

Caregiving burden of children with chronic diseasesPegah Piran¹, Zahra Khademi¹, Narges Tayari², Nafise Mansouri³

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Type of article: Original**Abstract**

Background: The care demands of children with chronic diseases can affect caregivers' health by imposing caregiving burden to them. The health status of caregivers plays a vital role in the quality of care provided to such children and in their quality of life.

Objective: To determine caregiving burden in caregivers and to identify relevant influential factors.

Methods: In this cross-sectional study, a total number of 249 caregivers of children with chronic diseases who referred to hospitalization and ambulatory departments of Bandar Abbas, Iran in 2016 were selected using convenience sampling method. The main caregivers who were older than 18 years and provided care to a sick child for at least three months consecutively were included. Caregiving burden was measured using the Caregiver Burden Scale. Data was analyzed SPSS 16 using descriptive statistics, Spearman's correlation coefficient and Mann-Whitney U test.

Results: Mean score of caregiving burden was 1.98 which was close to moderate level. The highest caregiving burden was observed in general strain dimension (2.35), and cerebral palsy imposed the maximum burden to caregivers (2.24). Correlation coefficient revealed that perceived caregiving burden was in connection with children's and caregivers' age, duration of disease and caregiving, child's level of disability, number of family members and income level ($p < 0.05$). Mann-Whitney U test showed that female caregivers, villagers, and caregivers dealing with more than one patient experienced higher burden ($p < 0.05$).

Conclusion: Different variables can increase caregiving burden. Therefore, planning for holistic and family-centered interventions to decrease caregiving burden is necessary for health care providers.

Keywords: Caregiving burden, Caregiver, Child

1. Introduction

The majority of children enjoy their childhood time, but more than 7% of them need costly health care services because of chronic disease involvement (1). A chronic disease refers to a condition disturbing the daily functions of people for at least three months out of a year. In another definition, it is a disease demanding hospitalization for more than one month (2). Today, advances in treatment approaches have raised the survival rate in children with chronic diseases. However, prognosis, life expectancy and quality of life are ambiguous in such children (3). According to research, the families of children with chronic diseases have trouble in coping with their disease (4). Generally, caregivers from within the family bear important and multidimensional responsibilities over time to manage a chronic disease (1). As the first and the most important caregivers, the parents of such children suffer various financial, family, social, mental and psychological problems (5). Even though caring for children is a routine

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role of parents, when a child experiences functional limitations and long-time dependency, this role becomes more highlighted. The effective management of problems associated with caregiving is a main challenge of involved parents. In some cases, providing such care may damage the physical and psychological health of parents on the one hand and may affect the whole family function on the other hand (1). Studies indicate that caregivers show more symptoms of depression compared with other people. According to the results of a study, 49.1% and 31.8% of parents of children with chronic depression suffer severe and moderate depression, respectively (3). In addition, it shows that highly depressed caregivers show lower self-efficacy. According to the results of another study, the mean scores of the quality of life of parents of children with leukemia is lower than the total score by 50% and the quality of life in female caregivers is lower than that of males (5). Giving care services to sick children depletes the energy of family members and exposes them to physical and emotional problems and insolation risk, and results in disappointment, desperation, distress, shame and suicidal thoughts (6). This is why patients' families are sometimes called hidden patients (7). Health care systems have received changes in the past two decades. The changes have redirected hospitalization care to ambulatory and home care. This, in turn, increases the responsibilities of non-official caregivers. In addition, different factors including small-sized families, increased divorce rate and technological advances in the medicine field, have increased the pressure and stress perceived by parents (1). Caregiving burden refers to responsibilities perceived by caregivers and to limitations induced to them and their family (8). It is defined as the physical, mental and social reactions of the caregiver. It originated from the lack of established balance between care needs and other duties of the caregiver. It consists of subjective and objective dimensions: the objective caregiving burden is considered as the extent of time and effort required for supplying patients' needs including financial costs, family relations and social functions. Subjective caregiving burden is the degree of stress imposed on the caregiver when they face objective caregiving burden including mental, emotional and behavioral problems (9). It is yet unknown why some caregivers can cope with problems and others cannot. Some factors can serve as the determinants of stress and caregiving burden in parents including caregiver's specifications, care receiver's specification, common history between caregiver and care receiver, social factors, economic factors and cultural background (1). To date, studies have examined the burden of care, and influencing factors are mainly in Western societies with different cultural and religious backgrounds and family structure from Eastern and especially Iranian community. To the author's knowledge, studies conducted in Iran have examined depression and anxiety in parents of sick children (3) and have evaluated caregiving burden only in children with cancer (5, 9). Therefore studies focusing on comprehensive assessment of caregiving burden are lacking. Although accurate prevalence of chronic diseases in Iranian children were not achieved, the prevalence of asthma as the most common chronic disease of children is 10 to 15% (10). Considering that most sick children depend on others in performing their daily duties, especially in Iranian culture, paying special attention to caregivers is of high importance. Therefore, this study aimed to determine the extent of caregiving burden in the caregivers of Iranian children with chronic diseases and to identify relevant influential factors.

