

## Catastrophic Health Expenditure and Its Determinants in Households with Pediatric Cancer and Oncology Disorders

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Received: 28 February 2022

Accepted: 18 June 2022

### Abstract

**Background:** Families are willing to spend their entire lives improving their children due to emotional attachments, which, in turn, increases their exposure to catastrophic health expenditures (CHEs). The present study aimed to estimate the level of exposure to CHEs and its determinants among households with pediatric cancer and oncology disorders.

**Materials and Methods:** This cross-sectional study was performed on 101 households with pediatric cancer and oncology patients who referred to Shahid Sadoughi Hospital of Yazd in 2021. The CHE in this regard was defined as the out-of-pocket payments for hypertensive care that equaled or exceeded 40% of the household capacity to pay. The data on each household were collected with reference to the patient's electronic file and through a questionnaire completed during an interview with the head of the household. The data were also analyzed with descriptive statistics and logistic regression in Excel (2019) and STATA ver.15.

**Results:** Out of 101 households in the study, 43 (42.6%) incurred CHEs (based on a threshold of 40% of disposable income). Regarding the job of the heads of households, manual workers were vulnerable to CHEs up to 11.7 times more than employees and self-employed individuals (OR=11.7,  $p<0.05$ ). Also, the lower the education level of the head of the household, the higher the risk of facing CHEs (OR=10.45,  $p<0.05$ ). Similarly, the lower his or her income, the higher the CHE.

**Conclusion:** The results showed that households with pediatric cancer and oncology disorders were significantly exposed to CHEs. Due to the limited resources of the health system in the treatment of cancer patients and the need for expenditure control programs, it seems better to focus on cost control strategies for this group of patients.

**Keywords:** Children, Health expenditure, Household, Pediatric cancer

### Introduction

Nowadays, cancer is one of the leading causes of death among children in developing countries (1). It is reported to account for almost 4% and 11% of deaths among children under 5 and those from 5 to 15 years of age, respectively (2). In Iran, cancer is the third leading cause of death in children (3) and accounts for about 4% of the deaths among children under 5 and 13% of the deaths of children aged 5 to 15 (4). With recent advances in the treatment

of pediatric cancers, more of these patients are saved from death (5), but the treatment and care of cancer patients take a significant portion of catastrophic health expenditures (CHEs) due to the increased incidence of cancers and rising cost of medical care (6, 7). Compared to other diseases, cancer is very expensive to treat due to frequent admissions, multiple outpatient visits, laboratory services, advanced diagnostic tests, chemotherapy, rare and expensive drugs, surgery, and radiotherapy (8). Consequently, cancer can

impose a significant economic burden on patients and affect their daily activities and families (9).

On the other hand, due to their high emotional engagement, families tend to spend their whole life on saving their children, which undermines the family economy and often drives it below the poverty line (10). This increases the risk of exposure to CHEs. Health expenditures begin to adversely affect a family when the cost of health services exceeds a certain threshold in the family's income. According to the World Health Organization (WHO), a household is faced with CHEs when more than 40% of its ability to pay is spent on healthcare services (11).

CHEs are not only a major barrier to receiving necessary health services but also a shock in spending because spending a large portion of household income to receive these services can reduce the power to pay for other needs such as education and food. In these circumstances, if a family member becomes so ill that he or she is unable to work, CHEs become an income shock (12).

Also, high Out-of-Pocket (OOP) expenditures make it difficult for households to afford catastrophic expenditures. Therefore, one of the policies of the health sector is to reduce direct payment by replacing it with fairer financing methods (13). This issue has been clearly emphasized in the health section of the Fifth Economic, Social and Cultural Development Plan of the Islamic Republic of Iran (14).

A study of 89 countries shows that 150 million people face CHEs each year, while low- and middle-income countries (LMICs) suffer from higher levels of CHEs than high-income nations (15). Therefore, it is important to investigate CHE in health care systems and identify its determinants. This can help health policymakers adopt preventive policies to reduce CHE levels (16).

There have been many studies on CHEs and their determinants worldwide; however, most of them focus on an entire population or a typical chronic population rather than vulnerable groups such as cancer patients. Therefore, with the dearth of research on CHEs in households with pediatric cancer, the aim of the present study is to estimate the level of exposure to CHEs and their determinants among households with pediatric cancer and oncology disorders.

