

## Predictors of Caregiver Burden among Parents of Children with Cancer

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### Abstract

**Background:** Cancer is one of the most common diseases in children. Cancer in children can cause many problems for parents, and impose heavy care burden on them, which can lead to negative health consequences. The aim of this study was to determine caregiving burden and relevant influential factors among parents of children with cancer.

**Materials and Methods:** This cross-sectional descriptive study was done on 125 parents of children with cancer in oncology department of Shohada Hospital, Tehran, Iran, during March to August 2017. Caregiving burden was measured using the Caregiver Burden Scale. Descriptive statistics, independent-samples T test, one-way ANOVA, Pearson's correlation analysis, and multivariate linear regression analysis (stepwise method) were used in data analysis with SPSS software (v.19).

**Results:** The mean score of parents' care burden was  $52.76 \pm 10$ . Moreover, 17.6%, 71.2% and 11.2% of parents had low, moderate, and high care burden, respectively. Regression analyses indicated that the factors associated with care burden were cancer type (Acute myeloid leukemia ( $\beta=0.36$ ,  $p<0.001$ ) and Ewing sarcoma ( $\beta=0.16$ ,  $p=0.007$ )), the number of hospitalization ( $\beta=0.38$ ,  $p<0.001$ ), duration of disease ( $\beta=-0.31$ ,  $p<0.001$ ), parent's age ( $\beta=-0.29$ ,  $p<0.001$ ), parent's income ( $\beta=-0.23$ ,  $p<0.001$ ), and child's age ( $\beta=0.24$ ,  $p<0.001$ ). These variables accounted for 65% of the variance in care burden.

**Conclusion:** The result of this study demonstrated that most of parents of children with cancer had moderate levels of care burden. Different variables increased care burden in parents. Therefore, planning for holistic interventions to reduce care burden in parents and improve quality of care is necessary.

**Keywords:** Burden, Caregivers, Child, Cancer, Parent

### Introduction

Today, Cancer is one of the most common diseases, and cancer in children has been on the rise (1). Approximately, 300,000 children aged 0 to 19 years old are diagnosed with cancer each year (2). According to American Cancer Society Statistics, 10,590 children under 15 years of age in the United States were diagnosed with cancer in 2018 (3). Cancer is the second leading cause of death among

children aged between 5 and 14 years old in the United States (3). This is the third leading cause of death in children aged 1-14 years in Iran (4). About 4% of deaths in children under 5 years old and 13% of deaths in children aged 5 to 15 years are due to cancer in Iranian population (5). Having a child with cancer is a tragic event for the family (6). Parents of a child newly diagnosed with cancer feel distress and turmoil. Cancer diagnosis makes parents

feel their life is out of control (6, 7), and they often worry excessively about future events (8). Deficient information and skill, and the inability to provide proper care cause feelings of inadequacy and inability in parents. In addition, ongoing concerns about their child and the anticipation of unpredictable problems cause the feelings of instability and doubt in parents, and finally create confusion about caregiving among them (9).

On the other hand, the process of cancer treatment can be a stressful experience for parents and their children (10). The emergence of various complications associated with the illness and treatment greatly change patterns of family life, and the family tries to cope with new situations and needs (6,11). Parents of a child with cancer are often forced to change the lifestyle as well as some of their roles and general life responsibility (12). In addition, they experience severe emotional and physiological stress during the care process, which leads to physical and mental health problems. They feel sadness, depression, anxiety, and disappointment (9, 13-15), which can lead to negative health consequences and poor quality of life (9, 15-18). This can impose caregiving burden on parents (7).

Caregiver burden is defined as the physical, emotional, social, or financial problems that can be experienced by a person who cares for a chronically ill or disabled family member and characterized as the negative reaction in the caregiver (19, 20). However, healthcare professionals often focus on patients' problems, and often overlook families. While, caring is a serious challenge and a painful experience for parents, and they need help and support in this regard (21). Providing care in a difficult and traumatic situation will reduce the quality of patient care. Therefore, health planners should consider the challenges and sufferings faced by parents and try to eliminate them through appropriate plans (9).

