Care Burden in Parents of Children with Leukemia: A Cross-Sectional Study in the West of Iran

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Abstract

Background
Parental caregiver burden is an important priority in children's oncology researches. The present study aimed to determine care burden among parents of children with leukemia.

Materials and Methods
This cross-sectional study was conducted among a total of 209 parents of children with leukemia who referred to Dr. Mohammad Kermanshahi Hospital, Kermanshah city, in the West of Iran, in 2018. Parents were surveyed with the caregiver burden scale and baseline characteristics items based on interview. Pearson correlation, t-test, and ANOVA analysis at 95% significant level were used in data analysis with SPSS software version16.0.

Results
The mean of care burden score was 56.43 ± 9.32 and ranged from 0 to 88. 10.7%, 79.7%, and 9.6% of parents had low, moderate and high care burden, respectively. The higher care burden score was associated with the lower age of parents (r= -0.255, P < 0.001), higher educational level (P=0.028), and better economic status (P=0.001).

Conclusion
Our findings indicated that most of the parents of children with leukemia had moderate-to-high levels of care burden. Thus, health care providers are expected to be more available to respond to their requests and pay more attention to planning educational programs.

Key Words: Care Burden, Leukemia, Health Promotion, Iran, Parents.

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1- INTRODUCTION

Cancers (after accidents) are still the second leading cause of death among children aged between 5 and 14 years old (1, 2). Meanwhile, a common cancer in children is acute lymphoblastic leukemia and the cancer detection in childhood is a life changing event occurrence not only for the child but also for their families (3). In recent years the survival rate of children with cancer has increased; unfortunately, this increased rate of survival is followed by high medical costs, long hospitalization and psychological problems in the patient and their family (4). Today most of the medical care is shifting to the home which puts a lot of burden on family members, especially parents; accordingly, parental caregiver burden is an important priority in children's oncology research (5). Parents play an important role in the treatment process of their child such as the relationship with the medical team, and management of medication in their children (6). Caregivers have a several problems such as social pressures, relationships with relatives and psychological distress including stress, depression, anxiety, etc., which can have a negative effect on their quality of life (7).

Additionally, the presence of a child with cancer may lead to emotional instability, uncertainty and tension among family members (8). Syse et al. indicated parents of a child with cancer may lose their job because of the length of treatment and the burden of responsibility (9). Caregiver burden is the stress or strain which is perceived by caregivers due to the problems and challenges of caregiving; this is one of the most important predictors for negative outcomes of the care situation– for the caregivers themselves as well as for the patients; caregiver burden is a multidimensional response to stressors resulting from caregiving (10). Caregiver burden is a theoretical construct which the conceptual basis is the Transactional Model (TM); the subjective evaluation of the stress or strain by the caregivers is critical for the development and maintenance of subjective burden. According to the TM, people deal with stressful situations by appraisals of stressor and resources. The primary appraisal deals with the individual meaning of the specific stressor, which is the care situation in this case; the secondary appraisal analyzes their own abilities and resources to cope with that situation. On this basis, the individual coping efforts are used to deal with the stressful situation. These efforts can focus on problem management or emotional regulation. High caregiver burden often comes along with dysfunctional strategies which means activities which do not solve the problem, but worsen it (11). The misbalance between burden and resources of the caregiver determines the consequences of a care situation (12). This may be the feeling of being needed or the knowledge that they have acquired new skills (13).

Caring is a serious challenge for caregivers, and caregiver burden is seen when the caregiver is usually not trained and intensive adaptations to the variety of aspects of the care situation are necessary (12). Studies showed that four aspects caregiver burden arises from are: care requires much energy, desire for recovery, too little time for own interests and sadness over the fate of the supported person (14). The timely identification of care burden plays an important role in designing health promotion program in caregivers (15). Furthermore, several studies indicated the first step for designing and implementing health promotion program is determining the existing situation (16). The aim of this study was to determine the care burden in parents of children with leukemia in the West of Iran.

2- MATERIALS AND METHODS

2-1. Participants and Procedure

This cross-sectional study was conducted among 209 parents of children with Leukemia who were contacted by the oncology department in a children hospital in the west of Iran, during autumn and winter 2018. The parents were selected based on snowball sampling method in Dr. Mohammad Kermanshahi Hospital, Kermanshah city, in the West of Iran among parents of children with Pediatric Leukemia. Data were collected among parents referred to hospital for receiving treatment and medical care for their child.