## Materials and Methods

This is a cross-sectional study that uses WHO standards to estimate the incidence and severity of CHE as well as the inequality in the distribution of exposure to it. Based on those standards, CHEs become significant when the OOP health expenditures are equal to or more than 40% of the household payment capacity (17). Since healthcare systems and their socio-economic conditions differ across countries, various thresholds have been introduced in the present study to accurately measure the level of exposure to CHEs and provide dependable evidence in this regard. According to WHO, in addition to the standard threshold of 40%, there are three other cut-off points, i.e., 20%, 30%, and 50%. In fact, the calculations in this study are based on four thresholds separately.

The calculation of CHEs based on the aforementioned thresholds takes a few steps. The first step is to calculate the household capacity to pay (CtP) after the ongoing costs of living are subtracted from the total expenditure. The payment capacity depends on the family size. It is, indeed, equal to the non-food expenditure. Then, considering the scale of household consumption, the equated household dimension is used instead of the real household dimension as follows:

$$eqsize_h = hsize^\beta$$

where  $eqsize_h$  is the equated household dimension,  $hsize$  is the real household dimension, and  $\beta$  is 0.56 based on a study

conducted in 59 countries (18). This equation implies that food expenditure increases with the rise in the number of household members, but this increase is less significant for a rise in the household dimension.

In the next step, the poverty line, which is the minimum resource for essential needs, is calculated. For this purpose, first, the equated food expenditure ( $Eqfood_h$ ) is obtained through dividing the household food expenditure by the equated household dimension. Then, the share of food expenditure in the total household expenses is calculated as a percentage. Also, given that poor households spend most of their expenditure on food, the weighted average of the household food expenditure, which is 45-55% of the ratio of the food expenditure to the total expenditure, is used to find the equated per capita subsistence expenditure. This is considered as a poverty line calculated as follows:

$$eqfood_h = \frac{food_h}{eqsize_h}$$

$$food45 < foodexp_h < food55$$

$$pl = \frac{\sum w_h \times eqfood_h}{\sum w_h}$$

In these relations,  $W_h$  is the sampling weight, and  $P_l$  is the poverty line. In addition, the essential expenditure ( $SE_h$ ) is obtained through multiplying the poverty line by the equated household dimension.

$$se_h = pl \times eqsize_h$$

Some households report lower food expenditures than subsistence expenditures, which may be because households do not consider food subsidies, coupons, their own products and other non-cash items as a part of their food expenditures. This is evident from their responses in the questionnaire. The food expenditure is lower than the poverty line in such situations. Therefore, the payment capacity is calculated as follows:

$$ctp_h = exp_h - food_h \quad \text{if } se_h > food_h$$

OR

$$ctp_h = exp_h - se_h \quad \text{if } se_h \leq food_h$$

where  $ctp_h$  represents the household payment capacity and  $exp_h$  equals the total household expenditure. Moreover, the ratio of the direct health OOP payments to the payment capacity ( $oop/ctp_h$ ) shows the financial burden of the payments for health services and is defined as direct OOP payments or a percentage of the household payment capacity. It is calculated as follows:

$$oopctp_h = \frac{oop_h}{ctp_h}$$

As mentioned before, CHEs are incurred when direct health OOP payments are equal to or greater than 40% of the payment capacity or non- subsistence expenditure of a household. The 40% threshold can be different depending on the specific situation of each country. In the status qua, CHEs have been found to be at the cut-off points of 20, 30 and 50% in addition to the standard 40% threshold, which provides a better picture of the society for policymakers. The percentage of exposure to CHEs ( $H$ ) at all cut-off points is calculated as follows:

$$H = \frac{1}{N} \sum_{i=1}^N E_i$$

where,  $N$  represents the number of household samples. If the ratio of direct health OOP expenditures to household pay capacity ( $oop/ctph$ ) is greater than or equal to the standard threshold, then  $E = 1$ . Otherwise,  $E = 0$ .

The study population consisted of households with pediatric cancer. The households included in the study were those whose patients referred to Shahid Sadoughi hospital in Yazd from March 21, 2021 to February 20, 2022. The inclusion criteria were the Iranian nationality and at least 10 times of referrals during the study period. The exclusion criteria included unwillingness to participate in the study and providing false financial information detected through a review of the patient's electronic file.

