.08]	1 (2.4)	4 (12.1)	
No specific monetary data	13 (31)	13 (39.4)	

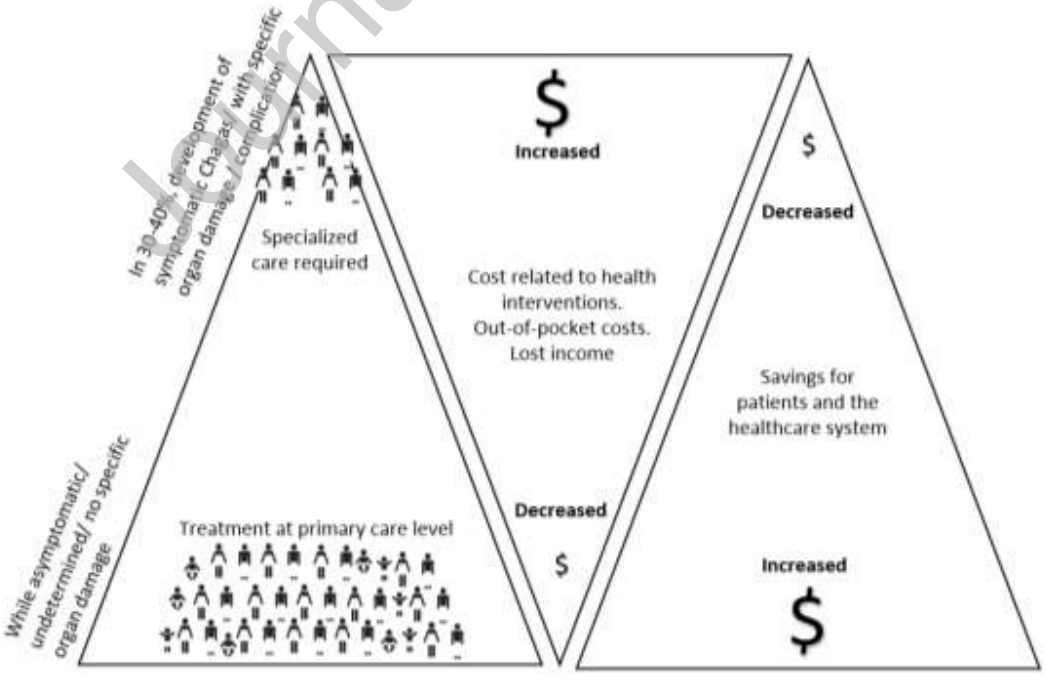
*COP: Colombian pesos [US$]

[a] Fisher's exact (to calculate the test, the category: - No specific monetary data - was exclude)

However, the average lost income recorded for the local primary care hospital and the specialized reference hospital was 22,982 ±21,395 COP [US $ 6.22] and 45,400 ±41,308 COP [US $ 12.29], respectively. Those who visited the reference hospital lost more income (*p=0.008*).

Finally, it is important to consider the relationship between the scenario and focus of healthcare, out-of-pocket expenditure, and the costs and savings associated with the health system. For *T. cruzi* infection/Chagas disease, detecting cases early and promptly means that most cases will not have complications and can be treated at the local levels of healthcare. Consequently, local care, close to the patients' place of residence, leads to lower or no out-of-pocket expenditure. From the perspective of the health system, the interventions needed for such patients would be much cheaper than those needed for chronic cases, such as heart transplants, cardiac devices, or lifelong medications, all of which are the product of a health care system focused on complications that privileges specialized care in high-complexity health centers where the patients lose income and spend more on out-of-pocket expenditure (Chart 2).