Care burden in parents is influenced by many factors, including economic, social, and cultural factors (22-24). Considering adverse consequences of caregiver burden, exploring the pattern of care burden and its related factors in parents of children with cancer is crucial for improving supportive care services. However, there are few studies in the field of care burden and related factors in parents of children with cancer in Iran. Comprehensive and deep identification of the nature of caregiver burden plays an important role in designing health promotion program and improving quality of life of parents and their children. Therefore, this study aimed to determine the extent of caregiving burden in the parents of children with cancer and the relevant influential factors.

## Materials and Methods

This cross-sectional descriptive study was done on 125 parents of children with cancer in oncology department of Shohada Hospital, Tehran, Iran, during March to August 2017.

The parents were selected based on convenience sampling method.

This study was approved by the Research Ethics Committee of the Shahid Beheshti University of Medical Sciences (code number:

IR.SBMU.RETECH.REC.1395.1128). All participants were informed about the aims of the study, and signed the informed consent form.

Inclusion criteria were as follows: Having a child with cancer (age: less than 15 years old), having at least three months' experience of providing care to child, having the ability to read, and having no history of mental diseases. Participants who did not answer all the questions were excluded from the analysis.

The sample size was estimated to be 120 people (based on the findings of a pilot study). A total of 135 parents were asked to participate in this research, of whom 10 either did not return the form or failed to complete it in an appropriate way, so

finally the study participants consisted of 125 parents of children with cancer. Data were collected through two questionnaires by a trained registered nurse in the clinic. Parents answered the questionnaires in a private room. Completion of the questionnaires lasted 15-20 minutes, and the researcher was present beside the parents during the questionnaires completion, and answered their questions about the questionnaires.

### Instruments

#### Demographic- clinical questionnaire

This questionnaire consisted of two parts: "the parent's demographic information" included age, sex, education, marital status, economic status, received aid from state institutions. The demographic information and clinical features of the child included age, sex, cancer type, disease duration, hospitalization time, and treatment type (chemotherapy, radiotherapy, chemotherapy, radio therapy, and other treatments).

#### Caregiver Burden Scale (CBS)

The caregiver burden scale was developed by Elmstahl et al. (1996) comprising of 22 items in five components of general strain (8 items), isolation (3 items), disappointment (5 items), emotional involvement (3 items) and environment (3 items) (25). It assesses the suffering experience of the caregiver who had chronic diseases patients. The parents' responses were rated on a 4 point Likert scale (never: 1, rarely: 2, sometimes: 3, and often: 4). The overall score of the questionnaire vary from 22 to 88, which a higher score represent a higher perceived care burden. The questionnaire categorizes care burden in to three levels of low burden (22-43.99), moderate burden (44-65.99), and high burden (66-88) (25-27).

The reliability and validity of the Persian version of the CBS have been assessed by Farajzadeh et al in 2017. According to their study, its content validity is 0.82 and its reliability is between 0.74-0.9 in all sub-scales (27). In the present study, the

reliability of the CBI using Cronbach's alpha coefficient was 0.84.

### Statistical Analysis

Data analysis was conducted using SPSS (version 19). Descriptive statistics, independent-samples T test, one-way ANOVA, Pearson's correlation analysis, and multivariate linear regression analysis (stepwise method) were used in data analysis. . P value<0.05 was considered significant.

### Results

In this study, 125 parents of children with cancer in Oncology Department of Shohada Hospital in Tajrish, Tehran, Iran, were chosen. The mean age of parents and patients was  $40.16 \pm 5.23$  and  $7.56 \pm 3.14$  years old, respectively. Demographic characteristics of parents and patients are shown in Table I. Mean score of care burden of parents was  $52.76 \pm 10$ . Moreover, 17.6% of parents had low burden of care and 71.2 % and 11.2 % of them had moderate and high burden of care, respectively (Table II).

Multiple linear regressions (stepwise method) were used to determine the predictors of care burden in parents of children with cancer. Before regression analysis, independent t-test and one-way ANOVA tests were used to compare the mean score of the care burden in terms of dichotomous demographic and clinical variables (Table I). Then, significant demographic and clinical variables were entered into the regression models as independent variables. Furthermore, the relationship between the care burden and demographic and clinical variables were calculated in a correlation matrix by Pearson correlation coefficients. Based on Pearson's correlation coefficient results, a significant positive correlation was found between care burden and number of hospitalizations ( $r = 0.42$ ,  $P < 0.001$ ) and child's age ( $r = 0.17$ ,  $P = 0.04$ ). Moreover, a significant negative correlation was found between care burden and parent's age ( $r =$

0.38,  $P=0.002$ ) and income ( $r=-0.24$ ,  $P=0.006$ ) (Table III).

