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Original Article

Direct non-medical and indirect costs for families with children with congenital cardiac defects in Germany: a survey from a university centre

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Abstract *Introduction:* Parents of children with congenital cardiac disease suffer from psychological stress and financial burdens. These costs have not yet been quantified. *Materials and methods:* In cooperation with paediatricians, social workers, and parents, a questionnaire was devised to calculate direct non-medical and indirect costs. Direct non-medical costs include all costs not directly related to medical services such as transportation. Indirect costs include lost productivity measured in lost income from wages. Parents were retrospectively queried on costs and refunds incurred during the child's first and sixth year of life. The questionnaire was sent out to 198 families with children born between 1980 and 2000. Costs were adjusted for inflation to the year 2006. Children were stratified into five groups according to the severity of their current health status. *Results:* Fifty-four families responded and could be included into the analysis (27.7%). Depending on severity, total direct non-medical and indirect costs in the first year of life ranged between an average of €1654 in children with no or mild (remaining) cardiac defects and an average €2881 in children with clinically significant (residual/remaining) findings. Mean expenses in the sixth year of life were as low as €562 (no or mild (remaining) cardiac defects) and as high as €5213 (potentially life-threatening findings). At both points in time, the highest costs were lost income and transportation; and day care/ babysitting for siblings was third. *Discussion:* Families of children with congenital cardiac disease and major sequelae face direct non-medical and indirect costs adding up to €3000 per year on average. We should consider compensating families from low socioeconomic backgrounds to minimise under-use of non-medical services of assistance for their children.

Keywords: Congenital cardiac disease; inborn cardiac defect; costs; lost productivity; transportation

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At present, with the technological and medical progress and refined surgical techniques about 85% of all children born with congenital cardiac defects reach adulthood. In Germany, of a total population of more than 80 million this amounts to about 200,000 children and adolescents up to the age of 18 years (German Society of Pediatric Cardiology).[1]

Yet, this success story is ambivalent in so-far as the survival of children puts psychological and social pressure on some families as could be shown in various studies worldwide[2–7] except for Spijkerboer et al[8] from the Netherlands who found that parents had lower scores of distress than the reference population 7.5 years and more after their

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child's cardiac surgery. Furthermore, the financial burden can increase the already felt pressure[2,5]. In order to help these families in a more targeted way, we explored the continuing costs that they incur with having a child with a congenital cardiac defect, according to the severity categories of cardiac defect.

The present study was devised to obtain exact data on direct non-medical and indirect costs for a family with a child with a congenital cardiac defect requiring long-term follow-up. Direct non-medical are costs not directly related to medical treatment; for instance, for transportation to and from hospital, for paying a babysitter for siblings etc. Further expenses could be for rebuilding within the house to compensate for motor deficits that the patient may have or attending specifically tailored exercise groups. Indirect costs refer to the problem that one parent may periodically or permanently not be able to pursue a job; this would count as lost income adding up to indirect costs.[9] Even in a system with universal coverage for medical treatment as well as financial subsidisation for some transportation cost, as given in Germany, families with sick or disabled children still have to face additional costs. As these costs may vary with regard to severity of the medical findings, we, the authors, used a sample of patients with a variety of congenital cardiac defects for a survey to ascertain direct non-medical and indirect costs.

We assumed that it would be the easiest for most families to remember milestone years relatively better. Therefore, we chose the first year and the sixth year of life, which is the year when children start school in Germany. We could, for the majority of cases, include the years before and after surgery with this approach.

Materials and methods

Ethics committee/institutional review board approval

The study and the questionnaire have been reviewed several times and approved by the ethics committee of the University of Cologne (Ref. no. 07-133). The ethics committee required consent and signature from both parents/legal guardians of the child.

Qualitative interviews and pre-test

Qualitative interviews with experts were performed in July and August, 2007 (AHT). One of the head physicians (SS), a social worker from the Department of Pediatric Cardiology and three parents from the local parents' self-help group, "Elterninitiative Herzkranker Kinder Köln e. V." were interviewed. The interview was open, but semi-structured on the basis of the previously developed guideline. The guideline was devised on the basis of what is theoretically included in the categories of direct non-medical and indirect costs and on what is to be practically found in the literature on children with special health-care needs.[9,10]

The questionnaire was altered after two phases of pre-testing. First, the questionnaire was tested with the aforementioned parents who are engaged in the self-help group. Second, three randomly selected families were asked to fill in the questionnaire and comment on it, while visiting the outpatient clinic of the department. In order to assure that the questions were easy to comprehend, a non-native German speaking family was included.

