

# Caregiver Burden and Its Associated Factors in Caregivers of Children and Adolescents with Chronic Conditions

Mohsen Adib-Hajbaghery<sup>1</sup>, PhD; Bahareh Ahmadi<sup>2</sup>, MS

<sup>1</sup>Trauma Nursing Research Center, Kashan University of Medical Sciences, Kashan, Iran;

<sup>2</sup>Department of Nursing, Imam Hossein Children's Hospital, Isfahan University of Medical Sciences, Isfahan, Iran

**Corresponding Author:**

Mohsen Adib-Hajbaghery, PhD; Trauma Nursing Research Center, Kashan University of Medical Sciences, Kashan, Iran

Tel: +98 31 55540021; Fax: +98 31 55546633; Email: adib1344@yahoo.com

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## ABSTRACT

**Background:** Few studies have been conducted on the burden of care in caregivers of children with chronic illnesses. This study investigated the burden of care and associated factors in first-degree caregivers of children and adolescents with chronic conditions.

**Methods:** A cross-sectional study was conducted from June to September 2017 on 385 first-degree caregivers of children and adolescents with chronic disorders. Data were collected using the Zarit burden inventory which assesses the caregiver burden in physical, psychological, economic, and relational areas and has a total score from 0 to 88. Scores 61-88, 41-60, 20-40, and <20 indicate severe, moderate, mild, and no burden. Data were analyzed using descriptive statistics and Chi-Square, Fisher's exact tests, t-test, analysis of variance, and multiple regression analysis.

**Results:** The mean age of the caregivers and children were 38.20±8.04 and 8.90±4.90 years, respectively. Also, 33 (8.5%), 135 (35.1%), and 181 (47%) of the caregivers suffered from severe, moderate, and mild burden, and only 9.4% perceived no burden. The mean caregiver burden scores were significantly different in terms of their education ( $P<0.001$ ), job status ( $P=0.04$ ), financial status ( $P<0.001$ ), family size ( $P<0.001$ ), numbers of children ( $P<0.001$ ), numbers of children with chronic illnesses ( $P<0.01$ ), type of supportive resources ( $P=0.004$ ), and children's education ( $P<0.01$ ), type of disease ( $P<0.001$ ), numbers of diseases ( $P<0.001$ ), and interval of medical visits ( $P<0.001$ ).

**Conclusion:** Caregivers of children and adolescents with chronic disease are under pressure. Our study showed a number of factors influencing caregiver burden. Health care providers should plan family-centered care plans to decrease the burden of care in caregivers of children with chronic conditions.

**KEYWORDS:** Caregivers, Child, Chronic disease, Parents, Pressur

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**INTRODUCTION**

A chronic disease is a condition requiring lifelong support, protection, intermittent monitoring, and continuous treatment.<sup>1</sup> It is estimated that 20-30% of children and adolescents in the United States suffer from chronic diseases.<sup>2</sup> Although no statistics are available on the overall prevalence of chronic conditions among children in Iran, some studies have reported that 5.8% of children in Iran suffer from asthma, about 48 to 144 per million suffer from cancer, and about 1.3% have intellectual disabilities.<sup>3-5</sup>

In the past two decades, advances in healthcare systems have increased the survival rate of patients with chronic conditions and decreased the duration of hospitalization. Therefore, an important portion of the care required is provided at home.<sup>6-8</sup> Parents are the primary caregivers of children and adolescents with chronic conditions.<sup>9,10</sup> When a child is diagnosed with a chronic disease or disability, it affects not only the patient, but also the caregivers' physical, psychological, and social health negatively.<sup>11</sup>

Evidence showed that depressive symptoms occurred more frequently in caregivers of patients with chronic diseases than in other people.<sup>12</sup> It has also been shown that parents of children with chronic illnesses suffer from sleep disorders, disturbances in familial and social communication, and decrease the quality of life. They also experience more arguments than other families.<sup>13</sup> Furthermore, psychosocial conditions of parents and their coping strategies may affect the parent-child interactions, and might negatively affect the quality of care they provide.<sup>14</sup>

Caregiver burden is another outcome of taking care of a patient with chronic disease. It is the physical, psychological, and social response of caregivers to the act of care and happens because of an imbalance between caring demands and other responsibilities of caregivers such as personal/social duties and work and family roles.<sup>15</sup> A previous study indicated that caregiver burden results in burnout, acute and chronic physical

disorders, depression, social isolation, and financial concerns.<sup>7</sup> It has also been revealed that parents of children with chronic disease experience moderate to severe burden.<sup>16,17</sup>