The data collection instrument included an electronic household information

questionnaire which was prepared as a checklist. The data were collected in face-to-face and telephone interviews with the patients and their companions in the ward. Some information about the expenditure covered by insurance, the hospital expenditure, type of disease, and the like was also obtained and verified using the patients' electronic files and records.

The data analysis was carried out with descriptive statistical indices such as means, standard deviations and frequencies. Logistic regression was also done to determine the socio-economic factors affecting the CHEs. For this purpose, the Excel 2019 and the STATA ver.15 software programs were used.

### **Ethical Consideration**

The proposal of this reach was approved by the ethics committee of Shahid Sadoughi University of Medical Sciences with the ID of IR.SSU.MEDICINE.REC.1398.300. The patients admitted to the hospital were asked to sign a general consent form upon admission. The form concerned the collection of the patients' data and the publication of the results.

### **Results**

A total of 112 household heads were eligible to participate in the study, of whom seven were reluctant to respond, and four cases provided false information, thus excluded from the study. The mean and the standard deviation of the patients' age were 6.3 years and  $\pm 3.4$ . The descriptive results of the study are presented in Table I.

#### **Exposure to CHEs**

Out of 101 households included in the study, 43 (42.6%) were faced with CHEs (based on the 40% threshold of their disposable income). Also, CHEs accounted for more than 60% of the disposable income of 25 households. By definition, they suffered from disease-related poverty. In other words, 24.75% of

the studied households had become poor due to their children's disease.

Another significant finding was the decrease in the household income due to the children's disease. Accordingly, the heads of the households especially fixed-wage employees and manual workers had to take unpaid leave or lose working days to accompanying their children. Totally, forty-nine studied heads of households stated that the average reduction in their monthly income 1,600,000 Tomans.

Another important issue was the insurance coverage, subsidies and discounts provided by the hospital to the patients. According to the calculations, if insurance, subsidies and discounts were eliminated, 69 (68.3%) households would face CHEs, and 62 (61.38) households would face expenditures leading to poverty. In other words, government funds in the form of insurance, subsidies and discounts have been able to reduce the suffering from CHEs by almost 19%.

#### **Socioeconomic factors affecting the exposure to CHEs**

Table 2 presents the socio-economic factors affecting the exposure of households to CHEs. As it can be seen, the families from the other provinces were up to 4.58 times more vulnerable to CHEs than those living in Yazd Province. Also, a total of 31.4% of the residents of Yazd Province had faced CHEs, while this percentage was 67.7% for those from the other provinces.

It was also observed that the manual workers were 11.7 times more vulnerable to CHEs than the employees and self-employed individuals. However, the employees and the self-employed individuals were equally faced with CHEs. The next influential variable was the education level of the heads of families. The risk of exposure to CHEs was negatively correlated to the education level. Compared to the individuals with bachelor's degree and above, those who had a diploma and lower degrees were 2.43 and 10.45 times more vulnerable to

CHEs, respectively. The descriptive statistics of CHEs exposure and non-exposure are reported in Table II.

### Inequality distribution in treatment expenditures

Figure 1 shows the inequality distribution in treatment expenditures. As it can be

seen, the chart is above the 45° line, which means a negative correlation between the treatment expenditures and the level of income. Also, the concentration index, which is twice the area under a curve up to the 45° line, is -0.67, which suggests that the inequality is against the poor.

Table I: Descriptive results of the research

Variable	Frequency (%)	
Provinces of origin	Yazd	70 (69.2)
	Kerman	21 (20.8)
	Hormozgan	3 (3)
	Sistan and Baluchestan	4 (4)
	South Khorasan	3 (3)
Patient's gender	Male	46 (45.5)
	Female	55 (54.5)
Insurance coverage (basic)	Social security	75 (74.2)
	Rural	12 (11.9)
	Public health	7 (6.9)
	Armed forces	3 (3)
	Government employees	1 (1)
	Other	3 (3)
Financing method	Just one source of income	31 (30.7)
	Income with selling precious objects	7 (6.9)
	Income with getting a loan	17 (16.8)
	Income with borrowing	19 (18.8)
	Income with charity	27 (26.8)
Diagnosis (cancer and oncology disorders)	Acute lymphocytic leukemia (ALL)	75 (74.26)
	Immune thrombocytopenic purpura (ITP)	3 (2.97)
	Neuroblastoma	3 (2.97)
	Thalassemia	3 (2.97)
	Lymphoma	2 (1.98)
	Acute promyelocytic leukemia (APL)	2 (1.98)
	acute myeloid leukemia (AML)	2 (1.98)
	Brain tumor	2 (1.98)
	Wilms tumor	2 (1.98)
	Anemia	2 (1.98)
	Myelodysplastic syndromes (MDS)	1 (0.99)
	Neuroblastoma	1 (0.99)
	Cellulite	1 (0.99)
	Thalassemia	1 (0.99)
	Epitaxy	1 (0.99)
Osteoarthritis	1 (0.99)	
<b>Total</b>	<b>101</b>	