2. Material and Methods

2.1. Participants and design

In this cross-sectional study, a sample was selected from the hospitalization and ambulatory departments of a pediatric hospital, the hospitalization and ambulatory department of chemotherapy, diabetes and thalassemia clinics of Bandar Abbas, a city in southern Iran. The participants were the caregivers of children with chronic diseases referred to the above centers from May to September 2016 to receive outpatient or follow-up services. Sample was selected using conventional sampling method. A total number of 249 main caregivers volunteered to participate in the study. A main caregiver was a member of family who consumes the maximum time and attention to providing care compared with other members, and was considered as the main person responsible for providing care services.

2.2. Selection criteria

2.2.1. Inclusion criteria

Inclusion criteria for caregivers were: aged over 18, at least three consecutive months' experience providing care to sick children. Patients group composed of children aged ≤ 14 who had at least one chronic disease diagnosed by a physician.

2.2.2. Exclusion criteria

Caregivers were excluded from the study if they suffered from a psychiatric disorder or did not wish to participate.

2.3. Measurement tool

Data was collected using a two-part questionnaire. The first part included the demographic information of children with chronic disease and corresponding caregivers. The second part included the Elmstahl et al. Caregiving Burden

Scale (CBS). The CBS is used to assess the mental perception of caregiving pressure. It is a valid and reliable tool for measuring caregiving burden, and good psychometric properties have been reported for it (11). This scale consists of 22 items with 5 sub-scales as follows: general strain (8 items), social isolation (3 items), environment (3 items), emotional involvement (3 items) and disappointment (5 items). The items were scored from 1 to 4 using Likert scale (1= never, 2= rarely, 3= sometimes and 4= often). The total caregiving burden score was derived by calculating the mean scores of all items. In addition, the mean score of caregiving burden in each sub-scale was derived by calculating the mean score of items associated with that sub-scale. Finally, caregiving burden was classified into three levels: low (1-1.99), moderate (2-2.99) and severe (3-4). Farajzadeh et al. have developed the Farsi version of this scale, and its content and face validities have been assessed (12). In addition, this study assessed the reliability of this scale using an internal consistency assessment method. Cronbach's alpha was derived 0.82 for the whole scale. It was at least 0.73 for all sub-scales.

2.4. Data collection

For executing this study, the researcher obtained permission from Hormozgan University of Medical Sciences and offered it to authorities of pediatric hospitals and thalassemia, diabetes and chemotherapy clinics. All eligible caregivers of children were identified and the questionnaires were submitted to them. If a participant could not read or write, the questioner read the items to them and recorded answers in the related questionnaire. Sampling was continued until achieving the considered sample size.

2.5. Data analysis

Data was analyzed using SPSS 16 (SPSS Inc., Chicago, Illinois, USA). The variables were described using percentage, mean and standard deviation. The correlation and comparison tests were conducted using non-parametric methods, namely Spearman's correlation and Mann-Whitney U test, respectively. Significance level was set at $p < 0.05$.