In recent years, more studies have been conducted to assess the caregiver burden all over the world. These studies showed that a number of factors such as caregivers' financial status, occupation, supportive resources, and culture might affect the way they experience caring for a patient with chronic disease.<sup>7,18</sup> In Iran, there are some studies about the burden of caregivers of adult patients.<sup>19-22</sup> However, only a study is available on the burden on caregivers of Iranian children with chronic illnesses.<sup>16</sup> The aforementioned study was conducted in the south of Iran and only on caregivers of children under the age of 12 years, who were currently hospitalized or referred to the outpatient clinics. Due to the association between the quality of care and the multidimensional health concerns of parents, and due to the effects of caregivers' culture on how they experience caring, it is crucial to conduct further multicenter studies to assess the burden of care and know about the associated factors in first degree caregivers of children with chronic disorders.<sup>7</sup> Therefore, this study aimed to evaluate the burden of care and its associated factors in caregivers of children and adolescents with chronic conditions.

**MATERIALS AND METHODS**

This cross-sectional study was conducted on the main caregivers of children and adolescents with chronic disorders. The study was conducted from June to September 2017. The participants were recruited from four centers, including two hospitals (i.e. Shahid Beheshti hospital of Kashan and Emam Hossein children's hospital of Isfahan) and two private rehabilitation centers (i.e. the children's rehabilitation center of Kashan and the Hazrate Abolfazl charity institution in Isfahan, Iran).

The sample size was estimated based on the results of a previous study in which the

mean±SD score of the caregiver burden was 31.80±6.46.<sup>23</sup> Then, using the formula for estimating the mean of a quantitative variable, and considering  $\sigma$  of 0.05,  $d$  of 0.64 (i.e. 0.1 of the given standard deviation), it was estimated that 385 subjects should be recruited in the study.<sup>24</sup>

$$n = \frac{(z)^2(s)^2}{d^2} \quad n = \frac{(1.96)^2 * (6.46)^2}{(0.1 * 6.46)^2} = 385$$

The inclusion criteria were: being the ones who care for and live with the child (i.e. a mother, father, sister, brother, or another close relative), having children aged 1-18 years with a chronic condition which have already been diagnosed and documented in the child's records by a physician and endured for more than three months, not having a severe mental or psychosocial illness, and willingness to participate in the study. The caregivers were excluded if they responded the questions incompletely.<sup>25</sup>

To select the study samples, we prepared a list of all children with inclusion criteria who had records in the study settings. Then, a convenient sample of the family caregivers with the inclusion criteria was invited to participate in the study. The process of sampling continued until the needed sample size was completed. The main caregiver of every child or adolescent was recruited into the study. This person was found through contacting and asking the family members. The main caregiver was the one who consumed the maximum time in caring for the sick child compared with other family members or relatives. Data were collected using a two-part questionnaire. The first part included questions about demographic information of the caregiver and the child such as age of the child and the caregiver, type of child's disease and its duration, education level of both the child and caregiver, the caregiver's job, income, supportive resources, the number of family members, presence of another child with chronic disorder in the family, frequency of hospitalizations in the past six months, and intervals of medical visits.

The second part was the Zarit burden inventory (ZBI) which was first developed by Zarit et al. (1985) to measure the burden of care among caregivers of people with cognitive and other chronic and refractory conditions.<sup>26</sup> It is a 22-item instrument designed for evaluation of the caregiver burden. It assesses the caregivers' stressors in physical, psychological, economic, and relational areas. All items are responded on a five-point Likert scale ranging from '0=never' to '4=always' with a total score ranging from 0 to 88. Higher scores mean higher levels of burden. Scores 61-88, 41-60, 20-40, and lower than 20 on the scale stood for severe, moderate, mild, and no burden, respectively. The validity of ZBI was assessed in caregivers of patients with different disorders.<sup>27, 28</sup> In a recent study, Seng et al. used different methods to assess the construct validity of the English version of ZBI (i.e. criterion validity, discriminative analysis, and internal consistency). They reported that ZBI score was highly correlated with the scores of the Burden Assessment Scale (BAS) ( $r=0.73$ ,  $P<0.001$ ) and the General Health Questionnaire (GHQ-28) total score ( $r=0.62$ ,  $P <0.001$ ). Moreover, the main caregivers had higher ZBI scores than those who spent less time in caregiving ( $P<0.001$ ). Cronbach's alpha of ZBI was also 0.93 and the intra-class correlation coefficient for the test-retest reliability of the ZBI was 0.89.<sup>29</sup> The ZBI has also been translated into Persian language and showed good validity and test-retest reliability ( $r=0.91$ ).<sup>30</sup> Recently, the short form of ZBI has translated into Persian and also showed good validity and test-retest reliability (Cronbach's alpha=0.78, ICC=0.78). Moreover, Pearson's correlation test showed a significant correlation between 10 items of the ZBI and physical and mental components of the Quality of Life Short Form (SF-36) ( $r$  ranging from 0.23- to 0.53- and  $P$  ranging from 0.001 and 0.04).<sup>31</sup> However, in the present study, we recalculated the scale's Cronbach's alpha as 0.87.