2-2. Sampling

The sample size was calculated at 95% significant level based on the findings of a pilot study and a sample of 209 was estimated. A total of 209 parents were asked to participate in our research, 187 persons [125 female (66.8%), and 62 male (33.2%), mean age: 39.45 (SD: 7.60)] agreed and completed the questionnaire, giving an overall response rate of 89.4%.

2-3. Data Gathering

Parents filled out a standard questionnaire and data was collected among them based on interview including the background variables and Persian version of the caregiver burden scale components (20).

2-4. Inclusion and Exclusion Criteria

Only those parents who had children with leukemia were eligible to participate in this study and participants who did not answer all the questions were excluded from the analysis.

2-5. Measures

Questionnaire included 2 sections of 31 items; 9 items about baseline characteristics and 22 items about parents' caregiver burden.

2-5-1. Baseline Characteristics

The baseline characteristics assessed included: parent's age (year), child's age (year), years of disease diagnosis, parent's education level (under diploma/diploma/academic), parent's sex (male/female), and child's sex (male/female), economic status (weak, average, good), health insurance (yes/no), and family member size (three /four/five /more than five).

2-5-2. Caregiver Burden Scale (17, 18)

Caregiver burden scale (CBS) is a multi-component questionnaire which assesses the care burden of people who had chronic diseases patients. Caregiver burden was evaluated by 22-items in five components of 1) General strain, 2) Isolation, 3) Disappointment, 4) Emotional involvement, and 5) Environment (17, 18). Eight items measured general strain (e.g., do you find yourself facing purely practical problems in the care of your child that you think are difficult to solve?). Three items measured isolation (e.g., has your social life, for example with your friends and family been lessened?). Five items measured the disappointment (e.g., had you expected that life would be different than it is at your age?).

Three items measured emotional involvement (e.g., are you sometimes ashamed of your child's behavior?). Three items measured environment (e.g., do you worry about not taking care of your child in the proper way?). A 4-point Likert type scale, ranging from 1 (not at all) to 4 (often) was used, in which a higher score represented a higher perceived burden. The reliability coefficient for the Persian version of the caregiver burden scale reported by Farajzadeh et al. was between 0.698 and 0.740 (17). In addition, Estimated reliability using Cronbach's alpha coefficient for each care burden component scale was as follows: general strain (α= 0.79); isolation (α= 0.67); disappointment (α= 0.82); emotional

involvement (α= 0.72); environment (α= 0.71). Also, the reliability of total caregiver burden scale was 0.89.

2-6. Ethical Approve

Ethical approval was obtained from the Research Ethics Board of the Ahvaz Jundishapur University of Medical Sciences (IR.AJUMS.REC.1397.440).

2-7. Statistical Analysis

Data were analyzed using SPSS software version 16.0 with appropriate statistical tests. Descriptive analyses were performed on the socio-demographic variables to describe the research population. In addition, Pearson correlation was computed to ascertain the magnitude and direction of the associations between the caregiver burden components scores, as well as age. Furthermore, independent-samples T-test, and One-way ANOVA were performed to compare significant relationship between background variables and caregiver burden components. Moreover, Cronbach's alpha was used to estimate the internal consistency of the various measures. The level of significance was ($P < 0.05$).

3-RESULTS

Parents, children and average years of disease diagnosis mean age were 39.45 (SD: 7.60), 5.57 (SD: 2.41), and 2.28 (SD: 1.03) years, respectively. About 66.8% (125/187) of parents were female and 33.2% (62/187) were male. 47.1% (88/187) of children were female, and 52.9% (99/187) were male. Regarding the educational status 35.3% (66/187), 52.9% (99/187), and 11.8% (22/187) of parents were under diploma, diploma and academic education, respectively. 24.6% (46/187), 44.9% (84/187), and 30.5% (57/187) of the parents reported their economic status as weak, average, and good, respectively. 82.9% (155/187) of parents reported having health insurance, and 17.1% (32/187) of them do not have health insurance. Furthermore, 38.5% (72/187), 51.9% (97/187), and 9.6% (18/187) reported family member size as three, four, and five, and more than five, respectively. The mean, standard deviation (SD), and correlation of the various domain of care burden are shown in **Table.1**.