The questionnaire

The questionnaire comprises 27 questions. It is drafted in German and may be obtained from the authors. All questions have two possibilities for answers relating to the two different periods of time in the lives of the children. Period I is the first year of life, period II is the year of school entry, which in Germany is around the age of 6 years. Parents were explicitly prompted in writing to fill in only costs that occurred in relation to the congenital cardiac defect of the particular child. Two open questions at the end were added to leave room for any kinds of costs that were not covered as well as any subsidies the families might have received. As all direct medical costs are fully covered for children in Germany, any questions about costs for medical treatment, drugs etc. were not included in the questionnaire.

The questionnaire consists of three sections. Part I with a total ofnine questions covers the time spent in hospital, physician appointments, and any additional therapies etc. Part II consists of 14 questions on cost of transportation, enquiring about the distance travelled and the frequency of hospital follow-up visits. In Part III, four questions deal with the cost for any siblings' day care/babysitting. In all sections, parents are also asked to fill in any reimbursements from the statutory health insurance or other organisations as well as any funding received with regard to the costs incurred.

Coding of patients

Patients were assigned a random number, between 0 and 198, and the questionnaires sent out. Only the data analyst (AHT) had access to both the patients' files for severity assessment and the questionnaire.

Patients and basic demographic data

A sample of 198 children born between 1980 and 2000 was contacted via a letter and received the questionnaire. Between 2002 and 2005, about 2120

children were seen annually with an average of 3190 visits per year at routine outpatient visits at the paediatric cardiology department of the University Hospital of Cologne. The 198 children are from this larger sample. Of them 51% were female; their average age was 15.7 years with a range from 8.4 to 27.4 years at the time of the study. Children with syndromes, disabilities, co-morbidities, and those with mental retardation were excluded. The sample represents the complete spectrum of congenital cardiac diseases.[11] Some of the patients included in this study have been described in a previous publication from our institution, comparing their psychomotor and psychosocial development with those of healthy peers.[11] The questionnaire was mailed because most likely children with no or mild residual findings would not have attended follow-up visits in the clinic but are seen by specialists in private practice in ambulatory care. Hence, they would have been lost to follow-up.

Categorisation of severity levels

For all patients included we had detailed case histories including all in- and out-patient visits, procedures etc. These were used to stratify the children according to their residual cardiac impairment. The categorisation scheme was developed at the University of Cologne in cooperation with the German Sport University in order to assess the children for the level of permissible exercise in the heart sports groups (Table 1).[12]

All patients were assigned to these categories according to their status at the time of entering the special cardiac sport groups as described previously by a paediatric cardiologist (SS).[11]

Cost data

As demanded, resources and prices were gathered separately. All categories of resources are from the questionnaire. The number and amount of resources used are given by the individual families. Pricing was done either on the basis of average cost in Germany for work, day care/babysitting and other services or as stated in the questionnaire.

The average hourly salary for the year 2006 was taken in order to calculate costs for lost productivity on the job, if a parent had to accompany a child to any in- or out-patient visits, physiotherapy, cardio-pulmonary exercise group, or any other services.[13] Expenses for siblings' daycare/babysitting was calculated based on hourly rates, and the frequency and duration of use. Costs per kilometre for a small or medium-sized vehicle were estimated at €0.38 per kilometre.[14]

Unpaid leave of absence was similarly rated on the basis of average wages.

Subsidies, for example, attendance allowance and refunds for transportation from the statutory health insurance were collected as well and then subtracted from costs. Tax rebates were not included.

Inflation and change of currency

As costs were incurred over various years, all were adjusted for inflation to the base year 2006, using the official inflation rates (Federal Statistical Office Germany = Statistisches Bundes-amt Deutschland). All costs given in German Marks were converted into euros with the official exchange rate of 1.95583 (European Central Bank, 1998).

Method of analysis

Total expenses were averaged within the five levels of medical findings. Data were entered in SPSS; calculations were made with Excel (inflation etc.).

