



Disease Burden in Caregivers of Children with Congenital Heart Disease in Children's Medical Center, Tehran, Iran

Nazila Shahmansouri¹, Azin Kamali², Sara Dehbozorgi³, Ataollah Delpak⁴, Mohammad Reza Mirzaaghayan⁵, Sepideh Dehghani⁶ and Bahare Oji^{7*}

1. Psychosomatic Medicine Research Center, Imam Khomeini Hospital, Tehran University of Medical Sciences, Tehran, Iran

2. Tehran University of Medical Sciences, Tehran, Iran

3. Department of Psychiatry, Faculty of Medicine, Shiraz University of Medical Sciences, Shiraz, Iran

4. Clinical Research Development Center of Imam Khomeini Hospital, Jiroft University of Medical Sciences, Jiroft, Iran

5. Department of General Surgery, School of Medicine, Children's Medical Center, Tehran University of Medical Sciences, Tehran, Iran

6. Faculty of Psychology and Educational Sciences, University of Tehran, Tehran, Iran

7. Research Center for Psychiatry and Behavioral Sciences, Shiraz University of Medical Sciences, Shiraz, Iran

Abstract

Background: Congenital Heart Disease (CHD) is the most common congenital malformation in infants. The burden is defined as the perceived caregiver's sufferings of their emotional or physical health, social and financial life as a result of caring for loved ones. Lifelong CHD endures significant burdens on patients, families, and society. Parents of children with chronic illnesses such as CHD are more likely to be challenged than other parents. Furthermore, evidence shows the impact of this burden on parents' health. Therefore, this study aimed to evaluate the burden on caregivers of patients with CHD.

Methods: In this cross-sectional study, 72 caregivers of patients with CHD in the Children's Medical Center, Tehran, Iran were recruited. Face-to-face interviews with caregivers had been done. The demographic and disease-related data were collected. Zarit Burden Interview (ZBI) was applied for disease burden assessment. Statistical analysis was performed in SPSS version 22.

Results: In the present study, most caregivers 34 (47.2%), suffered from moderate to severe burden. The mean caregiver burden score was 42.78 which is categorized as a moderate to severe burden score. The siblings' number and level of caregivers' education had a significant association with the caregiver's disease burden.

Conclusion: CHD is associated with a significant caregivers' disease burden. Although the disease-related factors were not related to disease burden, the higher caregivers' education was related to fewer caregivers' disease burden. Therefore, paying attention to the caregiver's burden is an important clinical issue.

Keywords: Burden, Caregiver, Congenital heart disease, Zarit burden interview

* Corresponding author

Bahare Oji, MD

Research Center for Psychiatry and Behavioural Sciences, Shiraz University of Medical Sciences, Shiraz, Iran

Tel: +98 713 647 9080

Email: bahare.oji@gmail.com

Received: Apr 15 2022

Accepted: Jul 11 2022

Citation to this article:

Shahmansouri N, Kamali A, Dehbozorgi S, Delpak A, Mirzaaghayan MR, Dehghani S, et al. Disease Burden in Caregivers of Children with Congenital Heart Disease in Children's Medical Center, Tehran, Iran. *J Iran Med Counc.* 2023;6(1):45-51.

Introduction

Congenital Heart Disease (CHD) is the most common congenital malformation in infants and is the leading cause of death from congenital anomalies (1). CHD is a structural disorder of the heart caused by abnormal growth and development of the heart and large vessels (2). The prevalence of CHD varies in different geographical places. In North America, CHD occurs in 8.1 per 1000 live births, whereas in Asia the prevalence is 9.3 per 1000 live births (3). In two studies conducted in Iran, the mean prevalence of CHD was reported as 8.6 per 1000 live births and 12.3 per 1000 live births (4,5). CHD is a multifactorial disease in which environmental and genetic factors play an important role in its pathogenesis (6). Over the past decades, the population of patients with congenital heart defects has increased dramatically, which can be attributed to improved surgical outcomes and advances in medical treatment (7). The severity and type of CHD affect the severity and complications of the disease (8). Due to the increment in life expectancy of these patients, the attention of recent studies was shifted towards long-term complications (8). The burden is defined as the perceived caregiver's sufferings of their emotional or physical health, social and financial life as a result of caring for loved ones (9). Lifelong CHD endures significant emotional and economic burdens on patients, families, and society (3). Children with CHD are more likely to develop psychiatric disorders, neurodevelopmental disorders, and emotional problems (10). CHDs are among the congenital defects of children that lead to the longest hospital stay, the highest mortality rate, and the highest medical and hospital costs (11). Due to the nature of the disease and its complications, patients have an exclusive need for personal, emotional, and social support at different stages of life, and most of the burden of such support and care is on their families. Parents of children with CHD encounter significant emotional stress since they were informed of their child's CHD, also some of them were informed of the diagnosis before the child's birth, so they have faced more prolonged stress (12). On the other hand, fear of subsequent treatment plans and illness outcomes may cause a psychosocial problem in caregivers, especially their mothers (13). Parents of children with chronic illnesses such as CHD are more likely