2.6. Ethics approval

This study was approved by the Ethics Committee of Hormozgan University of Medical Sciences (by number HUMS.REC.1395.67). All eligible participants were informed about objectives of the study. They were also assured of voluntary participation and confidentiality of information. Caregivers signed the consent form and were asked to give their phone number if they wished to receive the study results.

3. Results

A total number of 249 caregivers of children with chronic diseases filled the study questionnaire and were included in the study. In addition, 37 caregivers were not interested in participating in this study. The main reason was the lack of time to complete the questionnaire. The mean age of participants was 35.39 (SD=7.61) and most of them were the mothers of the sick children (89.6%), were married (94%) and had an education level of below diploma (47.4%). Of the studied caregivers, 25.7% were suffering from at least one chronic underlying disease and 13.7% of them were providing care services to another member of their family in addition to the sick child. Moreover, 78.3% of participants were unemployed and 60.60% were city dwellers. Regarding financial status, most of the participants reported poor financial status (57.8%) and only 24.5% of them were satisfied with their income level. The average number of family members was 4.59 (SD=1.24). Regarding the specifications of the studied sick children, the mean age of them was 7.27 (SD=4.06) and 53.8% of them were female. According to results, the most frequent chronic disease was thalassemia (27.3%) followed by cancer (19.3%). Mean caregiving burden total score was 1.98 (SD=0.43). Mean scores of general strain, isolation, disappointment, emotional involvement and environment was 2.35 (SD=0.57), 1.67 (SD=0.73), 1.95 (SD=0.60), 1.30 (SD=0.57) and 2.02 (SD=0.58), respectively. The comparison of different chronic diseases revealed that the maximum caregiving burden was seen in cerebral palsy (M=2.24, SD=0.36). In addition, these caregivers experienced the highest level of burden in general strain, isolation and disappointment sub-scales with mean scores of (M=2.60, SD=0.44), (M=2.30, SD=0.84) and (M=2.35, SD=0.71), respectively. In the present study, chronic respiratory diseases account for the maximum burden in environment sub-scale (M=2.21, SD=0.81) (Table 1). Spearman's correlation coefficient was used to evaluate the relationship of caregiving burden with caregivers and children's characteristics. According to findings, there is an inverse significant relationship between children's age and caregiving burden in isolation sub-scale ($r = -0.126$, $p = 0.048$). In addition, the correlation of duration of disease with isolation was inverse and significant ($r = -0.221$, $p < 0.001$). Children's inability and their dependency on others in performing daily duties correlated positively and significantly with isolation ($r = 0.239$, $p < 0.001$), disappointment ($r = 0.181$, $p = 0.004$) and total caregiving burden ($r = 0.178$, $p = 0.005$). As well as this, the study showed a positive and significant correlation between caregivers' age

and environment ($r=0.145$, $p=0.022$) while the correlation of number of family members with isolation ($r=-0.140$, $p=0.028$), disappointment ($r=-0.174$, $p=0.006$) and total caregiving burden ($r=-0.156$, $p=0.014$) was inverse and significant. The relationship of reported economic status with disappointment ($r=-0.254$, $p<0.001$) and total caregiving burden ($r=-0.140$, $p=0.027$) was also inverse and significant. The correlation of caregiving duration with isolation ($r=-0.221$, $p<0.001$) and disappointment ($r=-0.126$, $p=0.047$) was negative and significant (Table 2). Mann-Whitney U test was used to assess the difference of caregiving burden and its dimensions in different caregiver and children groups. According to the obtained results, female caregivers bore higher caregiving burden than males only in general strain ($p=0.022$). Villager caregivers reported higher caregiving burden in disappointment sub-scale than city dweller caregivers ($p=0.036$). In addition, 34 caregivers were the caregivers of another member of their family besides the sick children, and they suffered higher pressure in general strain ($p=0.037$), emotional involvement ($p=0.048$) and total caregiving burden ($p=0.012$). This study showed no difference in caregiving burden experience between employed and unemployed caregivers and between healthy and ill caregivers. In addition, the children's sex had no effect on the degree of caregiving burden (Table 3).