Results

A total of 198 patients were included in the study. In all, 10 letters came back because the address was incorrect. Of the remainder, 55 families returned the completed questionnaires. One of them had to be excluded from analysis as only one parent had signed the consent form. This makes a response rate of 27.7%; 42.6% (23 of 54) of the responding families had female children with an average age of 15.7 years with a range of 8.6–27.4 years (Table 2). The children included in the final analysis could be categorised as displayed in Table 3.

Table 1. Severity categories according to Schickendantz et al[12].

	Severity	Examples
A	No (residual/remaining) cardiac defect	
B	Mild (residual/remaining) findings	Trivial aortic or pulmonary (residual) stenosis/insufficiency
C	Clinically significant (residual/remaining) findings	Right ventricle = system ventricle, aortic (residual) stenosis with $p > 30$ mmHg
D	Severe (residual/remaining) findings	Pulmonary hypertension, hypertrophic obstructive aortic stenosis
E	Vitally threatening findings	

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Table 2. Basic demographic data.

	Average age (years)	Male (%)	Female (%)
Children included in survey (n = 198)	15.7	97 (49)	101 (51)
Children whose families answered and were included in the analysis (n = 54)	15.7	31 (57.4)	23 (42.6)

Table 3. Categorisation of children from participating families according to severity of congenital cardiac defect.

Category of severity on the basis of the residual findings	Total number of patients in category	Questionnaires received and included in analysis	Percentage of questionnaires included among all patients in category
A (no findings)	9	2	22.2
B (mild findings)	103	26	25.2
C (clinically relevant findings)	65	16	24.6
D (severe findings)	6	4	66.7
E (vitally threatening findings)	15	6	40
Overall	198	54	27.3

The rates of return varied among the five levels. The lowest one of two out of nine (22.2%) was in the category of no (residual) cardiac defect, the highest with four out of six in the category of severe (residual) findings (66.7%). The categories, no and mild residual findings, were merged for the small cell size and response rate in the no residual findings group. Other groups were not to be merged since the difference in the clinical consequences of the disease is significant among the other categories.

Not all families filled in all fields. For the first year of life, six families – one in the group with no (residual) cardiac defect, four in the group with mild (residual) findings, and one in the group of clinically significant (residual) findings – did not fill in any expenses. One parent, among those with mild (residual) findings, explained that their child's cardiac defect was only detected later. For year 6 four families – two in the category of mild (residual) findings, one in the group of clinically significant (residual) findings, and one in the group of severe (residual) findings – did not fill in any expenses. All others mentioned expenses for transportation. Of 54 families 20 indicated that they had incurred losses for a parent who was not able to go back to work; six families indicated costs for accompanying a child during a hospital admission. Overall, 63% of included patients had siblings. For the period of the first year in life, 21 families listed siblings – zero in the category of no (residual) findings, 11 in the category of mild (residual) findings, five in the category of clinically significant findings, two in the category of severe (residual) findings, and three in the category of vitally threatening findings. For the period of the sixth year in life, 28 families listed siblings – one in the category of no (residual) findings, 12 in the category of mild (residual) findings, eight in the category of clinically significant (residual) findings, two in the category of severe (residual) findings, and five in the category of vitally threatening findings. A total of seven families had more than one sibling; the maximum was four siblings in one family with a child at severity level of mild (residual) findings at both points in time. Only two families had domestic help; eight families had to cover additional costs and mentioned psychotherapy, ergotherapy, help with dyscalculia etc.

Overall indirect costs for families in the first year of life varied between €1654 in severity category no or mild (residual) findings with 28 (out of 112) respondents and a range of €0 to €18,905 and €2881 in severity category clinically significant (residual) findings with 16 respondents and a range of €0 to €10,987. In year 6 the lowest per year expenditure was incurred in the category of no or mild (residual) findings with €562 with the same 28 respondents and a range of €36 to €5961, the highest in the group with vitally threatening findings with €5213 per annum with six respondents and a range of €357 to €15,163 (see Table 4 and Fig 1). For severity categories no and mild as well as clinically significant (residual) findings, direct non-medical and indirect costs were higher in the first year of life than in the sixth year of life, while it was the other way round for categories of severe (residual) and vitally threatening findings.