Finally, regarding the results given in Table I and Table III, the variables that had higher correlation possibility with the parent's care burden were introduced in to the regression model (stepwise method). Regression analyses indicated that the factors associated with care burden were cancer type (Acute myeloid leukemia (AML) ( $\beta=0.36$ ,  $p<0.001$ ) and Ewing sarcoma ( $\beta=0.16$ ,  $p=0.007$ )), the number of hospitalization ( $\beta=0.38$ ,  $p<0.001$ ), duration of disease ( $\beta=-0.31$ ,  $p<0.001$ ), parent's age ( $\beta=-0.29$ ,  $p<0.001$ ), parent's income ( $\beta=-0.23$ ,  $p<0.001$ ), and child's age ( $\beta=0.24$ ,  $p<0.001$ ). These seven variables accounted for 65% of the variance in care burden.. Regarding the arrangement of entering the variables in seventh model and the

standardized (beta) regression coefficient of the regression equation, number of hospitalization with standard beta 0.384 had the highest share in predicting changes in parent's care burden. Then, children with AML (compare to acute lymphoid leukemia (ALL) as reference category) with standard beta 0.365 played significant role in parents with care burden. In subsequent steps, duration of disease, parent's age, child's age, parent's income, and children with Ewing Sarcoma (compare to ALL as reference category) with beta -0.315, -0.293, 0.242, -0.235, and 0.162, in terms of prediction of care burden changes in parents of children with cancer, were placed in the next ranks, respectively (Table IV).

Table I: Levels of caregiving burden among different characteristics of parents/children (n=125)  $p<0.05^*$ 

			General strain	Isolation	Disappointment	Emotional involvement	Environment	Care burden (total score)
Variables		N(%)	M±SD	M±SD	M±SD	M±SD	M±SD	M±SD
child's sex	Girl	75 (60)	19.2933±3.85	7.26±2.18	12.17±3.22	7.93±2.32	7.10±1.9	53.77±10.46
	Boy	50 (40)	18.56±4.5	6.50±2.01	11.38±3.55	8.06±1.37	6.76±1.89	51.26±9.18
	P value		0.3	0.05	0.1	0.7	0.3	0.1
Type of cancer	AML	19 (15.2)	23.36±3.89	8.73±1.24	16.05±3.08	8.73±2.18	8.31±1.33	65.21±8.97
	EwingSarcoma	12 (9.6)	23.16±4.40	7.25±2.95	14.83±3.43	7.58±2.38	7.75±1.21	60.58±11.02
	ALL	43 (34.4)	17.79±2.69	6.81±1.85	10.62±1.57	7.53±2.2	6.69±1.72	49.46±7.11
	Osteo Sarcoma	40 (32)	17.25±3.49	6.17±2.06	10.55±2.94	8.07±1.55	6.45±1.99	48.5±7.52
	Other	11 (8.8)	18±2.82	7±2.19	10.9±2.8	8.54±1.43	6.72±2.45	51.18±6.33
	P value		<0.001*	0.001*	<0.001*	0.1	0.003*	<0.001*
Duration of disease	<12 month	68 (54.4)	19.73±4.11	7.11±2.11	12.36±3.38	7.79±1.86	7.07±1.96	54.08±10.08
	≥12 month	57 (45.6)	18.12±4	6.77±2.17	11.24±3.26	8.21±2.12	6.84±1.82	51.19±9.76
	P value		0.02*	0.3	0.06	0.2	0.4	0.1
Treatment type	Chemotherapy	14 (11.2)	20.14±4.81	6.28±2.05	12.5±4.43	8.35±2.79	7.35±1.59	54.64±13.55
	Radiotherapy	13 (10.4)	18.46±4.5	6.76±1.96	12±4.3	7.84±1.72	7.69±1.75	52.76±11.56
	Combination therapy	98 (78.4)	18.9±3.99	7.08±2.17	11.74±3.08	7.94±1.9	6.81±1.93	52.5±9.28
	P value		0.5	0.4	0.7	0.7	0.2	0.7
Parent	Mother	95 (76)	19.2421±4.3	6.8211±2.19	11.8211±3.44	8.0632±1.99	7.0526±1.94	53±10.34
	Father	30 (24)	18.2333±3.45	7.4000±1.94	11.9667±3.16	7.7333±1.99	6.7000±1.74	52.03±8.97
	P value		0.2	0.1	0.8	0.4	0.3	0.6
Marital status	Married	104 (83.2)	18.93±3.97	6.78±2.08	11.69±3.24	7.83±1.89	6.83±1.97	52.08±9.66
	Divorced	21 (16.8)	19.33±4.93	7.80±2.27	12.66±3.91	8.71±2.34	7.61±1.28	56.14±11.21
	P value		0.6	0.04*	0.2	0.06	0.02*	0.09
Educational level	<High School Diploma	89 (71)	18.8±4.24	6.77±2.18	11.58±3.43	8.19±2.07	7.06±2.01	52.42±10.71
	≥High School Diploma	36 (29)	19.47±3.84	7.41±1.9	12.52±3.13	7.47±1.68	6.72±1.56	53.61±8.07
	P value		0.4	0.1	0.1	0.06	0.3	0.5
Received aid from state institutions	Yes	16 (12.8)	20±3.59	6.87±1.2	11.5±2.39	7.75±1.57	6.00±2.03	52.12±7.01
	No	109 (87.2)	18.85±4.19	6.97±2.25	11.9±3.49	8.01±2.05	7.11±1.84	52.86±10.39
	P value		0.3	0.8	0.6	0.6	0.02*	0.7

