Original Article

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Burden of Care Evaluation in Mothers of Cancer Children Admitted to Shahid Sadoughi Hospital, Yazd, Iran

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Abstract

Background: In the process of cancer treatment, mothers of children with cancer experience burden of care as a result of these conditions. Early detection of burden of care has an important role in promoting health care. The aim of this study was to evaluate burden of care in mothers of children with a malignancy.

Materials and Methods: This cross sectional study was done on 70 mothers of children with cancer in Oncology Department of Shahid Sadoughi Hospital, Yazd, Iran, during December 2015-March 2016. The required data were collected demographic information and burden of care questionnaire. Statistical analysis was performed using T-test, ANOVA, Pearson and Spearman correlation coefficient**.**

Results: In this study, the mean age of mothers and children was 47.5 ± 8.54 and 5.3 ± 3.2 years old, respectively. Moreover, 12.9٪of mothers had low burden of care and 71.4٪ and 15.7٪of them experienced moderate to severe burden of care, respectively. An inverse relation (R=-0.322)was found between emotional burden of care and education as well as age of mothers($p<0.05$).There was significant difference between burden of care in mothers who received aid from government institutions and those who didn't receive help from state institutions($p<0.05$).Moreover, significant difference was seen between burden of care in mothers with special disease and mothers without special disease, and between mothers whose children had surgery and those didn't have surgery. Moreover, burden of care was observed in mothers who take care of affected child lonely and mothers who were not alone ($p<0.05$).

Conclusion: The result of this study showed that the majority of mothers of children with a malignancy had moderate to severe burden of care. Therefore, effective interventions are recommended to medical team members to reduce burden of care in mothers

Key Words: Cancer, Children Burden of care, Mother

Introduction

The incidence of cancer in childhood and adolescence is 100-150 cases per one million people(1) Treatment of cancer is a complex process and different treatments including chemotherapy, radiation therapy, surgery or combination of these methods are used to treat the disease. After treatment, children will experience different side effects including fatigue, anemia, apathy, loss of appetite, diarrhea, vomiting, but in spite of this complication, treatment should be continued to ensure successful therapy (2). The Care of a child with cancer is associated with enormous physical, psychological, social, and economic burden upon the family (3-5).Mothers often experience this burden, because they assume responsibility of care (6).Emotional and physical care of child increase the mother's workload and stress (7-10) and they may suffer fatigue, headache, backache, loss of appetite, digestive problems, and palpitations (11).Therefore, mothers experience many problems and burden of care. The "Burden of Care" is the unfavorable occurrence and defined as physical, psychological, and social care (12, 13). In fact, burden of care is defined as a

multidimensional biopsychosocial reaction (13). Today, burden of care is considered as an important priority in pediatric oncology research and parents and caregivers should assume greater responsibility for care and report status and child related complications to medical team. Therefore, study in this regard can the basis for the improvement of care and family practice(14).Moreover, early detection of burden of care in caregivers plays an important role in promoting health care (15). During recent decade, care teams of children with cancer consider cancer diagnosis and treatment as a harmful incident to parents (16). Furthermore, the impact of disease on the lives of caregivers is in priorities (17, 3).Since studies conducted in Iran in terms of burden of care is limited, the aim of this study was to evaluate the burden of care in mothers of children with cancer.

Materials and Methods

This cross-sectional study was done on mothers of children with cancer in Oncology Department of Shahid Saoughi Hospital, Yazd, Iran, during December 2015-March 2016. Mothers with literacy and psychological healthy who had cancer children diagnosed 3 months ago and experience at least 2 times hospitalization in Oncology Department. The study was approved by Ethics Committee of Research Center of Shahid Sadoughi University and mothers were provided written informed consent. In this study, 70 patients were chosen based on Cochran formula. Demographic information and burden of care questionnaire were taken from patients. Burden of care tool was designed by Elmstahl et al, in 1996(18).