When a caregiver agreed to participate, an appointment was arranged to visit him/her in a

private room at hospital, charity institution or at their home door, where the study questionnaire was passed to them and they were briefed on how to complete it. The subjects were asked to read and answer the questions in a private and comfortable environment. Most of them returned the completed questionnaire after 30 min. If the subjects could not read any part of the questionnaire (52 subjects), the researcher read them the questions and recorded their answers.

Data were analyzed using the SPSS software v.16 (SPSS Inc., Chicago, IL, USA). The data were described through the mean, standard deviation, and frequency. Categorical data were compared using the Chi-Square and Fisher's exact tests. T-test was used to compare the means between two subgroups of the subjects. One way analysis of variance (ANOVA) and the Tukey post hoc test were used to compare the means between three or more subgroups of the subjects. Also, multiple regression analysis was used to examine the factors associated with caregiver burden. To this end, first, the backward model was conducted with the removal criterion of  $P > 0.10$ . Then, all the remaining variables with  $P < 0.10$  were again entered into the model and analyzed using the forward method.

Before we performed the multiple regression analysis, the categorical variables were first converted to dummy variables to represent subgroups of the samples. Also, to enter the ordinal variables to the model, we coded them as 0, 1, 2, and so on.  $P$  values  $< 0.05$  were considered significant.

This study was approved by the research ethics committee of Kashan University of Medical Sciences (Ethics approval code: IR.KAUMS.REC 1396.34). The aim of this study was explained to all subjects and they were assured that their personal data would be kept confidential. To this end, all questionnaires were kept anonymous and only identified with numerical codes.

All subjects were ensured that participation in and withdrawal from the study were voluntary. Then, they all signed the informed

consents before participation. Permission was also obtained from the authorities at the hospitals and the charity and rehabilitation centers, and the study findings were provided to them at the end.

## RESULTS

In this study, the level of caregiver burden in 385 family caregivers of children with chronic conditions was evaluated. Respectively, 33 (8.5%), 135 (35.1%), and 181 (47%) of the caregivers suffered from severe, moderate, and mild burden, and only 9.4% perceived no burden. The overall mean of caregiver burden was  $39.04 \pm 15.14$  which was in the range of mild burden.

The mean age of the caregivers and children was  $38.2 \pm 8.04$  and  $8.9 \pm 4.9$  years, respectively. Fifty percent of the participants were fathers. Also, 43.1% of the participants were self-employed and 45.7% were in official jobs (Table 1).

As presented in Table 1, t-test showed that the mean burden score was significantly higher in caregivers with insufficient income ( $P < 0.001$ ) and in those with a family size of 4 or more ( $P < 0.001$ ). Moreover, ANOVA showed that the mean burden scores were significantly different in caregivers with different education levels ( $P < 0.001$ ). According to the Tukey post hoc test, the mean burden was significantly different in all education levels at  $P < 0.001$ . ANOVA also showed that the mean burden scores were significantly different in caregivers with different job status ( $P < 0.04$ ). According to the Tukey post hoc test, only employees were significantly different from those who were retired and unemployed ( $P < 0.013$ ). ANOVA also showed that the mean burden scores were significantly different in caregivers with different numbers of children ( $P < 0.001$ ) and also between caregivers with different numbers of children with chronic illness ( $P < 0.001$ ). According to the Tukey post hoc test, the mean burden was significantly different among all levels at  $P < 0.001$ . Moreover, ANOVA showed that