Table II: Care burden mean and its domains in parents of children with cancer

Variables	M±SD
General strain	19±4.12
Isolation	6.96±2.14
Disappointment	11.85±3.36
Emotional involvement	7.98±1.99
Environment	6.96±1.89
Care burden (total score)	52.76±10

Table III: Factors related to parents/children and the levels of caregiving burden

CB Scale	Variables					
	Parent's age	Child's age	Parent's income	Number of hospitalizations	Duration of disease	
	r (p value)	r (p value)	r (p value)	r (p value)	r (p value)	
General strain	-0.35 (<0.001)*	0.06 (0.5)	-0.26 (0.003)*	0.33 (<0.001)*	-0.19 (0.02)*	
Isolation	-0.13 (<0.001)*	0.2 (0.02)*	-0.12 (0.1)	0.34 (<0.001)*	-0.08 (0.3)	
Disappointment	-0.33 (0.1)	0.13 (0.1)	-0.18 (0.04)*	0.32 (<0.001)*	10.16 (0.06)	
Emotional involvement	-0.2 (<0.001)*	0.11 (0.2)	-0.21 (0.01)8	0.14 (0.1)	0.1 (0.2)	
Environment	-0.27 (0.02)*	0.22 (0.01)*	-0.01 (0.8)	0.41 (<0.001)*	-0.06 (0.4)	
Care burden (total score)	-0.38 (0.002)*	0.17 (0.04)*	-0.24 (0.006)*	0.42 (<0.001)*	-0.14 (0.1)	
CB Scale: Caregiver's Burden Scale, p < 0.05*: correlations were statistically significant						

Table IV: Summery results of the multiple linear regression analysis by stepwise model with the care burden as dependent variable

Dependent variables	Summery model	Predictor		B	SE	β	t	p
Care burden	R=0.809	Constant		74.85	5.51	-	13.57	<0.001
	R <sup>2</sup> =0.655	Cancer type (ALL as Reference Category)	AML	10.12	1.65	0.365	6.12	<0.001
	Adj.R <sup>2</sup> =0.634		Ewing Sarcoma	5.48	2.00	0.162	2.73	0.007
	F=31.706	Number of hospitalizations		0.66	0.11	0.384	5.82	<0.001
	df1=7	Duration of disease		-6.30	1.27	-0.315	-4.94	<0.001
	df2=117	Parent's age		-0.56	0.11	-0.293	-4.76	<0.001
	P<0.001	Parent's income		-3.79	0.90	-0.235	-4.18	<0.001
		Child's age		0.76	0.18	0.242	4.06	<0.001