Chart 2. The relationship between the focus of healthcare, out-of-pocket costs, and the costs and savings associated with the health system



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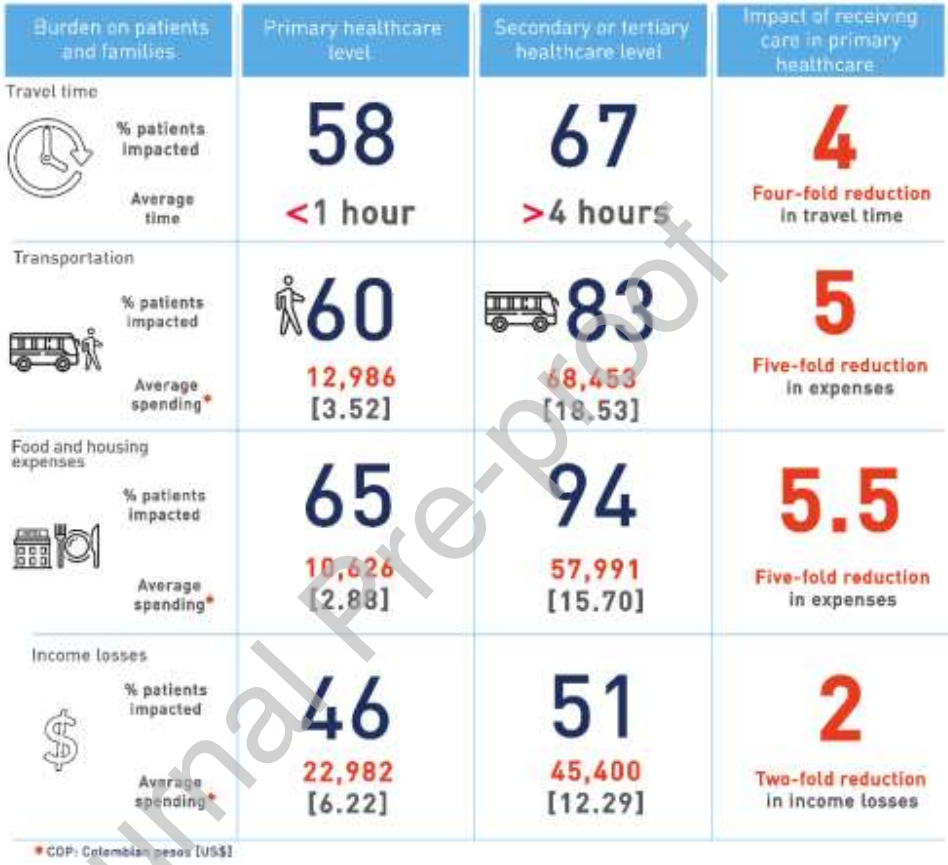
Of the patients attended, 70% (64/91) were referred to a higher-complexity level hospital to find care. In this case, the majority required the use of bus (83%) to access the referral hospital, which resulted in a longer travel time (over 4 hours for 67% (43/64) of those referred) and a consequent increase in transportation costs (with an average of 68,453 COP [US $ 18.53]), in addition to an increase in the length of stay at the health center (Chart 3).

Chart 3. Burden on patients and families



3. Discussion

The out-of-pocket expense (medical and non-medical costs) incurred by patients with CD to seek health care in endemic areas such as Soatá (Boyacá) and Mogotes (Santander) is five times higher when they are treated at higher-complexity level hospital than when this care is provided at the first level. In this regard, it is important highlight that the healthcare facility where patients in this conditions attend is not a patient election but defined by health insurance system. It is even of higher relevance if we take into account that out-of-pocket expenditure is mainly caused by non-medical expenses including transportation, food and accommodation. In agreement with previous analysis in other context, others costs, like those resulting from lost work and lost potential income (Leatherman T et al., 2014) were also documented in our study, being two times higher the expense when the patients were attended at higher-complexity level hospital. Due the relevance of the expense in people belonging to low income settings these indicators should be considered and analyzed in the context of out-of-pocket expenditure estimation due to *T. cruzi*/ Chagas disease management. However, as highlighted by other research groups, (McIntyre D et al., 2006; Organización Panamericana de la Salud., 2021), few of these “hidden costs” are recorded in the analysis of direct out-of-pocket costs of healthcare, and few studies have included additional

"informal" costs that healthcare users may incur at the point of care. Given the burden of out-of-pocket expenditure in healthcare related to *T. cruzi* management, it is important to assess its impact on households, people at risk and their communities, and healthcare local systems and work together to search for solutions.