**Table 1:** Comparison of the mean of burden score based on caregivers' characteristics

Characteristics of caregivers	N (%)	Burden score, Mean±SD	P value
<b>Age</b>			0.21*
Under 30 year	66 (17.1)	37.15±16.40	
30-40 years	198 (51.5)	38.28±16.64	
40 years and over	121 (31.4)	41.00±15.21	
<b>Education level</b>			<0.001*
Under diploma	179 (46.5)	43.54±14.44	
Diploma	182 (47.3)	36.31±14.17	
Academic	24 (6.2)	23.91±9.62	
<b>Kinship with the child</b>			0.07*
Mother	184 (47.8)	40.0±15.61	
Father	193 (50.1)	38.66±14.69	
Others	8 (2.1)	27.98±11.24	
<b>Marital status</b>			0.84*
Single	10 (2.6)	36.50±18.69	
Married	369 (95.8)	39.13±15.07	
Divorced	6 (1.6)	37.78±16.10	
<b>Job</b>			0.04*
Employee	35 (9.1)	32.73±13.67	
Self employee	166 (43.1)	39.07±15.20	
House keeper	176 (45.7)	39.97±15.16	
Retired and unemployed	8 (2.1)	46.52±13.25	
<b>Income</b>			<0.001**
Sufficient for expenses	60 (15.6)	26.33±12.38	
Insufficient for expenses	325 (84.4)	41.53±14.56	
<b>Family size</b>			<0.001**
Less than 4	98 (25.5)	33.60±14.12	
4 or more	287 (74.5)	40.94±15.11	
<b>Having another child with chronic illness</b>			<0.001*
No	290 (75.3)	36.13±14.82	
2 children	74 (19.2)	45.73±12.66	
3 or more	21 (5.5)	55.64±7.8	
<b>Numbers of children</b>			<0.001*
1	99 (25.7)	33.66±13.96	
2	168 (43.6)	28.18±15.08	
3 or more	112 (29.4)	45.22±14.35	
<b>Supportive resources</b>			0.004*
Family	254 (66)	37.38±14.15	
Social	54 (14)	40.22±15.73	
No support	55 (14.3)	44.56±16.46	

\*One Way ANOVA; \*\*t-test

the mean burden scores were significantly different in caregivers with different types of supportive resources (P=0.004), and only those who received support from the family were significantly different from those who received no support (P<0.001).

As presented in Table 2, t-test showed that the mean burden score was significantly higher in caregivers whose children were

currently hospitalized (P<0.001), and had more than a chronic disease (P<0.001). Moreover, ANOVA showed that the mean caregiver burden scores were significantly different in terms of children's education level (P<0.01). According to the Tukey post hoc test, only the burden of caregivers with low literate children was significantly different from those of children with secondary

**Table 2:** Comparison of the mean of the caregivers burden score based on children's characteristics

Characteristics of children	N (%)	Burden score, Mean±SD	P value
<b>Recruitment center</b>			<0.001*
Hospitals	225 (58.4)	42.09±13.05	
Rehabilitation center or charity	160 (41.6)	36.87±16.14	
<b>Disease duration</b>			0.18*
3-12 month	75 (19.5)	36.96±14.20	
12m<	310 (80.5)	39.60±15.41	
<b>Age</b>			0.38**
1-3 y	73 (19)	38.36±16.01	
3-6 y	56 (14.5)	36.24±13.41	
6-12y	152 (39.)	39.45±15.32	
12y<	104 (27)	40.43±15.11	
<b>Sex</b>			0.05*
Boy	232 (60.3)	38.23±14.98	
Girl	153 (39.7)	40.28±15.35	
<b>Education level</b>			<0.01**
>Low literate	212 (55.1)	40.73±15.53	
Elementary education	105 (27.3)	36.36±14.20	
Secondary education	45 (11.7)	34.46±13.67	
High school	23 (5.9)	36.66±11.36	
<b>Type of disease</b>			<0.001**
Renal	153 (39.7)	38.53±13.75	
Endocrine, metabolic and immune disorders	50 (13.0)	38.35±16.02	
Neural	33 (8.6)	37.13±18.64	
Cancers	22 (5.7)	32.69±12.44	
Cardiac and respiratory disorders	21 (5.5)	34.54±14.28	
Handicaps	20 (5.2)	41.40±13.70	
Gastrointestinal	12 (3.1)	25.11±8.21	
Combination of diseases	64 (16.6)	45.44±14.86	
<b>Numbers of diseases</b>			<0.001*
One disease	310 (0.5)	37.69±14.76	
More than 1	75 (19.5)	44.0±15.49	
<b>Intervals of medical visits</b>			<0.001**
Weekly	86 (22.3)	44.74±15.32	
Every 2 week	3 (0.8)	42.53±6.31	
Every month	262 (68.1)	37.80±14.78	
Every 2 month	14 (3.6)	38.15±14.58	
Every year	18 (4.7)	29.80±14.05	
<b>Number of hospitalizations in the last 6 months</b>			0.03**
0-1 times	164 (42.6)	37.61±16.17	
2-3 times	106 (29.5)	37.85±12.83	
4 and more times	89 (24.8)	42.73±16.00	

