*Cardiology in the Young*

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# Out-of-pocket medical expenses in severe CHD

Justin J. Elhoff[1], Kimberly E. McHugh[2], Jason R. Buckley[2], Shaine A. Morris[1], Kit N. Simpson[3] and Mark A. Scheurer[2]

[1]Texas Children's Hospital, Department of Pediatrics, Baylor College of Medicine, Houston, TX, USA, [2]Department of Pediatrics, Medical University of South Carolina, Charleston, SC, USA and [3]Department of Healthcare Leadership and Management, Medical University of South Carolina, Charleston, SC, USA

## Original Article

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**Author for correspondence:**
J. J. Elhoff, MD, Texas Children's Hospital, 6621 Fannin Street, Suite W6006, Houston, TX 77030, USA. Tel: 832 826 0634; Fax: 832 825 7422; E-mail: jxelhoff@texaschildrens.org

## Abstract

*Introduction:* Families of children born with CHD face added stress owing to uncertainty about the magnitude of the financial burden for medical costs they will face. This study seeks to assess the family responsibility for healthcare bills during the first 12 months of life for commercially insured children undergoing surgery for severe CHD. *Methods:* The MarketScan® database from Truven was used to identify commercially insured infants in 39 states from 2010 to 2012 with an ICD-9 diagnosis code for transposition of the great arteries, tetralogy of Fallot, or truncus arteriosus, as well as the corresponding procedure code for complete repair. Data extraction identified payment responsibilities of the patients' families in the form of co-payments, deductibles, and co-insurance during the 1st year of life. *Results:* There were 481 infants identified who met the criteria. Average family responsibility for healthcare bills during the 1st year of life was $2928, with no difference between the three groups. The range of out-of-pocket costs was $50–$18,167. Initial hospitalisation and outpatient care accounted for the majority of these responsibilities. *Conclusions:* Families of commercially insured children with severe CHD requiring corrective surgery face an average of ~$3000 in out-of-pocket costs for healthcare bills during the first 12 months of their child's life, although the amount varied considerably. This information provides a framework to alleviate some of the uncertainty surrounding healthcare financial responsibilities, and further examination of the origination of these expenditures may be useful in informing future healthcare policy discussion.

Families of children diagnosed with severe CHD experience intense, multi-faceted stress.[1] In addition to the emotional distress of their child facing a potentially life-threatening diagnosis, these families must cope with the uncertainty of the life changes this diagnosis will bring. One major source of anxiety is the unknown financial ramifications the family will experience related to their child's diagnosis and treatment. Families may face relocation, loss of income, and significant non-medical expenses. Although possessing healthcare coverage theoretically should ease some of the concerns regarding the economic impact of their child's healthcare needs, the incessant flow of bills and notices from hospitals and insurance companies, as well as the ensuing uncertainty regarding to what extent they will be responsible for these healthcare bills, may in fact compound the financial stresses experienced by these families. Interview and survey data have indicated that uncertainty regarding out-of-pocket medical costs adds a significant stress burden during already trying times.[2–4]

Although there is a significant body of research examining factors related to hospital cost in CHD, no information is available regarding out-of-pocket payments for which families are responsible.[5–14] Examination of families of children with special healthcare needs has revealed that out-of-pocket medical costs often amount to a significant financial burden, although heterogeneity of disease processes and insurance plans make it difficult to quantify actual family financial responsibility.[15–21] In addition, studies have shown that commercially insured families have higher out-of-pocket costs compared with publicly insured families.[22–26]

The diagnosis of CHD in a newborn probably has lifelong financial implications for families. However, infants with severe CHD generally require profound resource utilisation during the 1st year of life as they will require at least one surgical procedure, prolonged hospitalisation(s), and multiple outpatient visits. In general, clinicians and other healthcare providers have little information to provide families on the out-of-pocket medical costs for which they will be responsible during these times as such data have not previously been published. The object of this study is to describe the family responsibility for healthcare bills during the first 12 months of life for commercially insured children undergoing surgical repair for transposition of the great arteries, tetralogy of Fallot, and truncus arteriosus.

## Methods

A cohort of children born from January 1, 2010, through December 31, 2012, with diagnosis codes indicating severe CHD were identified in the MarketScan® database from Truven. This database identified commercially insured infants in 39 states with an ICD-9 diagnosis code for



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transposition of the great arteries, tetralogy of Fallot, or truncus arteriosus, as well as the corresponding procedure code for complete repair. The regional distribution of the sample was as follows: Northeast, 55; North central, 106; South, 201; West, 117; missing, 2. Data from these infants were extracted, and all insurance bills for 12 months after birth, or until death if sooner, were aggregated at the level of the individual patient by expenditure type. Data extraction identified inpatient, outpatient, and pharmaceutical payment responsibilities of the patient's family in the form of co-payments, deductibles, and co-insurance during the child's 1st year of life. All values are presented in 2012 United States dollars. The data set used for the study was reviewed by the university's institutional review board and deemed to constitute non-human research.

