Catastrophic Health Expenditures for Children with Disabilities in Iran: A National Survey

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Abstract

Background: Higher health costs and financial burden are imposed on people with disabilities due to their health status associated with their disability. Measuring the incidence of catastrophic health expenditures (CHE) can provide good evidence for health policymakers to assess the current state of financial protection of the health system. The aim of this study was to investigate the percentage of households with disabled children aged 0 to 8 years who had faced CHE due to the health costs of these children in Iran.

Methods: This cross-sectional study was carried out on 2000 households with disabled children aged 0 to 8 years in five provinces of Iran in 2020. Data were collected using the World Health Survey questionnaire and face-to-face interview. Households whose health expenditures for disabled members in the family were more than 40% of the household payment capacity were included in the group of households with CHE. Determinants of CHE were identified using logistic regression.

Findings: 32.7% of households with disabled children had faced CHE**.** Head of household being female (Adjusted OR=18.89, 95%CI: 10.88- 29.42), poor economic status of the household (Q1: Adjusted OR = 20.26, 95% CI, 11.42-35.94; Q2: Adjusted OR= 8.27, 95%CI, 4.45-15.36; Q3: Adjusted OR= 13.88, 95%CI, 7.89-24.41), lack of supplementary insurance by a child with disabilities (Adjusted OR= 6.13, 95%CI, 3.39-11.26), having a child with mental disability (Adjusted OR= 2.71, 95%CI, 1.60-4.69), and type of basic health insurance [having Iranian Health Insurance: Adjusted OR= 2.20, 95%CI, 1.38-3.49; having Social security insurance: Adjusted OR= 1.66, 95%CI, 1.06-2.61] significantly increased the chances of facing CHE.

Conclusion: A significant percentage of households with disabled children had faced CHE because of their disabled child's health costs. The key determinants of CHE should be considered by health policy-makers in order to more financial protection of these households.

Background

The International Classification of Functioning, Disability and Health defines disability as an “umbrella term for impairments, activity restrictions and participation limitations ” [1, 2]. More than 1 billion people in the world have disabilities, of which 93 million are children under 15 [3]. According to the census data of the Statistical Center of Iran in 2011, the prevalence of disability in the entire population and among children aged 0 to 14 years was 1.4% (1017659 people) and 1.3% (12620 people), respectively [4]. People with disabilities experience worse socio-economic conditions than people without disabilities and suffer disproportionately from poverty and various diseases [5-8]. In addition, people with disabilities experience more barriers to accessing health services than people without disabilities, and this can lead to health inequalities unconnected to their disabilities [9-15]. Lack of affordability has been reported as the most important reason for not receiving the required health services by people with disabilities in low-income countries. In these countries, 32 to 33% of people without disabilities and 51 to 53% of people with

disabilities have been reported to be unable to afford health services [16]. Compared to people without disabilities, more use of health services by people with disabilities due to health problems related to their disability leads to higher health expenditures for them [17]. According to the World Health Organization (WHO), families with disabilities are 50% more likely than other households to face catastrophic health costs [18].

Catastrophic Health Expenditures occur for the household when the household spends more than 40% of its income on health expenses out of pocket after deducting food expenses. Financial protection against health costs is one of the ultimate goals of health systems and the percentage of households facing catastrophic costs is used as an indicator to assess this goal [19]. Every year around the world, about 150 million people face financial problems and pressures due to the costs of consuming health services, and more than 100 million people fall below the poverty line [20].

Children with disabilities are a vulnerable group and an important group for policy-making and research planning. Disability in children not only affects their lives but also exposes their family's life with challenges such as the double economic burden resulting from the use of health services and rehabilitation[12]. Children with disabilities constitute a significant population of Iranian society. In Iran, many health services required by people with disabilities, including rehabilitation services (such as physiotherapy, occupational therapy, speech therapy) and their ancillary equipment (such as wheelchairs, hearing aids, crutches) are not covered by basic health insurance organizations. Therefore, this can prevent these people from accessing these services or if they use these services, it can impose a lot of financial burden on them and their families [8]. Paying for health services out of pocket can put extra pressure on families with disabled members [21, 22]. Timely access to and use of health services for children with disabilities and financial protection of these children against financial burden of health services can play a significant role in their current and future socio-economic status.

The purpose of this study was to investigate, for the first time in Iran, the health expenditures of children with disabilities and the frequency of exposure of these children's household to catastrophic health expenditures. The results of this study can be a feedback for health system policymakers to assess the state of the country's health system in the field of financial protection of children with disabilities against health costs and a basis for national health policy on how to finance the health services needed by these children.