\*t-test; \*\*One Way ANOVA

education ( $P<0.01$ ). Also, ANOVA showed that the mean caregiver burden scores were significantly different in terms of the type of children's diseases ( $P<0.001$ ). According to the Tukey post hoc test, the mean burden was significantly higher in caregivers whose children suffered from a combination of

disorders than that of cancer ( $P<0.001$ ), gastrointestinal ( $P<0.001$ ) and renal disorders ( $P<0.001$ ). Moreover, according to the Tukey test, the mean burden was significantly different in caregivers whose children suffered from gastrointestinal disorders than that of handicaps ( $P<0.001$ ),

and renal disorders ( $P < 0.001$ ). ANOVA also showed that the mean caregiver burden scores were significantly different in terms of the interval of children's medical visits ( $P < 0.001$ ). According to the Tukey post hoc test, the mean burden was significantly higher in caregivers whose children needed weekly medical visits than monthly ( $P < 0.01$ ) and yearly visits ( $P < 0.01$ ). In addition, ANOVA showed that the mean caregiver burden scores were significantly different in terms of the number of hospitalizations ( $P = 0.03$ ). According to the Tukey post hoc test, only the burden of caregivers whose children needed 4 times or more hospitalization in the last 6 months was significantly different from that of other levels ( $P < 0.02$ ) (Table 2).

Multiple linear regression showed that among all variables entered into the model, caregivers' insufficient income, being supported by the family members, and education level (over diploma, and academic educations), having two or more ill children in the family, occurrence of more than a chronic disease in a child, needing weekly medical visits, and hospitalization for four or more times in the past six months were significantly associated with the caregiver burden (Table 3).

## DISCUSSION

The present study showed that the majority of our participants experienced a mild burden. However, more than two-fifths of them suffered from a moderate to severe burden. Previous studies in Iran and the United States have found moderate levels of burden among caregivers of children with chronic illnesses.<sup>16, 32</sup> The differences might either be attributed to the different instruments used in the studies or to the fact that previous studies mostly examined the caregivers of hospitalized children, but more than forty percent of the sick children of our participants were not currently hospitalized and unstable; therefore, their caregivers perceived less burden.

Approximately, half of the caregivers in the present study were fathers. A recent study investigated the caregiver burden in a smaller sample of caregivers of children with chronic disorders in Iran and reported that in most cases, mothers played the role of the caregiver.<sup>16</sup> However, in the current study fathers accepted a greater role in caring for their sick child. This finding might be attributable to the fact that in the present study a majority of children with chronic disorders were boys. In this study, the mean perceived

**Table 3:** Results of regression analysis for determining the factors associated with caregiver burden

Variable (reference category)	Unstandardized	Standardized	Beta	P value
	Coefficients	Coefficients		
	B	Std. Error		
(Constant)	34.45	2.56		<0.001
Insufficient parents' income (sufficient income)	8.76	2.06	0.2	<0.001
Being supported by family members (receiving no support)	-3.58	1.41	-0.11	<0.001
Caregivers with academic education (less than diploma)	-5.35	2.32	-0.11	0.02
Caregivers' education over diploma (less than diploma)	-5.83	1.46	-0.19	<0.001
Having two ill children in the family (having no more ill children)	5.4	1.74	0.14	0.002
Having three or more ill children in the family (having no more ill children)	14.96	3.77	0.18	<0.001
Children with more than a disease (one disease)	3.06	0.93	0.15	<0.001
Needing weekly visits (needing yearly visits)	7.38	1.60	0.20	<0.001
Hospitalization for 4 or more times (hospitalization for 0-1 time)	4.72	1.47	0.15	<0.001

Adjusted R Square=0.35

burden was not significantly different between mothers and fathers. A number of studies also reported a greater caregiver burden in fathers, while most studies reported higher caregiver burden among mothers.<sup>16, 30, 32-35</sup> The relatively equal burden of mothers and fathers in the current study might be attributable to the fact that fathers usually had to take care of the other family members in addition to their sick child. Thus, the burden perceived by fathers would not be much less than that of mothers.