On the basis of all 54 questionnaires, irrespective of severity level, the first year of life and the sixth year do not vary much in the distribution of costs for the three major categories. During the first year, indirect costs for not being able to work make up

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Table 4. Ranges of costs in severity categories.*

Category of severity	Range: 1st year of life	Range: 6th year of life
A and B (no and mild findings; n = 28)	0–18,905	36–5961
C (clinically significant findings; n = 16)	194–10,987	38–6762
D (severe findings; n = 4)	291–3915	31–9496
E (vitally threatening findings; n = 6)	536–7556	357–15,163

*Families who did not give costs were excluded

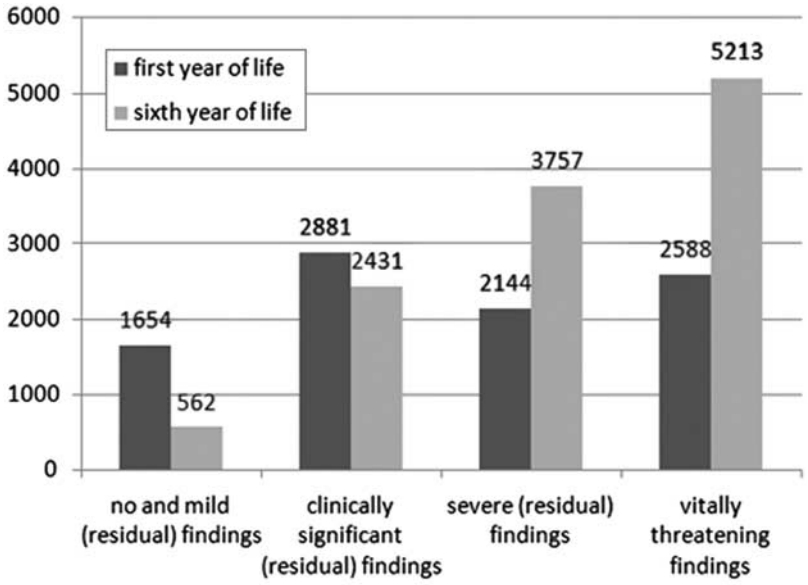

Figure 1.
Overall costs in first year of life and in year of school entry according to severity level indicated as averages in €.

the highest share with 55% followed by direct costs for transportation with 22% and day care/babysitting costs for siblings with 15%, which is a total share of 82%. In the sixth year the three respective categories account for 46, 19, and 16%, which is a total share of 71%. Home help did not accrue any costs in year 1, but amounted to 8% in year 6 (see Fig 2).

Within the category expenses for travelling, 72% was spent on the way to and from hospital in the first year of life, whereas this was only 27% in the sixth year of life. Seeing the paediatric cardiologist contributed to another 15%. During the second time period, 40% of transportation was spent on getting to the special cardiac sport group, 27% to the hospital and 26% to other therapies. Two families mentioned a household help averaging at €3909 per family.

Discussion

This is the first study in Germany and also worldwide that gathered data on direct non-medical and indirect costs accruing for families with children with congenital cardiac defects. Depending on severity, total non-medical and indirect costs in the first year of life ranged between €1654 (no or mild (remaining) cardiac defects) and €2881 in children with clinically significant (residual/remaining) findings. Expenses in the sixth year of life were as low as €562 (no or mild (remaining) cardiac defects) and as high as €5213 (vitally threatening findings). At both points in time, the highest costs were for lost income and transportation; costs of daycare/ babysitting for siblings were third highest.

Before discussing the social policy impact of our results, we would like to dwell upon some strengths as well as limitations of our study.