Materials And Methods

Study participants and sampling

This cross-sectional study was carried out on households with children aged 0 to 8 years having physical or mental disabilities in Iran in 2020. The sample size was estimated to be 385 households for each province based on considering the 50% exposure rate of households with disabled children to catastrophic health expenditures ($p = 0.5$), statistical confidence of 95%, and accuracy rate of 5%. Due to

the fact that the study was conducted in 5 provinces, the total sample size was equal to 2000 households (400 households from each province).

Multi-stage clustering method was used for sampling. At first, all provinces of the country were divided into 5 clusters (north, south, west, east and center clusters). Then, one province was randomly selected from each cluster (Kurdistan, Alborz, Kerman, Fars and Gorgan provinces). Among the cities of the selected provinces, the capital city of the province (cities of Sanandaj, Karaj, Kerman, Shiraz and Gorgan) was selected. In the next step, the list of children with disabilities (including visual, hearing, speech, mental and motor disabilities) and with the age of 0 to 8 years was obtained from the welfare organization of selected cities and 400 samples were selected by random sampling.

Data collection

After selecting the households, the families were first contacted by phone, and if they wanted to participate in the study, some trained interviewers, who had at least a bachelor's degree in rehabilitation-related fields, went to the household door to interview and complete the questionnaire. Questionnaires were completed with the help of an informed family member. An informed member of the household was the person who was at least 18 years old and had the most information about income, expenses, and consumption of household health services. Data were collected using the World Health Survey questionnaire, which was developed in 2003 to measure the performance of health systems. This questionnaire has been translated into Persian and its validity and reliability have been confirmed in previous studies [23].

The questionnaire consists of three parts: first part includes demographic characteristics and socio-economic status of the family of a child with disabilities, second part involves the type of disability and the status of benefiting from outpatient, rehabilitation and inpatient health services, and the third part relates to monthly household expenses. In this study we used two recall periods for expenditure questions: The last 30 days for the total household expenditures, and the last 30 days and the last 12 months for outpatient and inpatient expenditures, respectively.

In the present study, in order to reduce information bias caused by self-report and recall bias, the reminder period for using outpatient services and household expenses was reduced to the last 30 days and for using inpatient services to the last 12 months. Also, in order to reduce information bias, we selected two individuals with a bachelor's degree in public health from each province for data collection. These individuals were trained both theoretically and practically during a 4-hour workshop. Data related to the type and severity of children's disabilities were obtained from the database available in the Rehabilitation Department of the Welfare Organization of the selected provinces. Also, in order to identify and eliminate possible problems, we first conducted a pilot study in one province, then the study was conducted in other provinces.

One of the limitations of this study was selection bias. There is no comprehensive database in Iran that covers all people with disabilities. Therefore, in this study, the sampling frame did not cover all children

with disabilities. Also, in this study, sampling was done randomly but by replacement. In order to reduce the selection bias, we followed each selected sample up to three times and by explaining the importance of the results of this study and its possible impact on national health policies, we tried to encourage them and increase their participation. However, after three follow-ups and not being able to convince the participant to take part in the study, another person was randomly selected from the list and was replaced. Nevertheless, the number of replacements was very small. In this study, we did not calculate the response rate for calls and participation in the study, but the response rate was very high.

Outcome Variable

In this study, the method provided by WHO was used to estimate the incidence of CHE. Accordingly, if the out-of-pocket payment (OPP) for health expenses of a child aged 0 to 8 with a disability was more than 40% of the household's capacity to pay, the household would be in the group of households facing catastrophic health expenditures. The method and details of calculating the incidence of CHE are given in other studies [19].

Independent variables

The socio-economic status of the household was determined using the method proposed by O'Donnell et al. [24]. In this method, the status of household assets including LCD TVs, separate refrigerators, washing machines, cell phones, dishwashers, microwave ovens, Internet access, private cars, private homes, and the number of rooms were assessed. Then, the asset index for each individual was calculated using principal component analysis (PCA) and the study population was classified into 5 quantiles of 1 (the poorest), 2, 3, 4, and 5 (the richest). In some studies, the asset index has been used to determine SES in the Iranian population [6, 25]. The use of inpatient services is a dichotomous variable (yes / no) measured by asking the question "Have you been hospitalized for an illness in the past year?" The use of outpatient services is also a dichotomous variable (yes / no) assessed by asking the question "Have you used outpatient services including visiting a medical doctor, dentist, midwife, nurse, physiotherapist, occupational therapist, speech therapist, audiometrist , optometrist, and traditional therapists, and other rehabilitation services provided by other providers due to illness in the past month.