Descriptive statistics and crude outcome estimates were compared between the groups by using $\chi^2$ tests for categorical variables and t-tests or Mann–Whitney U/Wilcoxon tests as appropriate for continuous variables. Because of the non-normal distribution of the cost measures, we used a Gamma distributed generalised linear log-linked model to estimate confidence intervals for payment by lesion subgroups. This allowed us to examine effects of region and sex on cost, which were not significant, with $p > 0.05$. The use of a gamma distributed generalised linear model with a log-transformed link function has been shown to be a good method to estimate healthcare cost distributions that are generally right-skewed, especially when the log-transformed dependent variables do not have heavy tails or excessive heteroscedasticity.[27] SAS version 9.4 (SAS Institute) was used for analysis with p-values considered statistically significant for $\alpha < 0.05$.

## Results

A total of 481 infants with the diagnosis and procedure codes for the specified lesions and their corresponding procedure codes were identified. The average family responsibility for medical bills during the 1st year of life was $2928 (Table 1). Median out-of-pocket responsibility across the three groups was $2298. There was no statistical difference in out-of-pocket costs between the three cardiac lesions ($p = 0.62$). There was a wide range of family responsibility for medical bills, with some families responsible for less than $100, whereas other families faced over $18,000 in out-of-pocket expenditures (Fig 1).

Although the mortality rate during the first 12 months of life in this cohort was relatively low – 10 out of the 481 patients – we performed additional analysis using only the patients who survived through their first birthday. For these patients there was no difference in either the out-of-pocket medical costs ($p = 0.48$) or in the range of costs incurred by the family (Supplementary Table 1).

Overall, 46% of the cohort had one hospitalisation detected in the database during the 1st year of life. Meanwhile, 26% had two admissions, 12% had three admissions, and 16% had four or more admissions. There was no difference in the number of admissions during the 1st year of life among the three different cardiac lesion groups ($p = 0.56$).

We were able to determine the proportion of out-of-pocket medical expenses accounted for by initial hospitalisation, subsequent hospitalisation(s), prescriptions, and outpatient visits (Fig 2). Initial hospitalisation accounted for 28–37% of family expenditures, compared with 12–17% for subsequent hospitalisations, 7–15% for prescriptions, and 38–45% for outpatient visits. Across all three lesions the initial hospitalisation and outpatient visits combined to account for 75% of all out-of-pocket costs.

Using the MarketScan® database, we were able to determine the total payments made on behalf of each patient during the first 12 months of life by the private insurance companies themselves, the families of these patients, and any secondary forms of insurance. These totals are presented in Table 2. Mean total payments made were significantly lower for patients with transposition of the great arteries compared with the other two lesions ($p = 0.0002$). Univariate analysis showed that the 10 patients who died during the study had significantly higher total insurance payments made compared with the patients who survived the 1st year of life ($p < 0.0001$, Supplementary Table 2). Figure 3 displays the distribution of total payments made over the 1st year of life, revealing that ~90% of payments originate from services provided during hospitalisations. The payments made for "subsequent hospitalisations", "outpatient", and "prescriptions" must be interpreted in the context that these numbers are averages calculated only for patients using these services. In addition, the "initial hospitalisation" is not necessarily the surgical hospitalisation – for instance if an infant was admitted at an outside facility before transfer to a tertiary centre for further care.

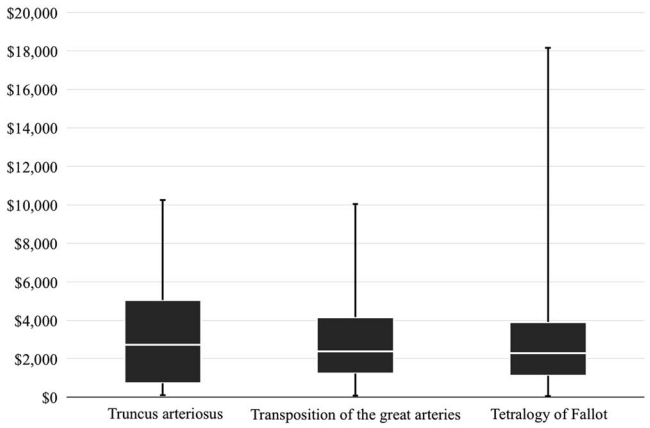


**Figure 1.** Box-and-Whisker plots illustrating median, 25th and 75th percentile, and range of family responsibility for medical expenses over the 1st year of life by cardiac lesion.