Among the limitations of study design and methodology are a rather small sample size. In connection with the overall sample size, we have categorised the children into levels of severity at only one point in time. Children might have switched among different categories between the ages of 1 and 6 years. Yet, if we grouped children into categories at both points in time, the groups would be too small to make any reasonable

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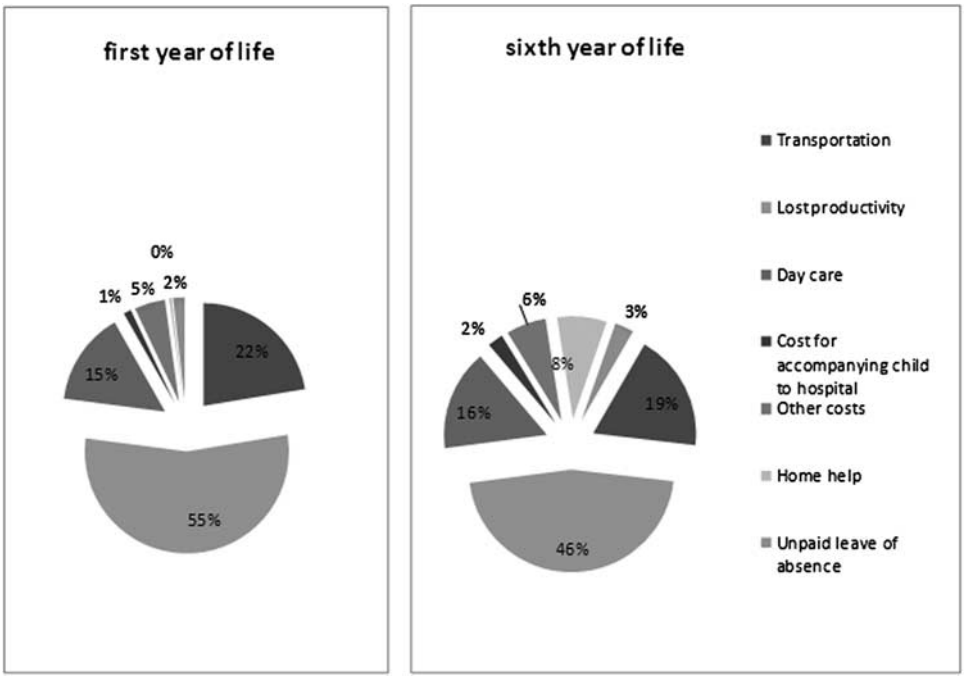

Figure 2.
Distribution of costs in years 1 and 6 as percentage of costs over all severity categories. Categories of costs: Transportation: expenses for transportation to in and from outpatient care as well as to and from additional services such as a cardiac exercise group etc.; Lost productivity: income loss due to cutting back or giving up a job; Day care: solely for siblings while parents accompany child with congenital cardiac disease; Cost for accompanying child to hospital: additional cost for food etc. while accompanying the child; Other costs: other services such as psychotherapy, ergotherapy etc; Home maker; Unpaid leave of absence: parent has to take off on additional days from work without payment.

statements about costs, as we would have to construct up to 5 × 5 subgroups. The groups would be so small that one child living at a relatively long distance from the hospital would cause an immense increase in the average costs of transportation. Yet, a response rate of 27% is reasonably acceptable considering that private data had to be revealed and that the average time taken to fill the questionnaire was around 40 minutes. In addition, as both parents had to give their consent, a requirement of German International Review Board protocols for studies with minors, this could have been a potential constraint for divorced parents. In contrast to many studies that work with aggregated data, we could correlate financial data with the clinical data of all children, including all details about days in hospital, ambulatory visits to the hospital, and time spent attending the cardiac sports group etc.

The average age among the contacted and the respondents was the same. There was a bias towards more boys among the families who filled in the questionnaire. Whether this would contribute to skewing the results remains an open question.

A strength of our study design is that our estimate is rather conservative with regard to the whole population of children with congenital cardiac defects, as we excluded children with syndromes, other aggravating co-morbidities etc.

Moreover, with regard to the rigidity of the methods, we measured the severity of health status and accounted for time bias in data collection. Both are methodological requirements that only few studies meet, as Anderson et al[15] in their review on personal cost for caring for a child with a disability point out.

Very few patients participated especially in category of no (remaining) cardiac defect. We assume that most parents in this group were happy with the status of their children and thus were not interested in filling up a questionnaire since they might not see many limitations for their children in their daily lives.

For some cost categories only few families entered the sums. Since we strictly instructed parents to list only those costs incurred in conjunction with the child's cardiac defect, we have to rely upon parents' honesty and ability to recall, as is the problem with any survey on income and expenses. Doubts that families exaggerated costs cannot be totally eliminated. Thus, we are aware that parents might not be able to truly separate costs for babysitting or household help from costs that they would have incurred anyway. However, as there were several families in all groups who did not declare any costs either in year 1 or year 6, we assume that the

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majority of families have been honest in filling up the questionnaire.