to be challenged than other parents. Further, evidence shows the impact of this burden on parents' health (14). Prolonged caregivers' burden can result in parents' social isolation, stress, hopelessness, anxiety, and depression (15,16). Therefore, this study aimed to evaluate the burden on caregivers of patients with CHD.

Materials and Methods

Participants

In this analytical cross-sectional study, the caregivers of patients with CHD who were referred to the Children's Medical Center, in Tehran, Iran from 2019 to 2020 were selected. Family caregivers were defined as co-resident family members who are responsible for most of the patients' daily care and needs. Among the referred patients, 79 caregivers met the inclusion criteria, and 72 caregivers were satisfied to participate in this study. All 72 caregivers signed an informed consent. The caregivers' inclusion criteria were 1. Having a child between the ages of 0 month and 10 years with CHD who are still being treated (Cardiology care), 2. Living with their children at home and, parents were responsible for their care, 3. Not having another child with pervasive developmental disorders such as autism, pervasive genetic disorders, Down syndrome, and intellectual disability, and 4. The child with CHD with no mental disorder such as autism, pervasive genetic disorders, Down syndrome, and intellectual disability. Sampling was done by available and non-random methods. Face-to-face interviews with caregivers had been done. Demographic information such as child and caregiver age, caregiver education, caregiver occupation, marital status, number of children, having another child or children with heart or physical problems, and guardianship by one or both parents were acquired during the face-to-face interviews by the researcher and then entering the special information sheets. Moreover, disease characteristics data like type of CHD, age of CHD diagnosis, history of cardiac surgery, and age of surgery were gathered.

Measures

Disease burden assessment was done by Zarit *et al*'s questionnaire (9). All of the participants completed Zarit Burden Interview Questioner (ZBI). It is the most common tool for measuring disease burden.

This questionnaire includes 22 questions about the psychological burden and personal, social, emotional, and economic pressures. Each question has a Likert range from 0 to 4: (0), rarely (1), sometimes (2), often (3), and always (4). The results of this questionnaire are based on the sum of the scores. The total score obtained by caregivers shows the amount of stress and the psychological burden they have endured in an estimated range between 0 and 88. A higher score indicates a higher burden of disease. The severity of the disease burden is classified into four groups:

0-20: Little or no burden

21-40: Mild to moderate burden

41-60: Moderate-to-severe burden

61-88: Severe burden

The reliability and validity of the ZBI Interview have been acceptable according to previous studies. Also, the Persian version of the ZBI Interview has acceptable reliability according to internal consistency (Cronbach's alpha 0.77) and test-retest (coefficient 0.78) (17,18).

Statistical analysis

Statistical analysis was performed in SPSS version 22. Descriptive statistics (frequency, mean, and standard deviation) were calculated, and an independent t-test was used to compare variable means. Pearson's Chi-square test (two-tailed) was also utilized to assess the correlations between variables. The multivariate logistic regression model was used to determine the relationship between the psychological burden of care and the factors related to the child and the family. A P-value of less than 0.05 was considered statistically significant.

Ethical considerations

The present study was approved by the ethics committee of Tehran University of Medical Sciences (IR. Tums. IKh.Rec.1397.013) and is in accordance with the Declaration Institutional of Helsinki.

Results

In the present study, 79 patients with their caregivers who met the inclusion criteria were included. Seven patients were excluded due to parental dissatisfaction. The response rate was 88%.

All the caregivers in this study were mothers with a mean age of 27.33±4.36 years. 25% of caregivers were illiterate, 15.27% had a low education level (lower than Diploma) and 48.62% had a high education level (upper than Diploma). All caregivers lived in the same house with their spouses and only 21.43% of them were employed and the rest were housewives.