Table II: Socioeconomic factors affecting the exposure to CHEs

Variable	Type	Odd-ratio	P-value	Exposure	Non- exposure
Referrals from other provinces	Patients from Yazd Province	4.58	0.001	22 (31.4%)	48 (68.6%)
	Patients from other provinces			21 (67.7%)	10 (32.3%)
Job of the head of the family	Employee and military personnel	-	-	3 (15%)	17 (85%)
	Self-employed	1.9	0.36	9 (26%)	26 (74%)
	Manual worker	11.7	0.00	31 (67.4%)	15 (32.6%)
Education level of the head of the family	Bachelor's degree and higher	-	-	3 (15%)	17 (85%)
	Diploma	2.43	0.05	9 (25.7%)	26 (74.3%)
	High school	10.45	0.00	31 (67.4%)	15 (32.6%)

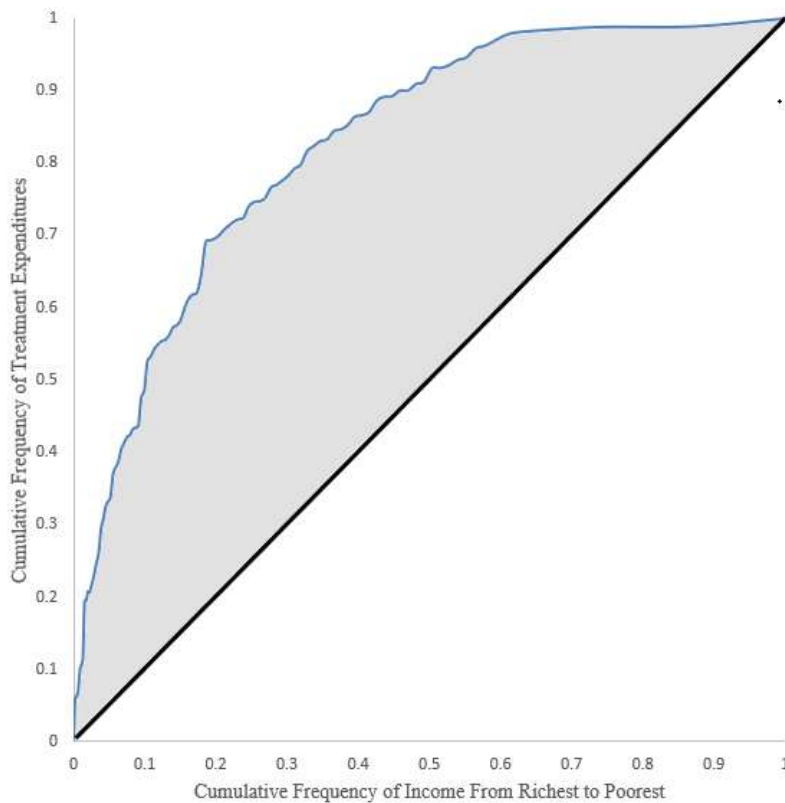


Figure 1. Curve for the disparity of treatment expenditures



## Discussion

According to the results, 42.6% of the studied households with pediatric cancer were faced with CHEs. This finding is based on the 40% threshold of their disposable income. Previous studies have reported different values for various Iranian patients based on that threshold. Imamgholipour et al. (2020) reported the exposure rates of 74.9% and 2.6% for rural and urban households, respectively. Another study on patients with cardiovascular diseases (20) showed that 55% of patients were faced with CHEs. Similarly, Kazemi et al. (2015) found that 29.9% of the studied households were beset with CHEs. This value was 12.6% and 11.8% in previous studies in 2003 and 2008, respectively (21). A comparison of the results of the present study and other studies indicates a higher CHEs exposure in households with cancer patients than in the general population and households with other diseases. It may be due to the different demographic characteristics in different parts of Iran as compared to the population of Yazd; the population of every city or province has its own structure in terms of socio-economic status, rate of immigrants, and employment conditions. It may also be due to the high treatment cost for children with cancer compared to other diseases; cancer treatment is very expensive considering such requirements as frequent admissions, multiple visits, laboratory services advanced diagnostic tests, chemotherapy, rare and expensive drugs, surgery, and radiotherapy (8). Pediatric cancer treatment requires frequent admissions and makes families especially those living in rural areas incur higher non-medical costs such as transportation and accommodation which may be not covered by health insurance. More frequent hospital admissions lead to higher financial cost and, consequently, greater economic burden on households with pediatric cancer (22). The results of this study emerged to be consistent with those of the other studies

on the issue of cost incurrence by households with pediatric cancer. For example, a rate of 42.78% was reported for cost problems in Chinese families engaged in six cancers including esophagus, colon, stomach, liver, lung, and breast cancers (23). The results were similar in other countries, including Malaysia (47.8%) (16), South Korea (39.8%) (24), and eight Southeast Asian countries (48%) (25). In this context, Sui et al. (2020) showed that the CHE burden on families with pediatric leukemia was 43.4% (22). The existing reports on CHEs incidence vary in different countries for such reasons as the threshold defined for CHEs and the inclusion of non-medical expenses and charitable assistance. However, all those reports agree on one point; households with cancer children are likely to face CHEs.