**Table 1.** Out-of-pocket medical costs during the first 12 months of life

| | Truncus arteriosus (n = 37) | Transposition of the great arteries (n = 176) | Tetralogy of Fallot (n = 268) | All lesions (n = 481) |
|---|---|---|---|---|
| Female [n (%)] | 17 (46) | 77 (44) | 111 (41) | 205 (43) |
| Mortality [n (%)] | 2 (5.4) | 7 (4) | 1 (0.4) | 10 (2.1) |
| Mean 12-month out-of-pocket (SD) | $3310 (2702) | $2855 (2094) | $2924 (2684) | $2928 (2483) |
| Median 12-month out-of-pocket (IQR) | $2721 (718–5046) | $2372 (1233–4156) | $2245 (1117–3733) | $2298 (1120–3907) |
| Range 12-month out-of-pocket | $101–10,236 | $80–10,029 | $50–18,167 | $50–18,167 |

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## Discussion

To the best of the authors' knowledge, this is the first study to examine out-of-pocket medical costs for commercially insured patients undergoing congenital heart surgery. We found that in three forms of severe CHD requiring cardiac surgery during infancy, the average family responsibility for medical bills during the 1st year of life was ~$3000, with median medical bills totalling nearly $2300. Although the average out-of-pocket costs were no different between patients with the three cardiac lesions examined, considerable variation exists between individual family responsibilities for medical bills.

The aetiology of this variability is not clear from this database research. It does not seem to be due to survivorship bias, as the wide variation of out-of-pocket costs persists among those who survived the 1st year of life. Although there were no differences in out-of-pocket costs for survivors, interestingly those patients who died within the 1st year of life actually had significantly higher total payments made compared with those surviving through their first birthday.

Although out-of-pocket medical costs have not previously been evaluated in this patient population, previous research has illustrated up to ninefold variation in adjusted hospital costs across institutions.[9] It is possible that factors contributing to variability in hospital costs play a role in the out-of-pocket costs families face, as hospital costs account for the vast majority of total healthcare expenditure in this study. Although we did not find a regional variability in out-of-pocket costs, this study is unable to examine for an effect at a centre-specific level. Further research into this potential correlation would lend considerable information into value in healthcare. However, despite this potential influence of centre variability, even at its most extreme this variability seems unlikely to fully account for the degree of variation observed between individual families' out-of-pocket responsibilities.

It is possible that anatomic or strategic therapeutic differences contribute to some of the variability noted. For instance, certain anatomic variants, especially in the tetralogy of Fallot population, may routinely be discharged home following birth and monitored in the outpatient setting before complete repair. Similarly centre-specific strategies such as optimal timing of repair of these lesions may influence healthcare utilisation, as well as out-of-pocket medical expenses for families. Although analysis of these data is unable to determine to what extent these factors may influence families' out-of-pocket medical expenses, this should be an important consideration as healthcare resource utilisation discussions continue.

It seems feasible that a significant proportion of this wide variability is due to differences in individual health plans. Health plan structures vary widely, and even issues such as timing of healthcare services may have striking effects on a family's out-of-pocket responsibilities, as insurance deductibles and out-of-pocket annual maximums generally reset at the beginning of the calendar year. This database is unable to provide details on individual patient health insurance plans, and we do not know what these families pay in insurance premiums in order to create a more comprehensive picture of healthcare costs. However, given the wide variation in out-of-pocket medical costs seen here, details regarding insurance plan composition will be another important consideration in further research investigating financial implications for families of children with CHD. Furthermore, the total burden of healthcare costs for patients and their families should be comprehensively evaluated as the United States continues to grapple with more effective and efficient ways to provide healthcare coverage. Of note, data from this study overlap with the signing of the Affordable Care Act (March, 2010) but predates the first open enrolment period (October, 2013). Further research

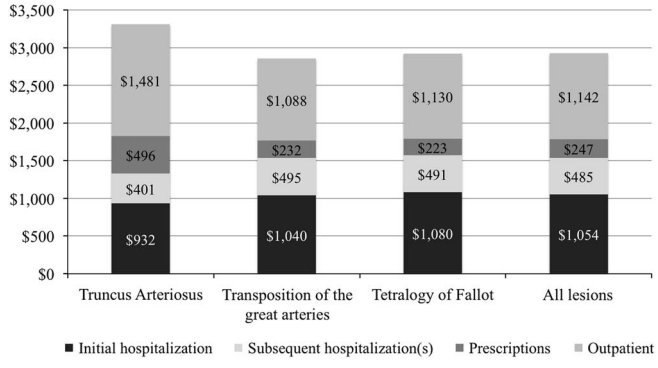


**Figure 2.** Breakdown of mean out-of-pocket medical expenses by initial and any follow-up hospitalisations, as well as expenses for prescription drugs and outpatient services during the 1st year of life.