In a retrospective study, the first and the sixth year of life should be the ones that parents recall more easily. Nevertheless, we assume that parents left out some costs. Only one out of the ten families who did not enter costs for either year 1 or year 6 explained that the child's cardiac defect was only detected after year 1. Therefore, we are not sure whether parents had simply forgotten expenses, were fully reimbursed, and did not enter costs despite the separate questions on costs and reimbursements or felt they would not want to disclose data. It is unlikely that parents did not have any costs in year 1 in the category of transportation to paediatric cardiology services, so we think that the estimates represent a very conservative low mean.

With regard to lost productivity of one parent, we infer that parents might not have thought of actually going back into their job. This means that only few families stated that one partner – still most commonly the mother in Germany – did not earn wages that they would not have lost with a child that would not have required a lot of medical treatment and care.

Even with regard to how we did the actual costing, we think that our results represent a rather low and conservative estimate, as, for instance, any visit to the hospital or a physician was calculated as half a working day. Some employers would not let somebody take off less than a whole working day. With regard to daycare/babysitting expenses for siblings, we instructed the parents to list solely the costs that accrued for time devoted to the medical and paramedical care of the child with the congenital cardiac disease. Therefore, we do not have to deduct the regular cost for daycare from the expenses listed, as has been recommended by Anderson et al.[15] The same holds for household help. The study did not account for any benefits in taxation for this would be too complex to adjust for.

While the costs from years 1 and 6 for a child may not be simply added up to the age of 18 years, it is a common method to summarise direct non-medical and indirect costs over long periods of time valued in euros of the year 2006.[9] This would mean that families with a child in the higher severity categories of clinically significant (residual), severe (residual), and vitally threatening findings have to bear on average about 55,000 to 60,000€ (inflation-adjusted to 206) until their child reaches the age of 18 years.

As Shattuck and Parish[16] report, 'research on the family financial burden associated with caring for CSHCN [children with special health care needs] is limited'. We only came across a few studies on other disease entities.[17–19] The most costly was the part of the health economic studies that, however, did not particularly focus on costs incurred by caregivers/parents.[20] In addition, no studies have yet focused on children with congenital cardiac defects nor implemented the method of a direct survey. Studies on other disease entities or from other countries[17] or on children with disabilities in general (see review in Anderson et al[15]) do not yield figures that could be comparable to ours for differences in disease – cancer has a rather sudden onset in otherwise healthy children in contrast to congenital cardiac disease – or in methodology. As Anderson et al[15] point out, disability and disease are two different entities.

With regard to a comparison with children with other conditions or children with congenital cardiac defects in other health systems, we would assume that families with children with diseases that cause wheelchair dependency might have to face higher annual as well as overall costs in general. The same might hold for children with severe metabolic or neurological disorders. Families with cancer might have higher annual costs, but these costs might accrue only over a few years in most cases. About the same costs or lower costs might accrue for children with severe asthma or excema. With regard to other health-care systems, we would speculate that our figures are a lower boundary since out-of-pocket costs are a small percentage in the German system. We would assume that families, especially in the United States, have a much higher financial burden in the higher categories of severity (cp[10]).

We think that our instrument could help other countries to assess costs to be faced by families with children with congenital cardiac disease. The instrument does have shortcomings such as University of Cologne International Review Board did not allow us to include costs for house renovation because they felt that families would enter costs that they would have had anyway, regardless of having a child with congenital cardiac disease; sosts for telephone calls etc. were not explicitly mentioned. Most parents might not have thought of adding these given that these are relatively small amounts.

In conclusion, on the basis of our study we recommend a prospective survey with several paediatric cardiac centres (in Germany) to get a representative picture of direct non-medical and indirect costs for families according to categories of severity. Despite this approach to further research, our pilot study could show that families with children with congenital cardiac disease and major sequelae face indirect costs adding up to €3000 per year on average. This adds up to about 55,000 to €60,000 until the affected child reaches the age of 18 years. In Germany, we should consider compensating families from lower socioeconomic backgrounds to minimise under-use of essential non-medical services for their children.

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