Regarding the unequal distribution of treatment costs, it has been shown that those costs and income level are negatively correlated. The inequality is, indeed, against the poor. A study in South Korea (24) revealed that CHEs were higher among low-income families. Similar results were found in developing countries such as China (26), Malaysia (16), and other Southeast Asian countries (25). Considering that the perception of income inequality may exacerbate the catastrophic OOP payments for lower-income households, it is important to eliminate or reduce income distribution inequality.

Regarding the job of the heads of families, the manual workers were found 11.7 times more vulnerable to medical expenses than the employees and self-employed individuals. Zhao et al. (27) explored the cases in which the heads of families experienced a shift in employment status, from employed to unemployed. They found that households with unemployed heads were more likely to incur CHEs than those with no shift of job. In another study (28), it was also found that households with self-employed heads were more likely



to face CHEs because self-employed people do not have a fixed salary and their employment is not permanent but often periodic and seasonal.

Regarding the education level of the heads of households, it was found negatively correlated to the risk of running into unaffordable costs. For example, compared to individuals with bachelor's degrees and above, those who had a diploma or a sub-diploma degree were 2.43 and 10.45 times more vulnerable to CHEs. A similar result was gained in South Korea (24).

### Limitations of the study

The households participating in this study were selected based on the census of several provinces, but, due to the socio-economic differences among the Iranian provinces, any generalization of the results of the study should be done cautiously. The studied sample included 101 families with children suffering from cancer. It is recommended that a larger sample be selected from more or preferably all the provinces of Iran in future research on catastrophic health expenditures. Since some of the measures, such as annual household income and expenses, required the participants to recall the information from the past, there might have been recall biases to affect the results. Therefore, to minimize the recall bias, the data were received as far as possible through the health information system and verified based on the existing systems.

### Conclusion

One of the reasons for the higher expenditures of low-income groups is the delayed diagnosis and treatment due to financial problems, the lack of awareness about diseases, and probably the lack of treatment. Besides, complicated disease conditions and increased costs of treatment lead to delay or completely abandoned treatment. During this study, two patients lost their lives for these reasons.

With regard to the limited treatment of low-income cancer patients and the need

for expenditure control programs, it seems better to focus on cost control strategies for this group of patients. According to the results of this study, inter-sectoral policies should be emphasized to improve the economic status of households, create a comprehensive insurance system, exempt the poor from some payments, and review the basic package of the health services given by insurance organizations. Besides, policies should be developed to reform the service delivery system, monitor the performance of service providers especially hospitals, enhance the payment methods, and check the prices the customers have to pay.

### Acknowledgments

The authors would like to thank Yazd University of Medical Sciences for partially funding the study.

### Conflict of interest

The authors declare no conflict of interest.

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