Table 1. Levels of caregiving burden in different types of children's diseases

| Disease type | n (%) | CB Scale; Mean (SD) | | | | | |
|----------------|-----------|---------------------|-------------|----------------|-----------------------|-------------|-------------|
| | | General Strain | Isolation | disappointment | Emotional Involvement | Environment | Total Score |
| Thalassemia | 68 (27.3) | 2.23 (0.57) | 1.39 (0.48) | 1.81 (0.57) | 1.25 (0.34) | 2.00 (0.53) | 1.86 (0.38) |
| Cancer | 48 (19.3) | 2.45 (0.55) | 2.01 (0.76) | 2.15 (0.56) | 1.33 (0.46) | 2.17 (0.69) | 2.13 (0.42) |
| Epilepsy | 22 (8.8) | 2.34 (0.48) | 2.11 (0.98) | 2.01 (0.49) | 1.35 (0.52) | 2.11 (0.55) | 2.07 (0.37) |
| Anemia | 21 (8.4) | 2.17 (0.67) | 1.55 (0.75) | 1.77 (0.69) | 1.30 (0.39) | 1.78 (0.55) | 1.82 (0.53) |
| Diabetes | 15 (6.0) | 2.48 (0.46) | 1.24 (0.32) | 1.92 (0.49) | 1.29 (0.37) | 1.98 (0.51) | 1.95 (0.27) |
| COPD | 14 (5.6) | 2.58 (0.67) | 1.93 (0.89) | 1.97 (0.80) | 1.26 (0.47) | 2.21 (0.81) | 2.12 (0.59) |
| CRD | 10 (4.0) | 2.26 (0.75) | 1.83 (0.77) | 1.90 (0.85) | 1.23 (0.42) | 1.80 (0.42) | 1.92 (0.56) |
| CP | 9 (3.6) | 2.60 (0.44) | 2.30 (0.84) | 2.35 (0.71) | 1.37 (0.39) | 1.93 (0.62) | 2.24 (0.36) |
| Hypothyroidism | 9 (3.6) | 2.32 (0.37) | 1.11 (0.17) | 1.44 (0.51) | 1.07 (0.15) | 1.81 (0.47) | 1.72 (0.25) |
| Hemophilia | 9 (3.6) | 2.35 (0.77) | 1.48 (0.44) | 1.98 (0.46) | 1.41 (0.40) | 1.89 (0.17) | 1.95 (0.46) |
| Cardiovascular | 6 (2.4) | 2.44 (0.33) | 1.33 (0.52) | 1.90 (0.17) | 1.17 (0.18) | 1.78 (0.50) | 1.90 (0.17) |
| Other diseases | 18 (7.2) | 2.39 (0.55) | 1.72 (0.66) | 2.19 (0.51) | 1.50 (0.61) | 2.11 (0.62) | 2.10 (0.44) |
| Total | 249 (100) | 2.35 (0.57) | 1.67 (0.73) | 1.95 (0.60) | 1.30 (0.42) | 2.02 (0.58) | 1.98 (0.43) |

CB Scale: Caregiver's Burden Scale, M: Mean, SD: Standard Deviation, COPD: Chronic Obstructive Pulmonary Diseases, CRD: Chronic Renal Diseases, CP: Cerebral Palsy

Table 2. Factors related to caregivers/children and the levels of caregiving burden

| Variables | | CB Scale | | | | | |
|---------------------|---|----------------|-----------|----------------|-----------------------|-------------|-------------|
| | | General Strain | Isolation | Disappointment | Emotional Involvement | Environment | Total Score |
| Age of the child | r | 0.038 | -0.126 | -0.071 | 0.113 | 0.102 | -0.016 |
| | p | 0.546 | 0.048* | 0.264 | 0.075 | 0.107 | 0.806 |
| Duration of disease | r | -0.087 | -0.221 | -0.120 | 0.057 | 0.036 | -0.122 |
| | p | 0.173 | <0.001* | 0.059 | 0.374 | 0.574 | 0.055 |
| Child disability | r | 0.093 | 0.239 | 0.181 | 0.011 | 0.028 | 0.178 |
| | p | 0.145 | <0.001* | 0.004* | 0.861 | 0.657 | 0.005* |
| Age of caregiver | r | 0.095 | -0.059 | -0.099 | 0.052 | 0.145 | 0.013 |
| | p | 0.136 | 0.356 | 0.120 | 0.413 | 0.022* | 0.843 |
| Family number | r | -0.106 | -0.140 | -0.174 | -0.009 | -0.078 | -0.156 |
| | p | 0.096 | 0.028* | 0.006* | 0.890 | 0.218 | 0.014* |
| Level of education | r | -0.002 | 0.046 | -0.030 | -0.041 | -0.054 | -0.023 |
| | p | 0.976 | 0.471 | 0.635 | 0.519 | 0.400 | 0.716 |
| Family income | r | -0.059 | -0.061 | -0.254 | -0.020 | -0.091 | -0.140 |
| | p | 0.351 | 0.340 | <0.001* | 0.752 | 0.150 | 0.027* |
| Duration of care | r | -0.082 | -0.221 | -0.126 | 0.059 | 0.037 | -0.121 |
| | p | 0.195 | <0.001* | 0.047* | 0.356 | 0.560 | 0.057 |

CB Scale: Caregiver's Burden Scale, $p < 0.05^*$: correlations were statistically significant

Table 3. Levels of caregiving burden among different characteristics of caregivers/children

| Variables | | | CB Scale | | | | | |
|-----------------------------------|-----------|---------------------|----------------|-----------|----------------|-----------------------|-------------|-------------|
| | | | General Strain | Isolation | Disappointment | Emotional Involvement | Environment | Total Score |
| Caregiver sex | Mean rank | Male (n= 18) | 87.61 | 123.78 | 103.94 | 134.03 | 121.64 | 98.28 |
| | | Female (n= 231) | 127.91 | 125.10 | 126.64 | 124.30 | 125.26 | 127.08 |
| | U | - | 1406.0 | 2057.0 | 1700.0 | 1916.5 | 2018.5 | 1598.0 |
| | Z | - | -2.292 | -0.077 | -1.294 | -0.603 | -0.210 | -1.635 |
| | p | - | 0.022* | 0.939 | 0.196 | 0.546 | 0.834 | 0.102 |
| Child's sex | Mean rank | Male (n= 115) | 128.65 | 133.45 | 121.07 | 121.53 | 129.25 | 129.81 |
| | | Female (n= 134) | 121.87 | 117.75 | 128.37 | 127.98 | 121.35 | 120.87 |
| | U | - | 7285.5 | 6733.0 | 7253.5 | 7306.0 | 7216.0 | 7152.0 |
| | Z | - | -0.742 | -1.759 | -0.801 | -0.770 | -0.880 | -0.977 |
| | p | - | 0.458 | 0.078 | 0.423 | 0.442 | 0.379 | 0.329 |
| Employment | Mean rank | Employed (n= 57) | 120.94 | 129.16 | 126.99 | 134.06 | 136.98 | 127.47 |
| | | Unemployed (n= 192) | 126.12 | 123.85 | 124.45 | 122.49 | 121.68 | 124.32 |
| | U | - | 5046.0 | 5040.5 | 5157.5 | 4776.0 | 4618.0 | 5131.5 |
| | Z | - | -0.469 | -0.492 | -0.231 | -1.141 | -1.408 | -0.285 |
| | p | - | 0.639 | 0.623 | 0.818 | 0.254 | 0.159 | 0.775 |
| Residency | Mean rank | Urban (n=151) | 122.13 | 127.08 | 117.33 | 128.08 | 125.96 | 121.00 |
| | | Rural (n=98) | 129.43 | 121.79 | 136.82 | 120.26 | 123.53 | 131.16 |
| | U | - | 6965.0 | 7084.5 | 6240.5 | 6934.5 | 7254.5 | 6795.5 |
| | Z | - | -0.783 | -0.581 | -2.097 | -0.914 | -0.265 | -1.088 |
| | p | - | 0.433 | 0.561 | 0.036* | 0.361 | 0.791 | 0.277 |
| Caring of other person in family | Mean rank | Yes (n=34) | 148.93 | 146.41 | 140.72 | 145.74 | 140.18 | 153.99 |
| | | No (n=215) | 121.22 | 121.61 | 122.51 | 121.72 | 122.60 | 120.42 |
| | U | - | 2841.5 | 2927.0 | 3120.5 | 2950.0 | 3139.0 | 2669.5 |
| | Z | - | -2.089 | -1.913 | -1.376 | -1.974 | -1.348 | -2.527 |
| | p | - | 0.037* | 0.056 | 0.169 | 0.048* | 0.178 | 0.012 |
| Suffering from underlying disease | Mean rank | Yes (n=64) | 139.59 | 131.82 | 129.74 | 127.01 | 135.49 | 134.24 |
| | | No (n=185) | 119.95 | 122.64 | 123.36 | 124.31 | 121.37 | 121.80 |
| | U | - | 4986.0 | 5483.5 | 5616.5 | 5791.5 | 5248.5 | 5328.5 |
| | Z | - | -1.885 | -0.901 | -0.614 | -0.283 | -1.378 | -1.192 |
| | p | - | 0.059 | 0.367 | 0.539 | 0.777 | 0.168 | 0.233 |

CB Scale: Caregiver's Burden Scale, p < 0.05*: statistically significant values, Z: Value of Mann–Whitney U-test analysis for large groups, U: Value of Mann–Whitney U test analysis for small groups

4. Discussion

This study was conducted to determine the caregiving burden perceived by the caregivers of children with chronic diseases and to recognize factors increasing caregiving burden. In this study, the mothers of children with chronic diseases were generally playing the caregiver role where female caregivers experienced higher caregiving burden in general strain sub-scale than male ones. According to other studies, as the main and key caregivers, mothers accept higher responsibilities than other members of family and bear higher caregiving burden than fathers (4). Our findings showed that the mean caregiving burden score was 1.98, which is close to the moderate level. In the study of Rubira et al., and Cobos et al., the mean caregiving burden was obtained 2.02 (13) and 2.1 (4), respectively using this scale. The maximum and the minimum caregiving burdens were seen in general strain and emotional involvement sub-scales, respectively. General strain covers physical and emotional disturbances induced by caregiving activities, caregiving problems and required time for providing caregiving services. Cobos et al. reported the highest caregiving burden in general strain, while in the study of Rubira et al., it was seen in isolation (4, 13). The comparison of different diseases revealed that cerebral palsy accounts for the most burden in total scale and in general strain, isolation and disappointment sub-scales. In addition to motor disorders, children with cerebral palsy syndrome experience some degrees of mental, emotional and communication disorders. This, in turn, seriously limits their self-caring function (1). The study of Khana et al. showed that the caregivers of children with cerebral palsy bear severe financial loads and face several problems including interruption and disturbance in family interactions and leisure time activities, so that their routine activities are affected by caregiving affairs (2). The findings of our study revealed that those caregivers who were responsible for caregiving for a longer period,