## Discussion

The results of this study indicated that majority of parents of children with cancer (71.2%) suffered from moderate level of care burden. In a study conducted by Motlagh et al., (2019) on parents of children with leukemia in Iran, 89% of parents reported moderate to high levels of care burden (28). In addition, Wang et al., (2017) in their study on parents of children with cancer in china reported 43.8% and 33.8% of parents had mild to moderate and moderate to severe burden, respectively (22). Shieh et al., (2012) in Taiwan, Yildiz et al., (2017) in Turkey, Salmani et al., (2016), and Ahmadi et al., (2018) in Iran studied caregivers of patients with cancer, and showed a moderate level of care burden in caregivers, that in line with the findings of the present study (29-32). However, there are different studies, which have reported a high level of care burden in the caregivers of patients with cancer (23, 33-36). This variation between the results can be due to methodological differences among the studies. However, it is clear that parents are suffering from care burden and it may be due to the length of treatment and the burden of responsibility. Many children with cancer receive most of the medical care at home, which puts a lot of burden on parents. Therefore, parents have to spend a lot of time and energy to care their children, which leads to reduction of their quality of life, and impose significant stress on them (18). A study by Nemati et al., (2018) indicated that caregivers of patients with cancer faced with challenges such as lack of knowledge and feeling inadequacy, inability, instability, hopelessness, and turmoil. They also discovered that caregivers of patients with cancer were always on standby and expected to hear the worst about their patient at any moment, influencing their health and imposing considerably care burden on them (9).

Results about predictors of care burden in parents indicated that type of cancer (AML

and Ewing sarcoma) played the most important role in predicting changes in care burden. In subsequent models, the number of hospitalization, duration of disease, parent's age, parent's income, and children's age had the highest predictive power of the parent's care burden, respectively. This finding is in line with that of Citlik Saritas et al.'s study (2017) and foster et al.'s study (2013), reporting significant difference between the care burden in caregivers of patients with cancer with respect to type of cancer (36, 37). In the current study, the parents of children with AML in the first model and with Ewing sarcoma in the second model had experienced a high level of care burden. Patients with AML often experience relapses and require aggressive treatment, such as induction chemotherapy, resulting in heavy caregiving burden for caregivers (16,38). Previous studies demonstrated that caregivers of patients with leukemia experience more care burden due to factors such as low chance of recovery in this group of patients, exacerbation of patient's status with progress of disease, lack of response to the treatment, and higher patient dependence on caregivers for daily life activities (16,39). In addition, previous studies indicated that Ewing sarcoma affected children and caregivers physically and psychologically although it is a rare malignancy in children and adolescents. They concluded that a holistic approach to address their needs and to provide comprehensive care is needed (40, 41).

The result of the current study showed a significant positive correlation between the number of hospitalizations and caregiver burden. Frequent hospitalizations of children with cancer and long-term care are stressful for the parents and can lead to reduction of their quality of life (42). This often occurs due to complications induced by cancer therapy and chemotherapy visits, which impose high financial burden on parents (43). Nemati et al. study (2018) indicated that frequent hospitalization of

patients with cancer and his long-term care, on the one hand, and lack of financial and social support, on the other create fatigue and distress, which impose them heavy caregiving burden

(9).

Results of the current study regarding duration of disease indicated that parents of children whose duration of illness was more than one year experienced lower caregiving burden in general strain sub-scale. In line with the present study, Given et al., (2005) also indicated that family caregivers of patients who were at initial stages of disease reported higher influence of the disease on their daily schedule (44). In addition, Piran et al., (2017) showed that the caregivers of children with chronic diseases, who were responsible for caregiving for a longer period, experienced lower caregiving burden in isolation and disappointment sub-scales (45). It seems that parents adapted with their child's illness and its related limitations over time, so they experienced less care burden. In this regard, Khademi et al., (2019) showed that the levels of care power of the mothers who had a child with cancer increased with increase of disease duration (46).