The mean age of the patients was 29.85±33.11 months with a minimum of one month and a maximum of 9 years. The mean age of patients at the time of diagnosis was 1.29±3.22 months and the mean disease duration was 28.56±32 months. The average number of siblings was 1.10 (min: 0, max: 3). The most frequent CHD in our study was Ventricular Septal Defect (VSD) with a prevalence of 20.83%, and the least of them was pulmonary hypertension+VSD and Tricuspid Atresia (TA) with a prevalence of 1.39%. Approximately half of (51.4%) the subjects had surgery (mean age of surgery: 11.40, min: 0.5, max: 72 months). The other participants' characteristics are presented in table 1. In this study, 8 (11.1%) of caregivers experienced a little or no burden, 9 (12.5%) did severe burden, and 21 (29.2%) experienced mild to moderate burden, while

Table 1. The participants characteristics

Patients' age group	N=72
0-2 m	14(20%)
2m-1 year	26(37.2%)
1-5 years	15(18.6%)
>5 years	17(24.2%)
Caregivers' education level	
Illiterate	25%
Low	15.27%
Intermediate	41.67%
High	18.06%
ZBI category	
Minimal	8(11.2%)
Mild to Moderate	21(32.8%)
Moderate to Severe	34(53.12%)
Severe	9(14.06%)

Zarit Burden Interview.

Table 2. Analysis of factors affecting the caregivers' burden

Variables	Significancy
Patents' age	0.73
Age at the time of CHD diagnosis	0.65
Age at the time of surgery	0.54
Number of siblings	0.000
Caregivers' Age	0.93
CHD Type	0.89
Caregivers' Education	0.000
Disease duration	0.42

most of them, 34 (47.2%), suffered from moderate-to-severe burden. The mean caregiver burden score was 42.78 which is categorized as a moderate-to-severe burden score (Figure 1).

Factors affecting the burden of disease on caregivers such as the age of the patient, age at the time of diagnosis, disease duration, age at the time of surgery, age of caregiver, siblings' numbers, type of CHD, and level of caregivers' education were examined. The more the number of siblings, the greater the association with the caregiver's disease burden (p-value<0.0001). Moreover, the higher level of caregivers' education had a significant association with the more caregiver's disease burden (p-value <0.0001).

In order to investigate the predictability of variables (the number of siblings and the level of education of the caregivers), the regression method was used. The

only independent variable conversely correlated with the disease burden of caregivers was the caregiver's educational level. It means that a higher level of education in caregivers of children with CHD was correlated with a lower disease burden (Table 2).

Discussion

In the present study, most caregivers 34(47.2%), suffered from moderate-to-severe burden. All caregivers of children with CHD were biological mothers with a mean age of 27.33±4.36 years and most of them were literate and unemployed. This finding is the same as other studies that showed most caregivers were mothers (15,16,19). Also, according to sociocultural issues, mothers were the main caregiver of children.

At the base of the main purpose of our study, most caregivers (47.2%) suffered from moderate-to-severe burden, and, the mean caregiver's burden (ZBI score) was in the range of moderate-to-severe disease burden. To the best of our knowledge, no study has assessed the burden of disease in CHD caregivers using the ZBI. However, studies that have examined psychosocial distress, anxiety, depression, and hopelessness in caregivers of CHD patients, have demonstrated a significant prevalence of these problems in caregivers (17).

In similar studies examining the burden of disease on caregivers of other chronic illnesses, most caregivers experienced moderate-to-severe disease burden and the caregivers of chronic illnesses suffered from the burden as much as the burden of caregivers of children and adolescents with Down syndrome and