The study presented some limitations: participants were selected from a non-probabilistic sampling, with an overexpression of answers coming from specific population group. As happened in similar studies described in the literature, we identify similar demographic bias in terms of age and gender distribution of responders, with mainly women answering the survey. This suggests that future studies should incorporate a better-balanced sampling approach to help identify healthcare practices that are effective for both sexes. It will be also important to add that other factors should be considered when proposing changes to healthcare practices, both at the level of the people at risk and at the level of the healthcare system. Our study found that women earn 80% less than men, which may be related to the fact that the majority of women are housewives who, although they have a big impact in terms of social dynamics (a high percentage of them (55%) are head of the household), do not receive a wage for their work.

The majority of the respondents were part of the subsidized regimen, a finding consistent with other studies in Colombia (Herazo et al., 2022) that highlights which sector of the population is affected by Chagas disease. This could be decisive in terms of the impact that out-of-pocket expenditure have on these populations and their role in perpetuating poverty. Given the weight of out-of-pocket expenses in health care, we feel it is necessary to development others studies that deepen the effect in households and communities, since our study was limited to collecting the individual costs and impact of the participants.

In contrast to other previously published studies, we did not find that patients had to pay considerable costs for their medication and medical exams (direct out-of-pocket medical costs), something that may be explained by the improvement in healthcare processes and the gradual expansion of the health benefits plan, as a consequence of the implementation of the law on the fundamental right to health (El Congreso de Colombia, 2015). In the case of Chagas disease, implementation of the Comprehensive Healthcare Pathways as a tool for healthcare organization has had a positive impact on patients' out-of-pocket expenditure, as exemplified by the fact that blood samples for diagnosis were send to be analyzed, without the need of patient to travel for blood extraction.

In this study, we found that there was a meaningful difference for patients in terms of non-medical direct costs, such as transportation, accommodation, food, and lost income, when care was provided closer to the patient and by a health service provider located in the area where the patient lives, compared to the costs incurred when specialized care required traveling to another municipality or city. In case of need to attend another municipality healthcare center, the costs were significantly higher, not only in terms of direct costs but also in terms of lost income. This difference has also been clearly demonstrated in other studies evaluating the determinant factors

for out-of-pocket healthcare costs (Petrera Pavone M et al., 2018).

The coordinate efforts with national and supranational initiatives to improve coverage and access to healthcare, especially in the context of the Agenda for Sustainable Development 2030, have focused on the creation of alternative approaches to economic and social protections in healthcare (Organización Panamericana de la Salud, 2014). Healthcare systems must, therefore, consider patients healthcare closer to where they live, to ensure healthcare access and quality. Moreover, this aligns with the (63rd) 2010 World Health Assembly's resolution urging all member states to integrate care for patients with both acute clinical and chronic forms of Chagas disease into their primary healthcare services (Pan American Health Organization., 2010).

At national level, it is essential that those who are responsible for health insurance create networks for the provision of healthcare services that ensure the fundamental right to health and uphold the principles of availability, continuity, accessibility and opportunity, among others. Specialized health care opportunities, even in specific days, at rural areas, as well as the implementation of telemedicine are two strategies that could considerably mitigate out-of-pocket expenditure.

Our study aimed reflect the circumstances of vulnerability in margin populations, including the double impact of both costs and lost income. In this regard, we have been able to identify the economic impact on patients of the absence of healthcare networks located close to where they live and to see how this perpetuates the poverty of those who are affected by *T. cruzi* infection/ Chagas disease.

Out-of-pocket expenses have a significant impact on the management and quality of life of patients who live with chronic disease. Limiting these costs would help patients adhere to their treatment and thus decrease complications.

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Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: