The economic impact of critical congenital heart disease to the health system and families in Colombia [version 1; referees: awaiting peer review]

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Abstract

Background: Critical congenital heart disease (CCHD) make up a group of heart diseases present in newborns since the prenatal period and requiring early intervention through surgery or percutaneous interventions in the first year of life. Little is known about the societal economic impact associated with their care in low to middle income countries. We estimated direct medical costs, out-of-pocket expenditures and indirect costs of CCHD patients in Colombia.

Methods: The methodology to estimate costs involved four stages: identification, measurement, and assessment of resources consumed, and total cost calculation. Regarding medical costs, hospital and ambulatory costs were estimated for the patient’s first year of life using clinical records of 73 patients and with thematic experts. A survey was carried out on 20 children’s caregivers to determine the out-of-pocket expenses and indirect costs. For this estimation, a descriptive analysis was made on the survey taking into account the reported salary. All costs are expressed in US dollars (2017 exchange rates).

Results: The average direct medical hospital costs for CCHDs were $25,835 and the ambulatory costs reached $480. Indirect costs were $1,303 and out-of-pocket expenses were $2,058, which for families with an income lower than one monthly minimum wage (1 SMMLV) in 2017 correspond to $250. The impact on their budget was 57%.
Conclusions: CCHDs represent an important economic impact both for the Colombian General Social Health System and for families. This study made it possible to estimate the costs that are not easily visible and thus quantified.

Keywords
Economic impact, Cost of Illness, Cost Analysis, Hospital Costs, Out-of-pocket Expenditures, Indirect Expenditures

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Introduction
The term critical congenital heart disease (CCHD) refers to a group of structural malformations of the heart which are present from the prenatal period. They represent more than one third of all Congenital Heart Diseases (CHD)\(^1\). Their incidence ranges from 1 in 15,000 to 1 in 26,000 live births and their prevalence corresponds to 147.4 cases per 100,000 live births\(^1\). CCHDs are an important cause of childhood mortality in the first month of life, and consequently it is necessary to start early surgical or interventional treatment in the first year of life to grant the patient’s survival\(^2\). 29.5% of newborns with CCHD are diagnosed late\(^1\), a fact associated with greater risk of morbidity and mortality\(^9\). The CCHD have a significant economic impact on the health systems and the patients’ families; thereby, no studies on indirect costs are available, and few of them address direct medical costs at world level\(^7\).

The purpose of carrying out a costs study on a disease (COI “Cost of Illness”), is to perform a descriptive analysis to identify and measure the costs of a disease in monetary terms to estimate its economic burden on society\(^6,8\). COI studies may take different perspective that determines the whole costs process; they estimate costs from the standpoint of society, the health system, the patient or the families. The perspective of society is the most comprehensive one and most widely recommended, since it includes all costs, independently from who incurs them. In consequence, besides direct medical costs, out-of-pocket expenses covered by the family, and indirect costs, are included. This society perspective allows to carry out a more complete analysis and include all costs of opportunity attributed to a disease. However, this perspective requires a larger collection and availability of information effort, a fact that hinders its use in COI for low prevalence diseases\(^1,3,11\).

Overall, COI studies contemplate three cost categories: direct, indirect and intangible costs, the latter are rarely quantified, so it is accepted that only direct and indirect costs are considered. Direct medical costs are costs related with medical assistance, treatment, rehabilitation, etc.; non direct medical costs involve expenses in non-medical resources, i.e., transportation and nutrition outside the home. Lastly, indirect costs refers to the loss of productivity associated with the disease\(^1\).

The micro-costing, and gross-costing approaches are used to estimate direct medical costs. The micro-costing is a “bottom-up” process whereby every resource is identified; measuring, assessment and calculation of the total cost are carried out; contrarily, the gross-costing estimates costs from a “top-down” approach, drawing an average of the total cost. The human capital approach and the friction cost approach estimate indirect costs. The loss of productivity is associated with the friction period, i.e., the time the patient takes to be replaced by another employee and for production to return to its former level\(^12\).

From the economic standpoint, the needs of the population are endless but the resources to meet them are limited. Additionally, factors like technological development, cause health expenses to increase. The estimation of costs is important in making decisions, as it helps to define and prioritize policies and intervention related with health assistance\(^11\). Also, it provides information to make future costs projections in medical assistance and allocate resources according to budget limitations, thus granting the efficiency of policies\(^11,12\).

In view of the importance of CCHD, the complexity presented in terms of costs for society and the scarce literature available on the subject, it was necessary for this study to estimate costs and hence approach the economic burden from a social perspective in Colombia. For this study we benefit from the information provided by Fundación Cardiñfantil – Institute of Cardiology (FCI-IC) and its social program\(^3,14\), to access a population that is difficult to study. Although many of the expenses incurred by the patients and their families are subsidized by FCI-IC’s social program, the use of resources is real, which allowed to approximate to the real cost incurred by these CCHD patients in Colombia.

Methods
The method used to estimate the costs was micro-costing, as the information collected allowed to reach a level of detail in the identification and measuring of resources, and to carry out the assessment based on the national reference prices, and not only on those of a particular institution. Besides, this method identifies gaps in expenses and include only events related with CCHD. The calculations were made in Microsoft Excel 2016. We did not perform any statistical tests.

The seven CCHDs included in the estimation of costs were: Pulmonary Atresia, Tetralogy of Fallot, Tricuspid Atresia, Truncus Arteriosus, Hypoplastic Left Heart Syndrome, Total Anomalous Pulmonary Venous Drainage and Transposition of Great Arteries. The decision to include these CCHDs was made following the approaches and recommendations taken on the subject at world level, thus the prioritization of these cardiopathies in the United States was taken as reference\(^9\).

The cost estimation process followed four stages\(^8\): 1. Identification of resources; 2. Measuring the use of resources; 3. Assessment of resources; 4. Calculating total costs. This methodology was followed, and the “bottom- up” process, i.e., the estimation of direct medical hospital costs followed an identification of resources, measuring (frequency and quantity) and assessment of resources (as per Tariffs Manual ISS 2001+35%, market prices in Colombia)\(^16\), and lastly, the total costs calculation, based on clinical records for 73 patients with the seven CCHDs from the data base of the Institute of Congenital Heart Disease at FCI-IC. Direct annual medical costs were estimated for every CCHD, and for indirect costs and out-of-pocket expenses, 20 surveys were applied to caregivers of children with three Infrequent Congenital Heart Diseases since there is a higher level of complexity in the collection of information on CCHDs. The caregivers were a convenience sample identified from a cohort of the PINOCCHIO Program (Innovation Program in Uncommon Human Congenital Heart Diseases for Colombia). This cohort was built through three main sources at Fundacion Cardiñfantil – Instituto de Cardiología – FCI-IC: medical databases of patients from the Congenital Heart Disease Institute; Pediatric Cardiovascular surgery service; and patients
diagnosed during pediatric brigades carried out by FCI-IC social program “Give a life” in 12 cities in Colombia from the period 2010 to October, 2018. The eligibility criteria for the 20 caregivers of children were patients from the PINOCCHIO Cohort with detectable critical congenital heart diseases with the following diagnosis: Ebstein’s anomaly, Interrupted Aortic Arch and Pulmonary Valve Stenosis and which were less than two years of age at the time of the survey. The caregivers filled a case report form (CRF) whereby information on out-of-pocket expenses and indirect costs was obtained. Before caregivers started to answer the survey, a research assistant explained the objective, asked for signed informed consent, and were present to respond to any question. A copy of the CRF translated to English is attached as extended data.

The perspective taken in cost estimation was that of society. All costs are expressed in US dollars, firstly estimated in Colombian pesos for 2017, and then the average exchange rate for 2017 was applied ($2,951.15 COP for one US dollar)\(^7\).

**Estimation of direct medical costs**

The collected information was filtered, and only the hospital events in which patients were admitted by causes directly related with CCHDs were selected. Then, a validation was made with experts on the amount of resources included in this data base to verify if they were similar to usual clinical practice. Then, an analysis of hospital events per patient was performed, including very detailed information on the resources used, grouped under large line items: surgical and non-surgical procedures, laboratories, diagnostic aids, blood bank, medication and surgical medical materials. Finally, a base case was drawn for a patient, including the average of hospital events (surgical and non-surgical) taking place in a year for every CCHD, weighing the frequency of these events and the average number of days in hospital for each.

The estimation of ambulatory costs was also carried out in four stages; the identification of resources for ambulatory events in the seven CCHDs, was validated by clinical experts. To measure resources, we asked the same experts how many medical consultations, echocardiograms, EKGS and chest x-rays are performed on average on these patients in their first year of life. The assessment of resources was carried out based on Tariff Manual ISS 2001\(^14\); finally, the following formula was applied Cost = frequency or quantity*prices.

The source for procedure prices was Tariff Manual ISS 2001\(^14\), a reference for tariffs used for contracting health services in Colombia. The adjustment of these tariffs for the Colombian market is done by taking the base tariff present in 2001 plus an increase of 35% (20% for the minimum cost and 50% for the maximum cost to perform a sensitivity analysis).

**Estimation of out-of-pocket expenses and indirect costs**

In order to estimate out-of-pocket expenses and indirect costs covered by the caregiver, a survey was applied to 20 caregivers of patients younger than two years with a CCHD, as detailed above. The survey included specific questions on monthly income, occupation, days on leave from work and expenses associated with the disease to establish the impact of out-of-pocket expenses and the loss of productivity in the family budgets.

The methodology used to estimate the out-of-pocket expenses corresponds to a weighted average according to the records of very family. The line items included were: transportation costs (transfer to the city), payments caused by private medical consultation, payment of sliding scale fees\(^8\), co-payment expenses (contributions from patients), paperwork expenses, expenses caused by transfer to a temporary residence, on meals outside the home, purchase of medication and other as payment for care of other children, telephone calls, among others. A monthly average for out-of-pocket expenses was estimated considering the age of the patient, to then calculate the annual out-of-pocket expense undertaken by every family.

Regarding indirect costs, the number of days of leave was calculated for the caregivers who were economically active at the time of the survey and the equivalent cost of productive days lost was established by means of the human capital method, based on the net salary reported in the surveys. The average daily income was calculated based on the distribution of income of all caregivers, leading to a summation of the frequency in the level of expenses times the average daily income.

Out-of-pocket expenses and indirect costs were differentiated considering the need for a surgical procedure. Lastly, to understand the magnitude of these costs, the impact of these expenses on the annual budget of the families was calculated, differentiated by levels of income and measured in terms of the minimal wage in Colombia, which corresponded to $250 monthly in 2017\(^9\).

**Ethical approval**

The ethical approval for the project was awarded by the Clinical Research Ethics Committee at FCI-IC (CEIC) for the supply and access to the database of patients with CCHD and for the collection of information on care providers. The informed consent was provided to be filled in by the CRF of patients from the PINOCCHIO Program Cohort, whereby information on out-of-pocket expenses and indirect costs of every care provided was obtained from those answering the survey.

**Results**

**Direct medical costs**

The average annual hospital cost for the seven CCHDs was $25,835. Diagnosis of Truncus Arteriosus caused the highest cost, at $42,419 and Anomalous Pulmonary Venous Drainage had the lowest cost, at $16,904. Table 1 shows the results for the seven CCHDs, including inpatient costs with and without a surgical event, and the total cost (base cost), and the lowest and highest cost.

**Table 2** shows the results of annual ambulatory costs. The highest ambulatory cost was found in the diagnosis for Hypoplastic Left Heart Syndrome, at $719, and the lowest cost was
represented by the Tetralogy of Fallot, at $357. The average ambulatory costs for the seven CCHDs was $487.

**Out-of-pocket expenses and indirect costs**
The variables for the socio-demographic characteristics of the target population were collected by means of a survey applied to caregivers: 90% of patients with CCHD belonged to a socio-economic level equal or lower than 3 (in a scale ranging from 1 to 6, 1 being the lowest level\(^\text{20}\)); 55% were female, and the average age for patients was 11 months. Regarding the characteristics of caregivers, 40% had a secondary school level of education; 53% were employed, 42% reported having another occupation (housewife, unemployed); 75% stopped doing their most frequent activity to take up the patient’s care and 54% had an income lower than one monthly minimum wage (SMMLV).

Indirect costs were estimated at $1,303 per caregiver; the average number of days caregivers were on leave was 140 days. Figure 1 shows the impact of indirect costs on the caregiver’s budget depending on their level of income. The highest impact is found among caregivers with incomes lower than one monthly minimum wage.

Besides, the differentiated indirect cost for patients undergoing surgery or not was estimated, where the difference between undergoing surgery and not is observed, reaching $498. When the patient undergoing surgery the indirect cost was $1,466 and in the other hand the cost was $969.

The average out-of-pocket expense incurred by a family with a CCHD patient is $171, approximately $2,058 per year. The line item most frequently reported by the largest number of families was transportation costs in the city and meals outside the home (Table 3).

An estimate of out-of-pocket expenses was also made, differentiated for patients undergoing surgery where the difference was $1,300. When the patient undergoing surgery, the out-of-pocket expenses was $2,383.

To understand the economic impact imposed on families, it is important to estimate the impact on the family budget by income

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**Table 1. Inpatient costs for CCHDs (all in USD in 2017).**

<table>
<thead>
<tr>
<th>CCHD</th>
<th>Number of patients</th>
<th>Surgical event cost</th>
<th>Non-surgical event cost</th>
<th>Total cost</th>
<th>Lowest cost</th>
<th>Highest cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Truncus Arteriosus</td>
<td>7</td>
<td>$40,003</td>
<td>$2,416</td>
<td>$42,419</td>
<td>$37,705</td>
<td>$47,132</td>
</tr>
<tr>
<td>Transposition of Great Arteries</td>
<td>6</td>
<td>$31,937</td>
<td>$288</td>
<td>$32,226</td>
<td>$28,645</td>
<td>$35,806</td>
</tr>
<tr>
<td>Tricuspid Atresia</td>
<td>9</td>
<td>$23,879</td>
<td>$1,286</td>
<td>$25,164</td>
<td>$22,368</td>
<td>$27,960</td>
</tr>
<tr>
<td>Pulmonary Atresia</td>
<td>10</td>
<td>$15,088</td>
<td>$9,531</td>
<td>$24,619</td>
<td>$21,884</td>
<td>$27,355</td>
</tr>
<tr>
<td>Hypoplastic Left Heart Syndrome</td>
<td>3</td>
<td>$19,741</td>
<td>$1,368</td>
<td>$21,109</td>
<td>$18,764</td>
<td>$23,455</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>26</td>
<td>$17,612</td>
<td>$791</td>
<td>$18,403</td>
<td>$16,359</td>
<td>$20,448</td>
</tr>
<tr>
<td>Total Anomalous Pulmonary Venous Drainage</td>
<td>12</td>
<td>$16,266</td>
<td>$638</td>
<td>$16,904</td>
<td>$15,026</td>
<td>$18,783</td>
</tr>
<tr>
<td>Average CCHD</td>
<td>73</td>
<td>$23,504</td>
<td>$2,331</td>
<td>$25,835</td>
<td>$22,964</td>
<td>$28,706</td>
</tr>
</tbody>
</table>

**Table 2. Ambulatory costs for CCHDs.**

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypoplastic Left Heart Syndrome</td>
<td>$719</td>
<td>$639</td>
<td>$799</td>
</tr>
<tr>
<td>Pulmonary Atresia</td>
<td>$536</td>
<td>$476</td>
<td>$595</td>
</tr>
<tr>
<td>Tricuspid Atresia</td>
<td>$536</td>
<td>$476</td>
<td>$595</td>
</tr>
<tr>
<td>Truncus Arteriosus</td>
<td>$536</td>
<td>$476</td>
<td>$595</td>
</tr>
<tr>
<td>Transposition of Great Arteries</td>
<td>$363</td>
<td>$322</td>
<td>$403</td>
</tr>
<tr>
<td>Anomalous Pulmonary Venous Drainage Total</td>
<td>$363</td>
<td>$322</td>
<td>$403</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>$357</td>
<td>$317</td>
<td>$397</td>
</tr>
<tr>
<td>Average for CCHDs</td>
<td>$487</td>
<td>$433</td>
<td>$541</td>
</tr>
</tbody>
</table>
levels. For families earning less than one SMMLV (up to $249) the out-of-pocket expense represented 57% of their budget, assuming an income of $249, the widest interval range.

**Discussion**

The results of this study are consistent with a high economic impact of CCHDs on the health system and on families in Colombia. The consumption of resources that is made evident represents high average annual direct medical costs, both for inpatient and ambulatory services. Even out-of-pocket expenses undertaken by the families have a high impact on their budget, mainly in families with lower incomes.

The scarcity of literature on this subject makes this study relevant, not only in Colombia but also in other low and middle income countries. In addition, it is noteworthy to highlight the incorporation of estimates on direct costs and out-of-pocket expenses, an economic burden for families which is rarely taken into account due to the difficulty in collecting this information. The estimation of costs in this study has been a comprehensive process, incorporating different sources of information to get an estimate of the data described, data bases, validation by experts, surveys to caregivers, complying with the cost estimation methodology involving the four stages previously described.