In the present study, younger parents reported significantly more caregiver burden. This finding is in line with that of others studies, reporting inverse correlation between age and caregiver burden (18, 22, 23, 28, 32). This may be related to the way parents adapt to their child's disease. Parents at young age have less life experience and they may not be able to adapt easily to this huge disaster. In addition, economic strength is usually weak in the young parents and they find it hard to maintain their employment (23), which definitely leading to increasing of caregiver burden.

In this study, care burden was associated with parent's income status. Parents who had a better financial status experienced less care burden. Wang et al., (2016) studied Chinese family caregivers of

patients with retinoblastoma and showed that the low monthly income of the family significantly increased the caregiver burden (23). These results are consistent with those of other studies, revealing an inverse relation between parents' income and burden of care (16, 17, 18, 22, 28, 29, 32). A poor economic situation is associated with high levels of care burden and severe financial loads in caregivers, which can be due to losing a job or high medical costs (47). On the other hand, as the economic situation improves, access to health care will increase; and the parents with high income can have better support from their families, so the caregiver burden decreases.

According to the present study, the caregivers of older children experienced higher caregiving burden in isolation and environment sub-scales as well as total caregiver burden score. In contrast, Piran et al., (2017) found that caregivers of younger children experienced higher caregiving burden in isolation sub-scale (45). The difference between the results can be attributed to the nature of cancer.

Sudden outbreaks of cancer have negative effects on parents and children, and older children usually have a greater understanding of the cancer, which may often leads to more psychological problems in their parents. While in other chronic diseases, as the child grows older, parents and children find more adaptation to disease and naturally experience lower care burden.

The findings of this study showed that divorced parents experienced higher caregiving burden in isolation and environment sub-scales. Actually, it seems that divorced people have to take care of their sick children alone and do not have the opportunity to meet their own needs, =naturally leading to increasing of caregiver burden. In this regard, Salmani et al., (2017) in their study on mothers of cancer children found a significant difference between caregiving burden in mothers who took care for their children



alone and mothers who were not alone(31). Previous studies also yielded that the increased number of caregivers could reduce caregiver burden (45,48). Current study, compared with previous studies, could identify predictive factors affecting caregiver burden. These variables accounted for 65% of the variance in care burden. However, a number of unknown factors are remained, and further studies to identify the trajectory of caregiver burden and influencing factors are required.

## Conclusion

This study demonstrated that mostly parents of children with cancer suffered from care burden. These findings underscore the need for health care providers to plan and implement holistic interventions to reduce care burden among parents of children with cancer and to improve the care quality of children. In addition, development of comprehensive care such as palliative and supportive care to improve quality of life of children and their caregivers is needed.

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## Conflict of interest

There is no conflict of interest.

## References

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2016. *CA Cancer J Clin* 2016; 66(1):7-30.

2. Steliarova-Foucher E, Colombet M, Ries LAG, Moreno F, Dolya A. International incidence of childhood cancer, 2001-10: a population-based registry study. *Lancet Oncol* 2017; 18(6):719-731.
3. Ritwik P. Dental care for patients with childhood cancers. *Ochsner J* 2018;18(4):351-357.
4. Khanali Mojen L, Rassouli M, Eshghi P, Sari AA, Karimooi MH. Palliative care for children with cancer in the Middle East: A comparative study. *Indian J Palliat Care* 2017; 23(4):379-386.
5. Lotfi Kashani F, Vaziri Sh, Ghaser Sh, Mousavi M, Hashemi M. The effectiveness of spiritual intervention on improving the quality of life of mothers of children with cancer. *Medic Ethic J* 2012; 4(11):125-149.
6. Khoury MN, Huijter HA, Doumit MA. Lebanese parents' experiences with a child with cancer. *Eur J Oncol Nurs* 2013; 17(1):16-21.
7. Altay N, Kilicarslan E, Sari C, Kisecek Z. Determination of social support needs and expectations of mothers of children with cancer. *J Pediatr Oncol Nurs* 2014; 31(3):147-153.
8. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA* 2014; 311(10):1052-1060.
9. Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scand J Caring Sci* 2018; 32(1):309-316.
10. Shamsi A, Azizzadeh Forouzi M, Iranmanesh S. Psychosocial risks among parents of children with cancer. *Iran J Pediatr Nurs* 2016; 2(3):44-55.
11. Panganiban-Corales AT, Medina MF. Family resources study: part 1: family resources, family function and caregiver strain in childhood cancer. *Asia Pac Fam Med* 2011; 10(1): 14-24.
12. Masa'Deh R, Collier J, Hall C. Parental stress when caring for a child with