Other independent variables included gender of head of household (male/female); age group of disabled child (< 5 years/ > 5 years); type of health insurance (Iranian health insurance, armed forces insurance, social security insurance, and other insurances); having supplementary insurance (yes / no); severity of disability (mild, moderate, severe); type of disability (physical, mental, blind, deaf, speech impairment); and number of disabled people in the household (one person, more than one person).

Statistical analysis

Mean (standard deviation) was calculated for the variables of total monthly household expenses, household food expenses, and out-of-pocket payments for health services. Frequency distribution tables were calculated for independent and demographic variables, and frequency percentage was measured for

incidence of CHE. The relationship between independent variables and incidence of CHE was evaluated by calculating Odds Ratio (OR) using Multivariate logistic regression. The variables with $p< 0.2$ in the univariate logistic regression analysis were included in the adjusted logistic regression models. Data analyses were performed using STATA software version 13 (College Station, TX, United States). $P<0.05$ was considered statistically significant.

Results

A total of 2006 households with disabled children participated in this study, of which 88.6% (n = 1777) of the heads of households were males. Almost 54% of households (n = 1085) had social security insurance and only 14.7 % (n = 296) had supplementary insurance. Mental and physical disabilities had the highest frequency in participants with 43.7% and 29.1%, respectively. In this study, 32.7% (n = 665) of households with disabled children had faced catastrophic health expenditures. The highest exposure to CHE was observed in households with female head (85.6%) and households with socio-economic status of Q1 (46.1%) (Table 1).

The mean (SD) of the monthly expenses of households with a disabled member was equal to 28287680 Rials (26519520 Rials); that is equal to $188.52. Average monthly out-of-pocket payment of a child with disability was 5805370 Rials (10605270 Rials) or $38.70. Also, average monthly household out-of-pocket payment was 6562600 Rials (8480330 Rials) or $42.75.

Based on the results of multivariate logistic regression, household head being female (Adjusted OR=18.89, 95%CI: 10.88- 29.42), having poorer economic status (Q1: Adjusted OR = 20.26, 95% CI, 11.42-35.94; Q2: Adjusted OR= 8.27, 95%CI, 4.45-15.36; Q3: Adjusted OR= 13.88, 95%CI, 7.89-24.41), lack of supplementary insurance (Adjusted OR= 6.13, 95%CI, 3.39-11.26), having mental disability (Adjusted OR= 2.71, 95%CI, 1.60-4.69), and type of health insurance (having Iranian Health Insurance: Adjusted OR= 2.20, 95%CI, 1.38-3.49; having Social security insurance: Adjusted OR= 1.66, 95%CI, 1.06-2.61) increased the chance of incidence of CHE (Table 2).

Discussion

In this study, 32.7% of households with disabled children had faced catastrophic health expenditures due to their child's health costs, which is significantly higher than this percentage among the general population of Iran. According to a systematic review and meta-analysis study in Iran, the percentage of households exposed to catastrophic health costs was 7.5% (95% CI, 6.2 - 9.1) [26]. In several studies in Iran, a statistically significant relationship has been reported between the presence of a member with a disability in the household and the household's chances of experiencing catastrophic health expenditures [27, 28]. People with disabilities are more likely to use health care services due to their disability-related situation, which in turn it imposes higher health care costs on them [17]. In Iran, rehabilitation services and equipment are not covered by basic insurance, and users without supplementary insurance must pay for such services out of pocket. Out-of-pocket payment for health services is a barrier to the use of health

services and leads to reduced financial protection and increased inequality in health and in the use of health services [8].

This situation can seriously challenge access to services needed by children with disabilities in Iran. Policymakers and managers of the country's health system should protect families with disabled children against health costs by formulating and implementing targeted policies and programs (based on the findings of domestic and international studies and benchmarking the successful global policies). According to the WHO, people with disabilities are 50% more likely to face CHE in comparison to people without disabilities [18].

Lack of affordability has been reported as the most important reason for not receiving health services by people with disabilities in low-income countries [16]. In a study in Ethiopia, a direct and significant relationship was found between disability and the chance of facing catastrophic health expenditures [29]. In a study in South Korea, the percentage of households faced catastrophic health expenditures among households with and without disabled children was 11.5% and 5.1%, respectively [22]. In another study in South Korea, the proportion of people suffering from catastrophic health costs was higher among households with disabled members than the general population [17]. In this country, the Medical Aid program has been implemented in order to financially protect poor people with disabilities from health costs. This program provides almost free access to medical services for poor people with disabilities and has led to a significant reduction in their chances of facing catastrophic health costs [17].

The average household health costs in this study were significantly higher than the average health costs reported by other studies conducted on the general population of Iran. In Iran, rehabilitation services and equipment as one of the basic needs of children with disabilities are not covered by basic insurance, and users without supplementary insurance must pay for them out of pocket [8].

