Original Article

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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 ± 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

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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 under15 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 sever 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

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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 ± 5.23 and 7.56 ± 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 ± 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= -

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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) (β=0.36, p<0.001) and Ewing sarcoma (β=0.16, p=0.007)), the number of hospitalization (β=0.38, p<0.001), duration of disease (β=-0.31, p<0.001), parent's age (β=-0.29, p<0.001), parent's income (β=-0.23, p<0.001), and child's age (β=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).

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*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

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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^2=0.655	Cancer type (ALL as Reference Category)	AML	10.12	1.65	0.365	6.12	**<0.001**
	Adj.R^2=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**

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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

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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.

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