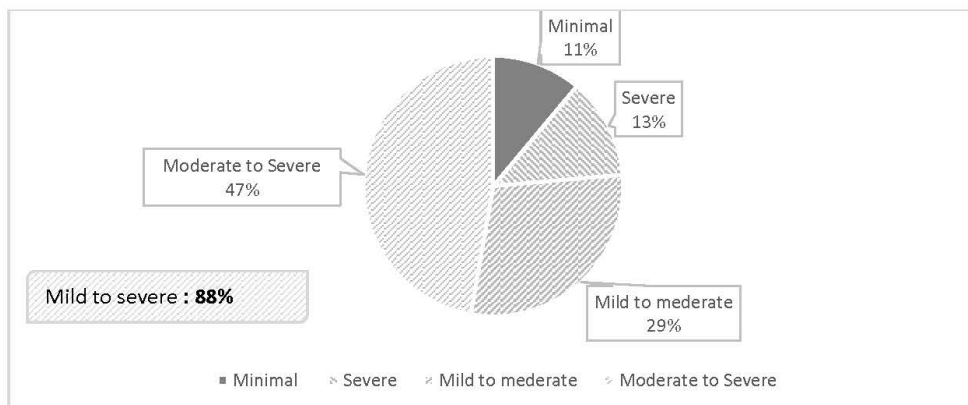


Figure 1. The frequency of caregivers' burden (Zarit Burden Interview Scale).

caregivers of adults with psychiatric patients (such as schizophrenia and mood disorders) (20,21). Also, Kobos *et al* found moderate-to-high disease burden in caregivers of children with type 1 diabetes which was consistent with the perceived suffering by the caregiver of children with CHD in our study (22). It is noteworthy that in a study conducted on caregivers of autistic children, the assessed burden of disease was lower than the burden of disease in caregivers of patients with CHD in this study (23). As discussed before, most chronic psychiatric and non-psychiatric disorders impose a significant burden on their caregivers. The higher disease burden in the caregivers of children with CHD than in caregivers of children with autism can be due to different tools used for the assessment of the burden.

Age of the patient, age at the time of diagnosis, disease duration, age at the time of surgery, age of caregiver, and type of CHD did not have any significant relationship with the burden of caregivers. These findings were the same as the results of a study of diabetic children caregivers', which indicated that disease-related factors were not associated with disease burden, and that disease burden was more influenced by concerns about disease progression than the disease itself (22). The siblings' number and level of caregiver's education had a significant relationship with the caregivers' psychological burden, but the only independent variable which was conversely correlated with the disease burden of caregivers was the caregiver's educational level. As shown in previous studies, high educated mothers have experienced a lower disease burden (22). It also seems that the number of siblings affects the economic situation of the family, and this financial burden can lead to an increase in the burden of illness in child caregivers (24). Furthermore, siblings can have a paradoxical effect on the burden of disease so that older siblings can reduce the burden of disease by helping parents, and the younger siblings can increase the burden of the disease by their own need for extra care. In the present study, the sibling number could not predict the burden of the disease. It may be due to the point that we did not consider the age of siblings and the financial status of the family in our study.

The first limitation of our study is that we only included mothers in the study since they were more

accessible. It is better to evaluate the disease burden in fathers in future studies. Second, we did not evaluate the socioeconomic status of caregivers. The socioeconomic status of caregivers could influence the disease burden. Third, as previously mentioned, we did not consider the age of siblings. Finally, the study included the children from 0 month to 10 years and they were not divided into different age groups. Given that child care needs are more at a younger age; caregivers' burden is affected. Fourth, caregivers were not interviewed for detecting the present and past history of psychiatric disorders, so the presence of psychiatric disorders can affect the disease burden.

Further research

The authors recommend further studies that address the impact of disease burden on the mental health of children and their caregivers. For this purpose, other studies could be designed that use semi-structured interviews and psychometric tools to assess the mental health of children with CHD and their caregivers.

Conclusion

CHD is associated with a significant caregivers' disease burden. Although the disease-related factors were not related to disease burden, the higher caregivers' education was related to fewer caregivers' disease burden. Therefore, paying attention to the caregiver's burden is an important clinical issue.

Funding

This research received no specific grant.

Acknowledgements

The authors have such deep respect for Dr. Azin Kamali's diligent efforts and how much time she had taken to do this well.

Conflict of Interest

The authors have no competing interests to report.