experienced lower caregiving burden in isolation and disappointment sub-scales. It seems that they have found approaches to coping with their responsibilities and caregiving-induced limitations over time. Unlike our findings, there is evidence indicating that as the duration of disease increases, the caregiving burden and stress increases and their quality of life decreases (14). Another study showed that as the hospitalization time of children with cancer increases, their parents' depression increases (3). The average number of family members in our study was 4.59, and results showed a negative correlation between the number of family members with caregiving burden as well as isolation and disappointment so that as the number of family members increase, total caregiving burden, isolation and disappointment decrease. Previous studies offered dissimilar results, they suggested that family structure affects the perception of caregivers of their health status, and caregivers in nuclear families are more satisfied with their health status than extended families, and experience lower emotional stress (15). The results of a study showed that the increased number of offspring results in the isolation of caregivers and decreases their social activities. However, the social support provided by extended families decreases caregivers' responsibilities and stresses, and affects the health impacts of them (1, 14, 15). According to our study, the existence of other healthy children may decrease the disappointment of caregivers because their responsibilities on other children increase their social interactions, and in turn, decrease their caregiving burden. According to our findings, employed and unemployed caregivers experience the same caregiving burden while in the study of Rubira et al., unemployment increased caregiving burden in isolation sub-scale. In the study of Cobos et al., parents' employment status was the main parent-related factor affecting the pressure imposed on caregivers so that housekeeper mothers obtained higher scores in general strain, disappointment and isolation sub-scales. In addition, unemployed fathers experienced higher pressures in general strain and disappointment sub-scales (4, 13). In our study, all patients referred to public hospitals and clinics and benefited from insurance services, so that employment status and income of caregivers did not affect burden of care. In this study sample, the education level of more than half of participants was below diploma (58.2%) and only a small number of them had a university degree. This agrees with the results of Rubira et al. where 60% of their cases had only a primary school degree (13). Our study obtained no relationship between the education level of caregivers and caregiving burden. However, other studies indicate that mothers with higher education levels have reported lower caregiving burden (4). Medway et al. reported that higher education levels promote parents' confidence on managing the health problems of their children (16). Education is an important ability source. It affects the perception of caregivers of stressful factors, promotes their problem-solving ability and mental flexibility and affects their quality of life. It is possible that support systems and training received by caregivers in public centers could diminish the role of caregivers' education on experience of burden. In present study, most of the caregivers were healthy people (74.3%). Our study showed that those caregivers who suffer a chronic disease do not experience higher caregiving burden than healthy ones, while the results of another study showed that ill caregivers experience more stress and the extent of disappointment is higher in them (13). Similarly, Chen et al. reported that the likelihood of involvement in mental disorders and physical problems is higher in the caregivers of children with chronic diseases compared with normal individuals (17). This study showed that social isolation increases in the caregivers of younger children. According to other studies, the caregivers of younger children experience higher caregiving burden in social isolation, disappointment and environment sub-scales and bear more stress (4, 18). Younger children need continuous support. The higher dependency of them on parents causes caregivers to consume more time for caregiving activities. This limits their social activities and makes it impossible for them to achieve their life targets and plans. The disability level of children and their dependency on caregivers were other variables, which were in connection with total caregiving burden as well as isolation and disappointment sub-scales. Children with degrees of disability require more care, especially in performing daily duties so that in our study, children with cerebral palsy induced higher caregiving burden on their caregivers than other children. Despite the fact that our study showed no difference in caregiving burden between sexes, Jafari Manesh et al. reported that the parents of male children with chronic diseases experience higher anxiety levels. The reason may be traced in the difference of cultural beliefs between the two research places (3). The participants of this study were the caregivers of children with chronic diseases referred to public treatment centers for outpatients or follow-up purposes. However, the patients who refer to private centers may have different socio-economic features. Therefore, the findings of this study cannot be generalized to the total society of caregivers.

5. Conclusions

This study reported a close to moderate caregiving burden in caregivers of children with chronic diseases. Chronic diseases of children affect caregivers and their families. Therefore, the finding of this research can help health care providers in planning a holistic and family-centered program considering factors that increase burden of care. These interventions can maintain integration of families and promote caregivers' health, and as a result, improve quality of

care of children. Due to various factors affecting caregiving burden, further studies are recommended to investigate and compare burden of care in diverse societies with different characteristics.

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Conflict of Interest:

There is no conflict of interest to be declared.

Authors' contributions:

All authors contributed to this project and article equally. All authors read and approved the final manuscript.

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