In the present study, caregivers with lower education and also those whose sick children were less educated experienced higher burden. These findings were consistent with the results of previous studies.<sup>16, 19, 22, 34, 35</sup> Perhaps more educated caregivers are more self-confident in dealing with various life situations, have better ability to cope with problems and have access to social support which can consequently alleviate their perceived burden. Furthermore, perhaps, children with higher education possess a greater ability to take part in their self-care process, which then enhances the quality of life in their families and allows the parents to enjoy a lower burden.<sup>20, 21</sup> Nonetheless, older children are usually more educated and it is not exactly clear which of these two variables (i.e. age or education) are more effective on caregiver burden. Perhaps, the combined effects of the child's age and education impact the burden their caregivers experience.

In the current study, caregivers who were employed and had a sufficient income experienced less burden. A review study reported low financial status as a risk factor for caregiver burden.<sup>35</sup> However, a recent study reported that although low monthly income is not a direct risk factor for the caregiver burden, it decreases the caregivers' quality of life which in turn increases their perceived burden.<sup>36</sup> The parents' financial status might also be considered as an outcome of their occupation. These two variables might also be influenced by the parents' education level. Then, the combined effect of the caregivers' financial, educational, and

occupational status might affect not only their quality of life and mental health, but also their perceived burden.

In this study, the mean perceived burden was higher in caregivers with a family size of four or more, in caregivers with more children, and in those with more children with chronic illnesses. This finding was in contrast to that of a recent study which concluded that in families with a larger size, the other family members may take part in the act of caregiving allowing the burden to be shared among them. Moreover, being responsible for another healthy child may leave no choice for the parents to have more social interactions, which could in-turn, lower their burden levels.<sup>16</sup> Another study has also shown that mothers with only one sick child experienced higher levels of burden.<sup>26</sup> However, based on our findings, an increase in the size of family, meeting the demands of the other children, and taking care of another sick child are associated with an increased perceived burden, perhaps due to the increase in their responsibilities and financial concerns. This situation may force the parents to change their lifestyle, spend more time and money, which will consequently increase the perceived burden.

Availability of supportive resources was an important factor affecting caregiver burden in this study. Interestingly, the mean perceived burden was even less in parents who received good familial support even than that of those who had access to some social supports. A number of studies also confirmed the beneficial effects of familial and social supports on decreasing the caregiver burden.<sup>17, 22, 36</sup> Although a number of existing social support systems in Iran may offer some teaching, counseling, and financial supports to the parents of children with chronic conditions, it seems that good familial support was more favorable for our participants. Perhaps, families cannot only help parents in providing care for the sick child, but also may compensate their shortages in doing their home responsibilities and caring for their



other children which consequently can reduce their concerns and perceived burden.

In this study, the mean perceived burden was higher in parents of children with more than one chronic illness, needing more medical visits, and more frequent hospitalizations in the last six months. Earlier studies on mothers of children with chronic conditions and caregiver of patients with heart failure also reported similar findings. Regular visits and frequent hospitalizations require spending more time and money.<sup>22, 32</sup> In the case of hospitalization of the child, one of the parents should also disregard his/her home and work responsibilities and stay with their sick child. This interferes with their daily life, induce them some concerns, and make them more stressed and frustrated.

In this study, the mean perceived caregiver burden was not significantly associated with the disease duration, caregivers' age, and children's sex and age group. Some studies have reported a direct association between the disease duration and caregiver burden.<sup>22, 30</sup> A study has reported that as time goes on, parents learn new strategies for coping with care-related challenges which reduce their perceived burden.<sup>16</sup> Nevertheless, it seems that the concerns related to disease and the child's future may persist despite the learned coping strategies. Studies are conflicting about the association between the caregivers' age and their perceived burden. Some studies reported a direct association between these two variables, while others could not confirm such an association.<sup>16, 17, 19, 33, 37</sup> Based on these conflicting results, it seems that some factors specific to different societies such as culture and pedagogical methods can affect this matter. Then, more studies are yet needed to be conducted on this issue.