According to the findings of this study, less than 15% of these children had supplementary insurance. In this study, more than 90% of monthly household health expenditures were spent on the health expenditures of children with disabilities alone. Having a member with special needs in the household can affect the pattern of consumption of health services and the average health costs of other household members. In a study in Iran, the effect of having a member with cancer in the family had a significant impact on the refusal of other family members to use health services [30]. In a study in Cameroon, the average health costs of children with disabilities were significantly higher than other children [31].

In this study, based on the results of logistic regression, head of household being female, poor economic status of the household, not having supplementary insurance, having a child with mental disability and type of basic health insurance significantly increased the chances of facing catastrophic health costs. In a study conducted by Moradi et al. among families with members suffering from certain diseases and disabilities in Iran, a direct and significant statistical relationship was reported between the chances of facing catastrophic health costs with the low economic status of the patient, the use of rehabilitation services and lack of supplementary insurance [32]. In another study conducted in Iran among patients with gastrointestinal cancer, a statistically significant and direct relationship was found between the

chances of facing catastrophic health costs and lack of supplementary insurance and low economic status of the patient [30]. In the study of Kavosi et al., which was conducted on the general population, there was a direct and statistically significant relationship between the presence of a person in need of care in the household and the low socio-economic status of the household with the chance of facing CHE [28]. In another study conducted in Iran as a systematic review and meta-analysis, the variables of inpatient, outpatient, and dental services, level of education, place of residence and household income were identified as determinants of exposure to CHE [33]. In a study in South Korea, variables of low economic status, presence of a member with a chronic illness in the household and lack of public assistance were the main determinants of exposure to CHE [22].

Limitations

Similar to other observational studies, self-reporting and recall bias were among the limitations of the current study. Meanwhile, self-reporting of expenses and consumptions may be accompanied by some errors. We tried to reduce these errors by reducing the reminder period to one month for household expenses and outpatient services, and to 12 months for inpatient services. Another limitation of this study was selection bias. In this study, random sampling was performed by replacement. In order to reduce sampling error, we followed each selected sample up to three times and by explaining the importance of the results of this study and its possible impact on national health policies, we tried to encourage them and increase their participation. In addition, in this study, we did not calculate the response rate for calls and participation in the study, but the response rate was very high.

Policy implications

Health policymakers should pay special attention to the families of children with disabilities. Implementation of payment exemption programs, direct and indirect financial support programs, and prepaid mechanisms are essential to reduce out-of-pocket payments for health services. Use of health care services without enduring the financial crisis by families with disabled children should be a priority on the agenda of Iranian health policy makers.

Conclusion

According to the findings of the present study, a significant percentage of households with disabled children had faced catastrophic health costs due to the health costs of their disabled child. A significant percentage of the household health costs alone was spent on the health of a child with disabilities. Variables of household head being female, poor household economic status, lack of supplementary insurance, having a child with a mental disability and the type of basic health insurance significantly increased the chances of facing catastrophic health costs. The key determinants of CHE should be considered by health policy-makers in order to more financial protection of the households of children with disabilities. Health policymakers should pay special attention to the families of children with disabilities. Implementation of payment exemption programs, direct and indirect financial support programs, and prepaid mechanisms are essential to reduce out-of-pocket payments for health services.

Use of health care services without enduring the financial crisis by families with disabled children should be a priority on the agenda of Iranian health policy makers.

Abbreviations

CHE: catastrophic health expenditures; WHO: World Health Organization; OR: Odds Ratio; CI: Confidence Interval; SD: Standard Deviation

Declarations

Acknowledgment

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Authors' contributions

BP, AMB, and GM designed the study and drafted the article. AMB, SR and MA prepared it for publication. FB, FF and AA designed the study and reviewed the article. All authors have read and approved the manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Participation in this study was voluntary. Before completing the questionnaire, verbal and written consent was obtained from all participants and the questionnaire was collected anonymously. The proposal of this article was reviewed by the ethics committee of Kurdistan University of Medical Sciences and was approved with the code IR.MUK.REC.1398. 75.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no conflicts interests.