Table-1: The mean and correlation of the various domains of care burden among parents of children with leukemia

Domains of care burden	Mean (SD)	X1	X2	X3	X4	X5
X1. General strain	20.88 (3.82)	1				
X2. Isolation	8.23 (1.96)	$p < 0.001^*$ r= 0.553	1			
X3. Disappointment	14.13 (2.86)	$p < 0.001^*$ r= 0.632	$p < 0.001^*$ r= 0.555	1		
X4. Emotional involvement	7.17 (1.66)	$p < 0.001^*$ r= 0.529	$p < 0.001^*$ r= 0.398	$p < 0.001^*$ r= 0.605	1	
X5. Environment	6.00 (1.71)	$p < 0.001^*$ r= 0.326	$p =0.053$ r= 0.142	$p < 0.001^*$ r= 0.305	$p < 0.001^*$ r= 0.486	1
X6. Care burden	56.43 (9.32)	$p < 0.001^*$ r= 0.875	$p < 0.001^*$ r= 0.705	$p < 0.001^*$ r = 0.848	$p < 0.001^*$ r = 0.755	$p < 0.001^*$ r =0.528

*The significance level $p < 0.01$.

The relationship between background variables and the various domains care burden is shown in **Table.2**. Parents' educational level was significantly associated with the domains of disappointment, environment and total care burden. Also, economic status was associated significantly with the domains of general strain, disappointment, environment and total care burden. Furthermore, parents 'age had inverse and significant coloration with the general strain (r= -0.269, p < 0.001), disappointment (r= -0.154, p= 0.035), emotional involvement (r= -0.157, p= 0.035), environment (r= -0.290, p < 0.001), and total burden care (r= -0.255, p < 0.001), while it did not confer significant correlation with the isolation (r= -0.075, p= 0.308). In addition, 10.7% (20/187), 79.7% (149/187), and 9.6% (18/187) of parents had low, moderate, and high care burden, respectively.

Table-2: Relationship between background variables and the various domain of care burden in parents of children with leukemia

Variables		General strain Mean (SD)	Isolation Mean (SD)	Disappointment Mean (SD)	Emotional involvement Mean (SD)	Environment Mean (SD)	Care burden Mean (SD)
Parent gender	Female	21.21 (3.51)	8.30 (1.99)	13.88 (2.94)	7.14 (1.62)	5.95 (1.75)	56.49 (9.10)
	Male	20.22 (4.33)	8.09 (1.90)	14.64 (2.65)	7.22 (1.75)	6.11 (1.64)	56.30 (9.81)
	Independent-samples T-test	1.675	0.679	-1.726	-0.316	-0.603	0.131
	P-value	0.096	0.498	0.086	0.752	0.547	0.896
Children's gender	Female	20.67 (3.78)	8.35 (2.01)	13.95 (2.85)	7.00 (1.61)	6.14 (1.68)	56.12 (9.20)
	Male	21.08 (3.86)	8.13 (1.92)	14.29 (2.88)	7.32 (1.70)	5.87 (1.73)	56.70 (9.46)
	Independent-samples T-test	-0.732	0.768	-0.804	-1.329	1.071	-0.425
	P-value	0.465	0.443	0.422	0.185	0.286	0.671
Education level	Under diploma	21.63 (4.01)	8.16 (1.87)	14.80 (2.66)	7.54 (1.71)	6.74 (2.01)	58.89 (9.76)
	Diploma	20.54 (3.57)	8.19 (2.00)	13.65 (2.93)	6.97 (1.63)	5.70 (1.41)	55.08 (8.66)
	Academic	20.18 (4.13)	8.63 (2.05)	14.27 (2.86)	6.90 (1.50)	6.90 (1.50)	55.13 (9.73)
	One-way ANOVA	2.060	0.522	3.267	2.646	11.607	3.656
	P-value	0.130	0.594	0.040	0.074	< 0.001	0.028
Economic status	Weak	22.34 (3.40)	8.41 (2.21)	15.32 (2.78)	7.58 (2.02)	6.93 (2.19)	60.60 (9.59)
	Average	21.09 (3.75)	7.95 (1.78)	13.86 (3.11)	7.08 (1.65)	5.89 (1.62)	55.89 (9.24)
	Good	19.40 (3.78)	8.50 (1.96)	13.56 (2.26)	6.96 (1.26)	5.42 (0.96)	53.85 (8.15)
	One-way ANOVA	8.392	1.627	5.740	2.015	11.390	7.405
	P-value	< 0.001	0.199	0.004	0.136	< 0.001	0.001
Health insurance	Yes	20.87 (3.85)	8.20 (2.00)	14.11 (2.90)	7.14 (1.68)	5.90 (1.68)	56.25 (9.66)
	No	20.96 (3.72)	8.37 (1.75)	14.21 (2.74)	7.28 (1.57)	6.46 (1.83)	57.31 (7.51)
	Independent-samples T-test	-0.131	-0.442	-0.184	-0.410	-1.687	-0.585
	P-value	0.896	0.659	0.854	0.682	0.093	0.559
Family member size	Three	21.12 (3.04)	8.12 (1.97)	14.18 (2.49)	7.20 (1.45)	5.83 (1.50)	56.47 (8.24)
	Four and five	20.46 (4.34)	8.42 (2.01)	14.06 (3.29)	7.10 (1.89)	6.10 (1.85)	56.15 (10.52)
	More than five	22.22 (3.37)	7.66 (1.49)	14.33 (1.64)	7.38 (1.03)	6.16 (1.75)	57.77 (6.17)
	One-way ANOVA	1.848	1.317	0.083	0.251	0.597	0.229
	P-value	0.160	0.270	0.921	0.778	0.552	0.795