Among the variables entered in the regression analysis, being supported by the family members, caregivers' insufficient income, and education level (over diploma, and academic educations), having two or more sick children in the family, presence of more than a chronic disease in a child, need to

weekly medical visits, and hospitalization for four or more times in the past six months were significantly associated with the caregiver burden. Consistently, a study reported that the parents' stress, support status, and type of family were the most important predictors of caregiving burden in primary caregivers of patients with chronic conditions.<sup>1</sup>

Only a few studies on the burden of care among caregivers of children and adolescents with chronic diseases are available from Iran. Examining a relatively large number of caregivers and recruiting caregivers of children and adolescents with different types of chronic disorders might be considered as the strengths of the present study. However, while reading the results of this study, some limitations should be noted. First, we selected a convenient sample of caregivers. Further studies on random samples of caregivers are recommended. Although we conducted a multicenter study, because the study was a thesis and due to the time limitation, we did not consider the effect of quality of services in different centers and the severity of disorders on the caregiver burden. A number of additional variables such as the presence of an elderly patient at home, residing at a private or a rented home, and also the severity of the child's illness and his/her dependency might also affect the level of caregiver burden. Therefore, we suggest that future researchers should consider these variables in their data collection and analysis.

## CONCLUSION

The current study revealed that most of the caregivers of children with chronic diseases experience a mild to a moderate burden. According to the results of this study, in addition to the caregiving pressures, a number of factors such as insufficient income and lower education, the amount and type of support the caregivers receive, numbers of their ill children, number of the children's disorders and the frequency of needing medical visits and hospitalizations might affect the burden the caregivers perceive.

Therefore, health care providers should develop family-centered care plans and try to decrease the factors that amplify the burden of care. Referring the low-income caregivers to some social support groups and organizations for receiving financial, training, and caring supports might reduce the perceived burden in some of them. Moreover, holding some periodic workshops and presenting some easy-to-follow care instructions, and tailored consultation might help the caregivers not only manage their stressors, but also provide better care for their sick children, and consequently diminish their burden and improve their quality of life.

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#### REFERENCES

- 1 Yigitalp G, Surucu HA, Gumus F, Evince E. Predictors of caregiver burden in primary caregivers of chronic patients. *International Journal of Caring Sciences*. 2017;10:1168-77.
- 2 Brown RT, Wiener L, Kupst MJ, et al. Single parents of children with chronic illness: an understudied phenomenon. *Journal of Pediatric Psychology*. 2008;33:408-21.
- 3 Gooya M, Shirkani A, Tahmasebi R, et al. Prevalence of Asthma and Allergic Diseases and Its Risk Factors in School Children Aged (6-7 and 13-14 Years) in Assalouyeh City, Bushehr Province Based on III ISAAC Protocol Phase I, in 2014. *Iranian South Medical Journal*. 2017;20:57-69. [In Persian]
- 4 Mousavi SM, Pourfeizi A, Dastgiri S. Childhood cancer in Iran. *Journal of Pediatric Hematology/Oncology*. 2010;32:376-82.
- 5 Soltani S, Khosravi B, Salehiniya H. Prevalence of intellectual disability in Iran: Toward a new conceptual framework in data collection. *Journal of Research in Medical Sciences*. 2015;20:714-5.
- 6 Raghupathi W, Raghupathi V. An Empirical Study of Chronic Diseases in the United States: A Visual Analytics Approach. *International Journal of Environmental Research and Public Health*. 2018;15:431.
- 7 Brown BJ, Okereke JO, Lagunju IA, et al. Burden of health-care of carers of children with sickle cell disease in Nigeria. *Health & Social Care in the Community*. 2010;18:289-95.
- 8 Chen HM, Huang MF, Yeh YC, et al. Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics*. 2015;15:20-5.
- 9 Macedo EC, da Silva LR, Paiva MS, Ramos MNP. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. *Revista latino-americana de enfermagem*. 2015;23:769-77.
- 10 Eccleston C, Fisher E, Law E, Bartlett J, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Syst Rev*. 2015;(4):CD009660.
- 11 Elmore D. The Impact of Caregiving on Physical and Mental Health: Implications for Research, Practice, Education, and Policy. In: Talley RC, Fricchione GL, Druss BG, editors. *The Challenges of Mental Health Caregiving*. New York: Springer; 2014.
- 12 Anandi BS, Dhadave MM. Anxiety and depression among caregivers of inpatients suffering from chronic debilitating and terminal illnesses. *International Journal of Community Medicine and Public Health*. 2018;5:1903-8.