Studies on costs related with CCHDs mostly refer to the process of screening followed to detect these heart diseases, but not to the economic burden caused by these diseases as a whole. One study made by Peterson *et al.* approached this topic, although it focused on comparing inpatient events among CCHD patients diagnosed timely and late, and not on estimating the total financial burden assigned to the disease. However, inpatient costs for the first year of life were estimated for 2011 prices, which reached

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**Table 3. Average monthly out-of-pocket expenses.**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation costs (transportation in the city)</td>
<td>20</td>
<td>100%</td>
<td>$46</td>
<td>$46</td>
</tr>
<tr>
<td>Meals for caregiver outside the home</td>
<td>19</td>
<td>95%</td>
<td>$34</td>
<td>$32</td>
</tr>
<tr>
<td>Sliding scale fees</td>
<td>16</td>
<td>80%</td>
<td>$6</td>
<td>$5</td>
</tr>
<tr>
<td>Co-payment</td>
<td>15</td>
<td>75%</td>
<td>$16</td>
<td>$12</td>
</tr>
<tr>
<td>Purchase of medication</td>
<td>14</td>
<td>70%</td>
<td>$14</td>
<td>$10</td>
</tr>
<tr>
<td>Other expenses</td>
<td>10</td>
<td>50%</td>
<td>$37</td>
<td>$19</td>
</tr>
<tr>
<td>Paperwork expenses</td>
<td>8</td>
<td>40%</td>
<td>$2</td>
<td>$1</td>
</tr>
<tr>
<td>Payments caused by consultation to private doctors</td>
<td>7</td>
<td>35%</td>
<td>$18</td>
<td>$6</td>
</tr>
<tr>
<td>Expenses incurred by transfer to temporary accommodation</td>
<td>6</td>
<td>30%</td>
<td>$134</td>
<td>$40</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td><strong>$171</strong></td>
<td></td>
</tr>
</tbody>
</table>

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**Figure 1. Impact of indirect costs on the caregiver’s budget.**
$100,200 in patients diagnosed late versus a cost of $69,500 for patients timely diagnosed.

Regarding indirect costs and out-of-pocket expenses for CCHD, Connor et al.23 carried out a qualitative study that explored the perceptions of parents on the costs associated with having a child with congenital heart disease regarding direct medical and non-medical costs undertaken by the family, and how this economic burden resulted in more stress and emotional impact. Mughal et al.22 developed an observational study at a hospital in Lahore (Pakistan), and identified that 63.1% of the families contributed with the cost associated with the CHD patient’s treatment, and 12.3% of them contributed at 100%. A study by Raj et al.21, conducted in India, estimated costs associated with CHD. Although not focusing specifically on CCHD, it is the study that approaches this topic more closely. The main results indicated that the connection between total inpatient expenses and the family income was 0.93 times the annual family income; the average time lost due to leave of absence by the father was 35 days and the loss of working days was 15 days on average. A quantitative estimation on the indirect costs and out-of-pocket expenses associated with CCHDs was not found in the literature.

There were some limitations in this study, mainly related with the low number of cases available due to the low prevalence of most CCHDs, a fact that hindered the collection of more data which may have led to imprecision. This situation led to having to carry out the surveys within a period of nine months. In addition, since records did not provide enough information to identify ambulatory costs, the data had to be obtained by consensus with experts.

Conclusions

CCHDs represent a high economic impact on the health system and families, especially on those with lower incomes. Cost analysis is a relevant topic for the health system and it requires a systematic and complex process. In this case, different primary and secondary information sources were available: data bases, surveys to caregivers and validation with experts on the topic. In addition, the bottom-up approach as a way to estimate a more real cost can be highlighted.

One of the most relevant added values included in the analysis for this study was the social perspective, which includes the measuring of indirect costs and out-of-pocket expenses. This dimension led to a larger data collection effort, more so when dealing with low-prevalence diseases. The results deriving from this study show the impact of these costs on the budgets of families when one of their members is diagnosed with a CCHD.

Data availability

Underlying data

In the following repository, you can find the dataset used for ambulatory costs, hospital costs and the survey data:

Open Science Framework: Underlying data of economic impact of CCHD in Colombia. DOI http://dx.doi.org/10.17605/OSF.IO/9J8K724

Extended data

The survey asked to 20 caregivers has been deposited in the following repository:

Open Science Framework: Survey asked to 20 caregivers of CCHD in Colombia. DOI http://dx.doi.org/10.17605/OSF.IO/67S4G23

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).

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References


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