- cancer in Jordan: a cross-sectional survey. *Health Qual Life Outcomes* 2012; 10(1):88-94.
13. Yakar HK, Pinar R. Reliability and validity of Turkish version of the caregiver quality of life index cancer scale. *Asian Pac J Cancer Prev* 2013; 14(7): 4415-4419.
  14. Nemati Dehkordi SH; Rassouli M; Ilkhani M; Baghestani AR. The spiritual challenges faced by family caregivers of cancer patients: A qualitative study. *Holist Nurs Pract* 2017; 31(2): 110-117.
  15. Abbasnezhad M, Rahmani A, Ghahramanian A, Roshangar F, Eivazi J, Azadi A, Berahmany G. Cancer care burden among primary family caregivers of Iranian hematologic cancer patients. *Asian Pac J Cancer Prev* 2015; 16(13):5499-5505.
  16. Deniz H, Inci F. The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheral stem cell transplantation. *J Psychosoc Oncol* 2015; 33(3):250-262.
  17. Rha SY, Park Y, Song SK, Lee CE, Lee J. Caregiving burden and the quality of life of family caregivers of cancer patients: the relationship and correlates. *Eur J Oncol Nurs* 2015; 19(4):376-382.
  18. Klassen AF, Raina P, McIntosh C, Sung L, Klaassen RJ, Odonnell M, et al. Parents of children with cancer: Which factors explain differences in health related quality of life. *Int J Cancer* 2011; 129(5):1190-1198.
  19. Zarit SH. Family care and burden at the end of life. *CMAJ* 2004; 170(12):1811-1812.
  20. Chiou CJ, Chang HY, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Arch Gerontol Geriatr* 2009; 48(3):419-424.
  21. Santo EA, Gaiva MA, Espinosa MM, Barbosa DA, Belasco AG. Taking care of children with cancer: evaluation of the caregivers' burden and quality of life. *Rev Latino-Am Enfermagem* 2011; 19(3):515-522.
  22. Wang J, Shen N, Zhang X, Shen M, Xie A, Howell D, Yuan C. Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China. *Support Care Cancer* 2017; 25(12):3703-3713.
  23. Wang LJ, Zhong WX, Ji XD, Chen J. Depression, caregiver burden and social support among caregivers of retinoblastoma patients in China. *Int J Nurs Pract* 2016; 22(5):478-485.
  24. Choi YS, Hwang SW, Hwang IC, Lee YJ, Kim YS, Kim HM, et al. Factors associated with quality of life among family caregivers of terminally ill cancer patients. *Psycho-Oncol* 2016; 25(2):217-224.
  25. Elmstahl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch Phys Med Rehabil* 1996; 77(2):177-182.
  26. Mashayekhi F, Jozdani RH, Chamak MN, Mehni S. Caregiver Burden and Social Support in Mothers with  $\beta$ -Thalassemia Children. *Glob J Health Sci* 2016; 8(12):206-212.
  27. Farajzadeh A, Akbarfahimi M, Maroufizadeh S, Rostami HR, Kohan AH. Psychometric properties of Persian version of the Caregiver Burden Scale in Iranian caregivers of patients with spinal cord injury. *Disabil Rehabil* 2018; 40(3):367-372.
  28. Motlagh ME, Mirzaei-Alavijeh M, Hosseini SN. Care Burden in Parents of Children with Leukemia: A Cross-Sectional Study in the West of Iran. *Int J Pediatr* 2019; 7(6): 9541-9548.
  29. Shieh SC, Tung HS, Liang SY. Social support as influencing primary family caregiver burden in Taiwanese patients with colorectal cancer. *J Nurs scholarsh* 2012; 44(3):223-231.
  30. Yildiz E, Karakas SA, Gungormus Z, Cengiz M. Levels of Care Burden and Self-efficacy for Informal Caregiver of