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Tables

Table 1. Descriptive characteristics of households and children with disability by incidence of catastrophic health expenditures in Iran

Variables	Number (%)	Incidence of CHE Number (%)
Observation	2006 (100)	655 (32.7)
Gender of household head		
Male	1777 (88.6)	459 (25.8)
Female	229 (11.4)	196 (85.6)
Age of child with disability		
≤5	911 (45.4)	302 (33.2)
>5	1095 (54.6)	353 (32.2)
Type of the basic health insurance		
Iranian Health Insurance	658 (32.8)	258 (39.2)
Armed Forces health insurance	78 (3.9)	10 (12.8)
Social security insurance	1085 (54.1)	339 (30.9)
Others[a]	185 (9.2)	52 (7.9)
Status of supplementary health insurance		
No	1711 (85.3)	627 (36.6)
Yes	296 (14.7)	28 (9.5)
Economic status†		
Q1 (the poorest)	384 (20.1)	177 (46.1)
Q2	382 (20.0)	175 (45.8)
Q3	460 (24.0)	183 (39.8)
Q4	362 (18.9)	16 (4.4)
Q5 (the richest)	326 (17.0)	12 (3.7)
Type of disability		
Mental	877 (43.7)	336 (38.3)
Physical	584 (29.1)	192 (32.9)
Deaf	274 (13.7)	74 (27.0)
Blind	157 (7.8)	22 (14.0)
Speech	114 (5.7)	31 (27.2)
Number of disabled members		
Just one	1342 (66.9)	446 (33.2)
Two and more	664 (33.1)	209 (31.5)
Severity of disability		
Mild	334 (16.7)	128 (38.3)
Moderate and severe	1672 (83.3)	527 (31.5)
Use of inpatient services in last year		
No	1673 (83.4)	536 (32.0)
Yes	333 (16.6)	119 (35.7)
Use of outpatient services in last month		
No	438 (21.8)	144 (32.9)
Yes	1568 (78.2)	511 (32.6)
Family Size	3.98 (0.98)	

Note: a: no health insurance, Imam Khomeini health insurance etc.; †Quartile 1 (Q1) is the poorest and quartile 5 (Q5) is the richest; CHE: catastrophic healthcare expenditures.

Table 2. Results of multivariate logistic regression of determinants of incidence of catastrophic health expenditures for children with disability in Iran

Variables	Crude OR (95% CI)	P-value	Adjusted OR (95% CI)	P-value
Gender of household head				
Male	*Ref*		*Ref*	
Female	17.05 (11.61-25.03)	0.001	17.89 (10.88-29.42)	0.001
Age of child with disability				
≤5	1.04 (0.86-1.25)	0.664		
>5	*Ref*			
Type of the basic health insurance				
Iranian Health Insurance	1.65 (1.15-2.35)	0.006	2.20 (1.38-3.49)	0.001
Armed Forces health insurance	0.37 (0.18-0.78)	0.009	0.65 (0.27-1.57)	0.345
Social security insurance	1.14 (0.81-1.61)	0.450	1.66 (1.06-2.61)	0.027
Others[a]	*Ref*		*Ref*	
Status of supplementary health insurance				
Yes	*Ref*		*Ref*	
No	6.51 (3.69-8.24)	0.001	6.13 (3.39-11.26)	0.001
Socioeconomic status†				
Q1 (the poorest)	22.65 (13.26-38.71)	0.001	20.26 (11.42-35.94)	0.001
Q2	17.72 (10.33-30.41)	0.001	8.27 (4.45-15.36)	0.001
Q3	13.39 (7.84-30.41)	0.001	13.88 (7.89-24.41)	0.001
Q4	1.30 (0.67-2.51)	0.427	1.19 (0.60-2.35)	0.600
Q5 (the richest)	*Ref*		*Ref*	
Type of disability				
Mental	1.66 (1.07-2.56)	0.022	2.71 (1.60-4.69)	0.001
Physical	1.31 (0.83-2.05)	0.235	1.02 (0.59-1.75)	0.939
Deaf	0.99 (0.60-1.61)	0.970	0.99 (0.54-1.81)	0.984
Blind	0.43 (0.23-0.80)	0.008	0.61 (0.29-1.26)	0.185
Speech	*Ref*		*Ref*	
Number of members with disability				
Just one	*Ref*			
Two and more	0.92 (0.76-1.12)	0.429		
Severity of disability				
Mild	*Ref*		Ref	
Moderate and Severe	0.74 (0.58-0.94)	0.016	0.71 (0.52-1.00)	0.056
Use of inpatient services in last year				
Yes	1.18 (0.92-1.51)	0.201		
No	*Ref*			
Use of outpatient services in last month				
Yes	0.98 (0.78-1.23)	0.910		
No	*Ref*			

Note: a: no health insurance, Imam Khomeini health insurance etc.; CI: confidence interval; †Quartile 1 (Q1) is the poorest and quartile 5 (Q5) is the richest; OR: odds ratio; *p>0.05; **p<0.05; ***p<0.01; R^2=0.459; Predicted probability area: 0.860)