- 13 Golics CJ, Basra MK, Salek MS, Finlay AY. The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *International Journal of General Medicine*. 2013;6:787-98.
- 14 Mikolajczak M, Brianda ME, Avalosse H, Roskam I. Consequences of parental burnout: Its specific effect on child neglect and violence. *Child Abuse & Neglect*. 2018;8:134-45.
- 15 Valizadeh L, Joonbakhsh F, Pashae S. Determinants of care giving burden in parents of child with cancer at Tabriz children medical and training center. *Journal of Clinical Nursing and Midwifery*. 2014;3:13-20. [In Persian]
- 16 Piran P, Khademi Z, Tayari N, Mansouri N. Caregiving burden of children with chronic diseases. *Electron Physician*. 2017;9:5380-7.
- 17 Kahraman S, Çiftçi EK, Timuçin A. Determination of caregiving burden of parents providing care to their children with epidermolysis bullosa. *Egyptian Journal of Dermatology and Venereology*. 2017;37:1-6.
- 18 Abuosi AA, Adzei FA, Anarfi J, et al. Investigating parents/caregivers financial burden of care for children with non-communicable diseases in Ghana. *BMC Pediatrics*. 2015;15:185.
- 19 Dada MU, Okewole NO, Ogun OC, Bello-Mojeed MA. Factors associated with caregiver burden in a child and adolescent psychiatric facility in Lagos, Nigeria: a descriptive cross sectional study. *BMC Pediatrics*. 2011;11:110.
- 20 Rubira EA, Marcon SR, Belasco AGS, et al. Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer. *Acta Paulista de Enfermagem*. 2012;25:567-73.
- 21 Datta S, Kar S. Assessing Health and Quality of Life burden on Caregivers of Chronically and Terminally Ill Patients - Evidence Based Systematic Review from a Global Perspective. *Athens Journal of Health*. 2016;3:319-34.
- 22 Hu X, Dolansky MA, Hu X, et al. Factors associated with the caregiver burden among family caregivers of patients with heart failure in southwest China. *Nursing & Health Sciences*. 2016;18:105-12.
- 23 Singh K, Kumar R, Sharma N, Kumar Nehra D. Study of burden in parents of children with mental retardation. *Journal of Indian Health Psychology*. 2014;8:13-20.
- 24 Charan J, Biswas T. How to calculate sample size for different study designs in medical research? *Indian Journal of Psychological Medicine*. 2013;35:121-6.
- 25 Tsai YH, Lou MF, Feng TH, et al. Mediating effects of burden on quality of life for caregivers of first-time stroke patients discharged from the hospital within one year. *BMC Neurology*. 2018;18:50.
- 26 Sulkers E, Tissing WJ, Brinksma A, et al. Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. *Psycho-oncology*. 2015;24:318-24.
- 27 Bianchi M, Flesch LD, Alves EV, et al. Zarit Burden Interview Psychometric Indicators Applied in Older People Caregivers of Other Elderly. *Revista Latino-Americana de Enfermagem*. 2016;24:e2835.
- 28 Al-Rawashdeh SY, Lennie TA, Chung ML. Psychometrics of the Zarit Burden Interview in Caregivers of Patients with Heart Failure. *The Journal of Cardiovascular Nursing*. 2016;31:E21-8.
- 29 Seng BK, Luo N, Ng WY, et al. Validity and Reliability of the Zarit Burden Interview in Assessing Caregiving Burden. *Annals of the Academy of Medicine, Singapore*. 2010;39:758-63.
- 30 Navidian A, Bahari F. Burden Experienced by Family Caregivers of Patients with Mental Disorders. *Pakistan Journal of Psychological Research*. 2008;23:19-28.
- 31 Rajabi-Mashhadi MT, Mashhadinejad H, Ebrahimzadeh MH, et al. 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. *The Archives of Bone and Joint Surgery*. 2015;3:56-63.
- 32 Javalkar K, Rak E, Phillips A, et al. Predictors of Caregiver Burden among Mothers of Children with Chronic Conditions. *Children*. 2017;4:E39.
- 33 Fitzjerald C, George S, Somerville R, et al. Caregiver burden of parents of young children with cystic fibrosis. *Journal of Cystic Fibrosis*. 2018;17:125-31.
- 34 Ge L, Mordiffi S. Factors Associated With Higher Caregiver Burden Among Family Caregivers of Elderly Cancer Patients. *Cancer Nursing*. 2017;40:471-8.
- 35 Adelman RD, Tmanora L, Delgado D, et al. Caregiver Burden: A Clinical Review. *Journal of the American Medical Association*. 2014;311:1052-60.
- 36 Guo M, Gao G, Guo J, et al. Burden among caregivers for children with asthma: A mixed-method study in Guangzhou, China. *International Journal of Nursing Sciences*. 2015;2:394-401.
- 37 Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*. 2012;64:846-55.