References

1. Van Der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *J Am Coll Cardiol* 2011 Nov 15;58(21):2241-7.
2. Hoffman JI, Kaplan S. The incidence of congenital heart disease. *J Am Coll Cardiol* 2002 Jun 19;39(12):1890-900.
3. Fahed AC, Gelb BD, Seidman J, Seidman CE. Genetics of congenital heart disease: the glass half empty. *Circ Res* 2013 Feb 15;112(4):707-20.
4. Nikyar B, Sedehi M, Mirfazeli A, Qorbani M, Golalipour MJ. Prevalence and pattern of congenital heart disease among neonates in Gorgan, Northern Iran (2007-2008). *Iran J Pediatr* 2011 Sep;21(3):307-12.
5. Joundishapour A. Prevalence of congenital heart disease in Iran: a clinical study. *J Med Sci* 2008 Sep 15;8(6):547-52.
6. Nazari P, Davoodi M, Faramarzi M, Bahadoram M, Dorestan N. Prevalence of congenital heart disease: a single center experience in southwestern of Iran. *Glob J Health Sci* 2016 Oct 1;8(10):56421.
7. Ávila P, Mercier LA, Dore A, Marcotte F, Mongeon FP, Ibrahim R, et al. Adult congenital heart disease: a growing epidemic. *Can J Cardiol* 2014 Dec;30(12 Suppl):S410-9.
8. Marino BS, Lipkin PH, Newburger JW, Peacock G, Gerdes M, Gaynor JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012 Aug 28;126(9):1143-72.
9. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986 Jun;26(3):260-6.
10. Olsen M, Sørensen HT, Hjortdal VE, Christensen TD, Pedersen L. Congenital heart defects and developmental and other psychiatric disorders: a Danish nationwide cohort study. *Circulation* 2011 Oct 18;124(16):1706-12.
11. Control CfD, Prevention. Hospital stays, hospital charges, and in-hospital deaths among infants with selected birth defects--United States, 2003. *MMWR Morb Mortal Wkly Rep* 2007 Jan 19;56(2):25-9.
12. Wei H, Roscigno CI, Hanson CC, Swanson KM. Families of children with congenital heart disease: A literature review. *Heart Lung* 2015 Nov-Dec;44(6):494-511.
13. Sabzevari S, Nematollahi M, Mirzaei T, Ravari A. The burden of care: mothers' experiences of children with congenital heart disease. *Int J Community Based Nurs Midwifery* 2016 Oct;4(4):374-85.
14. Brehaut JC, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL, et al. Changes over time in the health of caregivers of children with health problems: growth-curve findings from a 10-year Canadian population-based study. *Am J Public Health* 2011 Dec;101(12):2308-16.
15. Lawoko S, Soares JJ. Psychosocial morbidity among parents of children with congenital heart disease: a prospective longitudinal study. *Heart Lung* 2006 Sep-Oct;35(5):301-14.
16. Lawoko S, Soares JJ. Distress and hopelessness among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children. *J Psychosom Res* 2002 Apr;52(4):193-208.
17. Bachner Y, O'Rourke N. Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging Ment Health* 2007 Nov;11(6):678-85.
18. Rajabi-Mashhadi MT, Mashhadinejad H, Ebrahimzadeh MH, Golhasani-Keshtan F, Ebrahimi H, Zarei Z. The Zarit caregiver burden interview short form (ZBI-12) in spouses of veterans with chronic spinal cord injury, validity and reliability of the Persian version. *Arch Bone Joint Surg* 2015 Jan;3(1):56-63.
19. Navidian A, Pahlavanzadeh S, Yazdani M. The effectiveness of family training on family caregivers of inpatients with mental disorders. *Iran Journal Psychiatr Clin Psychol* 2010 Aug 10;16(2):99-106.
20. Navidi an A, Bahari F. Burden experienced by family caregivers of patients with mental disorders. *Pakistan J*

Psycholo Res 2008 Jun 22;23(1-2):19-29.

21. Barros ALO, Barros AO, Barros GLdM, Santos MTBR. Burden of caregivers of children and adolescents with Down Syndrome. Cien Saude Colet 2017 Nov;22(11):3625-34.

22. Kobos E, Imiela J. Factors affecting the level of burden of caregivers of children with type 1 diabetes. Appl Nurs Res 2015 May;28(2):142-9.

23. Lerthattasilp T, Charernboon T, Chunsuwan I, Siriumpunkul P. Depression and burden among caregivers of children with autistic spectrum disorder. J Med Assoc Thai 2015 Mar;98 Suppl 2:S45-52.

24. Brown B, Okereke J, Lagunju I, Orimadegun A, Ohaeri J, Akinyinka O. Burden of health-care of carers of children with sickle cell disease in Nigeria. Health Soc Care Community 2010 May;18(3):289-95.