SD: Standard deviation.

4- DISCUSSION

The aim of this study was to determine the care burden among parents of children with leukemia in the West of Iran. Our results indicated that Parents'care burden of children with Leukaemia was at mild level. Additionally, the baseline characteristics of caregiver, including age, economic status and educational level had an influence on care burden. In this regard, several studies indicated that caregivers experience moderate-to-high levels of

burden (19-21). Ahmadi et al. carried out a cross-sectional study among parents of children with cancer in Tehran and indicated 17.6%, 71.8%, and 10.6% had little, moderate and severe burden, respectively (19). In addition, Wang et al. carried out a study on 130 parents of children with cancer in China and reported 13.08%, 43.85%, 33.84%, and 9.23% had little, mild-to-moderate, moderate-to-severe, and severe burden, respectively (20). Also, in line with our study, Kahriman and Zaybak carried out a research in İzmir, Turkey, and reported that the care burden score in caregivers of patients with cancer was at mild level (21).

Our result indicated about 89% of parents had moderate-to-high levels of care burden. These results can be a warning to health policy makers in Iran; and applicable strategies should be designed to reduce parents' care burden of child with cancer. Our results indicated the parents' educational level was a positive determinant for the lower care burden, which is in line with the findings of earlier studies investigating the care burden of family caregivers (22, 23).

In this regard, Rha et al. in their study on Korean family caregivers of cancer patients found quality of life of family caregivers was positively related to caregiver's high educational level (22). Economic status was another factor that had a significant statistical relationship with the care burden and parents who had a better economic status experienced less care burden. The serious economic burden is surely a key factor related with caregivers care burden (24-26). In this regard, Deniz and Inci in their study on 123 caregivers of cancer patients found care burden to be higher among low income parents (24). Wang et al. also conducted a research on 117 Chinese family caregivers of patients with retinoblastoma in China and showed that lower monthly income was associated with heavy caregiver burden (25). A concerned point in relation to the income of families of child with cancer is the probability of losing a job. In this regard, study on caregivers of child with acute lymphoblastic leukemia in North India indicated 34% of fathers lost their job (26). Our finding showed, parents with better economic status had lower care burden. The reason could be that high-income parents can have better support from their families. Moreover, they can choose better treatment for their child, which makes them less likely to experience stress and decreases their care burden. However, our study investigated economic status by using Likert (weak, average, and good) scale in order to more accurately analyze the need for validated financial burden tools for caregivers (20), which was one of the research limitations.

Therefore, more attention should be given when interpreting this finding. In our study the age was inversely correlated with caregiver burden. This finding is similar to those reported by other studies (20, 27). Maybe this can be attributed to the way parents adapt to their child's disease. It should be noted that the economic problems are usually higher in the younger age group which naturally affects on increasing caregiver burden. Also, younger parents may not have enough experience to use supportive resources.

4-1. Study Limitations

This study had potential limitations. First, our study was a cross-sectional study conducted on parents in one children's hospital in the West of Iran, and these can lead to bias or limit the generalization of our results. Second, the internal consistency of the questionnaire was relatively low ($\alpha= 0.67$) for assessing isolation. Third, the relatively small sample size is another limitation of our study. Fourth, the economic scale was limited by having only one item for identifying economic status of family.

Fifth, the high rejection rate is another limitation of this research.

5- CONCLUSION

The present study demonstrated that most of parents of children with leukemia had moderate-to-high levels of care burden. Parents with lower score of care burden tend to have higher age, better economic status and higher education level. Our findings could be critical in planning and implementing the reduction of care burden programs among parents of children with Pediatric Leukemia. Thus, health care providers such as doctors, nurses and psychologists are expected to be more available to respond to their requests and pay more attention to planning educational programs.

6- CONFLICT OF INTEREST: None.

7- ACKNOWLEDGEMENT

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