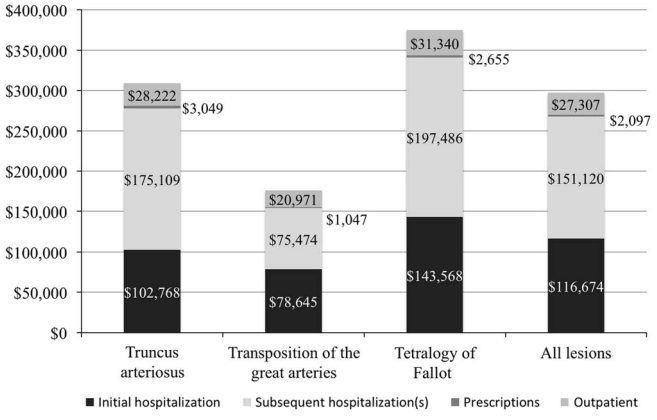


**Figure 3.** Breakdown of mean total payments made on the behalf of patients during 1st year of life. Of note, subsequent hospitalisation(s), prescriptions, and outpatient payments are averaged only among those who received respective services.

**Table 2.** Total payments made by all payers over first 12 months of life.

| | Truncus arteriosus (n = 37) | Transposition of the great arteries* (n = 176) | Tetralogy of Fallot (n = 268) | All lesions (n = 481) |
|---|---|---|---|---|
| Mean total payments (SD) | $349,500 (298,520) | $214,056 (221,028) | $300,081 (335,577) | $272,841 (298,820) |
| Median total payments (IQR) | $252,053 (162,437–416,664) | $174,155 (48,4423–264,458) | $194,665 (118,591–341,021) | $191,595 (107,735–317,475) |
| Range of total payments | $14,849–1,467,398 | $3727–1,315,877 | $8540–2,341,901 | $3727–2,341,901 |

*Mean total payments were significantly lower for patients with transposition of the great arteries (p = 0.0002)

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investigating any changes in families out-of-pocket costs coincident with this healthcare reform may be of interest.

Additional data to emerge from this study are that, although hospital costs have been routinely studied in the field of CHD, ~50% of families' out-of-pocket costs in the patients studied originate from outpatient services and prescription drug costs. This information may point us towards areas to focus efforts to lower costs for families. It is revealing that while outpatient and prescription expenditures account for only 10% of all total payments made during the first 12 months of life for patients in this study, nearly 50% of family's out-of-pocket responsibilities originate from these categories.

Although this study reveals that commercially insured families of patients with three forms of severe CHD often face significant financial liability from out-of-pocket medical costs, by comparing average out-of-pocket costs with payments made by insurance companies we find that families' responsibility is on average only ~1% of the payments made on their behalf by insurance companies. Although this does not change the significance of the burden on individual families, it does provide evidence that in this population commercial health insurance is probably succeeding in picking up the majority of the financial burden during these catastrophic situations.

This study has several limitations. As discussed, the MarketScan® database does not provide granular insurance plan details on individual levels. In addition, as health policy has evolved over the past several years, it is possible that data from 2010 to 2012 may not fully reflect the current situation, and studying out-of-pocket costs as healthcare coverage continues to evolve may provide valuable feedback. Our access to this database does not provide information on publicly insured patients, and although previous research has shown decreased costs for publicly insured patients, comparison of costs for commercially versus publicly insured patients may educate policy decisions. In addition, the tetralogy of Fallot cohort in particular is potentially more heterogeneous, and this study does not address anatomic or therapeutic variability that may influence costs. It should be emphasised that the out-of-pocket expenses are not necessarily all related to cardiac care, as these data indicate comprehensive costs for families and it is likely that many of the patients studied have co-morbid conditions requiring medical care. Furthermore, this study only addresses expenses occurring from medical bills and in no way quantifies the potential additional financial and social hardship that may occur secondary to missed time at work, transportation and lodging costs, or the possibility of the need to relocate, to name a few possible uncertainties.

In conclusion, this study is the first to examine out-of-pocket hospital costs for commercially insured patients with CHD. On average, families of patients with three forms of severe heart disease requiring surgery during infancy were responsible for ~$3000 in direct healthcare costs in the 1st year of life, although this value varies greatly. This information may serve as a starting point to help prepare families for their potential out-of-pocket medical costs while also revealing questions for future inquiry.

**Supplementary material.** To view supplementary material for this article, please visit https://doi.org/10.1017/S1047951118000768

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**Conflicts of Interest.** None.

**Ethical Standards.** The data set used for the study was reviewed by the university's institutional review board and deemed to constitute non-human research.

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