- Patients With Cancer. *Holist Nurs Pract* 2017; 31(1):7-15.
31. Salmani N, Sheikhpour R, Hashemi A, MirakhorAli M. Burden of Care Evaluation in Mothers of Cancer Children Admitted to Shahid Sadoughi Hospital, Yazd, Iran. *Iran J Ped Hematol Oncol* 2017; 7(1):16-24.
  32. Ahmadi M, Rassouli M, Karami M, Abasszadeh A, Poormansouri S. Care burden and its Related Factors in Parents of Children with Cancer. *Iran J Nurs* 2018; 31(111):40-51.
  33. Pashae S, Khalili A, Shirvani H, Valizadeh L, Joonbakhsh F. Investigation of time and effort required for care activities among parents of children with cancer in pediatric educational treatment center. *Health Sci* 2016; 5(9S):44-48.
  34. Salmani N, Ashketorab T, Hasanvand S. The burden of caregiver and related factors of oncology patients of shahvali hospital. *Adv Nurs Midwife* 2014; 23(84):11-17. (Persian)
  35. Maheshwari Preksha S, Kaur MR. Perceived social support and burden among family caregivers of cancer patients. *Int J Health Sci Res* 2016; 6(1):304-314.
  36. Saritas SC, Kavak F, Aksoy A, Saritas S. Examination of care burden of caregivers of oncology patients and the perceived social support form family. *Int J Caring Sci* 2017; 10(1):447-455.
  37. Foster RE, Bardos JI, Wilson TJ. The burden of caregiving in cancer: The status of clinical research. *Value Health* 2013; 16(7):8-10.
  38. LeBlanc TW, Wolf S, Davis DM, Samsa G, Locke SC, Steinhauer KE, et al. Symptom burden, quality of life, and distress in acute myeloid leukemia patients receiving induction chemotherapy: A prospective electronic patient-reported outcomes study. *J Clin Oncol* 2015; 33(15):e20702-e20702.
  39. Tamayo GJ, Broxson A, Munsell M, Cohen MZ. Caring for the Caregiver. *Oncol Nurs Forum* 2010; 37(1):E50-57.
  40. Gulia A, Byregowda S, Panda PK. Palliative care in musculoskeletal oncology. *Indian J Palliat Care* 2016; 22(3):244-251.
  41. Datta K, Choudhuri M, Guha S, Biswas J. Childhood cancer burden in part of eastern India-Population Based Cancer Registry data for Kolkata (1997-2004). *Asia Pac J Cancer Prev* 2010; 11(5):1283-1288.
  42. Frank NC, Brown RT, Blount RL, Bunke V. Predictors of affective responses of mothers and fathers of children with cancer. *Psycho-Oncol* 2001; 10(4):293-304.
  43. Warner EL, Kirchhoff AC, Nam GE, Fluchel M. Financial burden of pediatric cancer for patients and their families. *J Oncol Pract* 2014; 11(1):12-18.
  44. Given B, Wyatt G, Given C, Gift A, Sherwood P, DeVoss D, et al. Burden and depression among caregivers of patients with cancer at the end-of-life. *Oncol Nurs Forum* 2005; 31(6):1105-1117.
  45. Piran P, Khademi Z, Tayari N, Mansouri N. Caregiving burden of children with chronic diseases. *Electron Physician* 2017; 9(9):5380-5387.
  46. Khademi F, Rassouli M, Khanali Mojen L, Heidarzadeh M, Shirinabadi Farahani M, Borumandni N. Caring power of mothers who have a child with cancer and its predictors. *Iran J Ped Hematol Oncol* 2019; 9(3):173-183.
  47. Pagano E, Baldi I, Mosso ML, Montezemolo LC, Fagioli F, Pastore G, et al. The economic burden of caregiving on families of children and adolescents with cancer: a populationbased assessment. *Pediatr Blood Cancer* 2014; 61(6):1088-1093.
  48. Abbasi A, Shamsizadeh M, Asayesh H, Rahmani H, Hoseini sa, Talebi M. The relationship between caregiver burden with coping strategies in Family caregivers of cancer patients. *Iran J Psychiatry Nurs* 2013; 1(3):62-71.