In this study, the reliability and validity of this instrument based on the interclass correlation coefficient using Cronbach's alpha coefficient was 0.87. The questionnaire contains 22 items and 5scopes. It was numbered based on four point Likert scale including never (score 1) until most of the time (score 4). The mean score of 22 represents the total score of burden of care. The burden of care can be divided into three ranges. Score 22-43 is considered little burden of care, 44-65 and 65-88 are medium and sever burden of care, respectively. Moreover, 5 scope of this instrument are known, 1- the overall pressure (8 items) indicates lack of freedom caregiver and burden of care. 2-Soleness (3 items) reflects the limited social interactions and lack of special times for self-care.3-Disappointment (5 items) represents financial problem, soleness and physical suffering.4-Emotional difficulties (3 items) show anger and embarrassment. 5-Environmental problems (3 items) reflect the lack of experience and ability to deal with problems of patient care. Statistical analysis was performed using SPSS version 18. To examine the relationship between demographic characteristic and burden of care, Pearson and Spearman correlation coefficients were used. The burden of care mean according to demographic variables of mother and children was analyzed by Independent t-test and ANOVA.P-value<0.05 was considered significant.

Results

In this study, 70 mothers of children with cancer in Oncology Department of Shahid Sadoughi hospital, Yazd, Iran were chosen. Demographic characteristics of mothers are shown in Table I. The mean age of mothers and patients was 47.5 ± 8.54 and 5.3 ± 3.2 years old, respectively. Demographic characteristics of children are shown in Table II.Burden of care mean score and its components are presented in Table II.The result of this study showed that 12.9 ٪ of patients had low burden of care. Moreover, 71.4 ٪ and 15.7 ٪ of them had medium and high burden of care, respectively.

In this study, there was an inverse correlation between education and emotional burden of care in mothers (r=-0.275, p=0.023). Furthermore, there was

an inverse relation between the age of mother and emotional burden of care (r=-0.322, p=0.008). The burden of care mean score in mothers with different financial level was significant (p=0.006).

In addition, a significant difference was observed between mothers who received aid from government institutions and those who didn't receive aid from state institution (p= 0.027). The burden of care mean score was significant between mothers who took care of a affected child lonely and mothers who were not alone (p=0.035). Also, the burden of care mean score was different between mothers with special disease and mothers without special disease (p=0.05). There was significant difference regarding burden of care between mothers whose children had surgery and those didn't have surgery (p=0.021).

Table I: Mother's demographic variable

Variable	Group	Percent	F	Frequency
Job	Housewife	72.9		51
	Employee	8.6	6	6
	Labor	8.6	6	6
	Other	10	7	7
Education	High School	38.6	2	27
	High school Diploma	34.3	24	24
	College Education	27.1		19
Financial Education	Weak	32.9		23
	Moderate	55.7		39
	Well	11.4		8
Received aid from state institutions	Yes	67.1	47	47
	No	32.9		23
take care of sick child lonely	Yes	77.1	54	54
	No	22.9		16 16
Take care for another person other than sick child	Yes	20		14
Special disease	No	80		56
	Yes	18.6		13
	No	81.4		57

Table II: Demographic characteristic of children with cancer

Type of cancer	ALL	68.6	48
	AML	7.1	5
	lymphoma	7.`1	5
	Other	17.2	12
Duration of disease	Less than a year	51.4	36
	1-3 years	18.6	13
	4-6 years	14.4	10
	More than 6 years	15.6	11
Number of hospitalization	1-3 times	31.4	22
	4-6 times	12.9	9
	7-10 times	11.4	8
	More than 10 times	44.3	31
Relapse	Yes	44.3	31
	No	55.7	39
Relapse Rate	No times	55.7	39
	Once	15.7	11
	Twice	8.6	6
	3 times	8.6	6
	Four times	11.4	8
Surgery due to illness	Yes	33.86	27
	No	61.4	43
Hospitalization in intensive care due to illness	Yes	35.8	25
	No	64.2	45

Table III: Burden of care mean and its scopes in mothers of children with cancer

Variables	Variable
Burden of care	54.71± 11.27
overall pressure	19.21± 5.28
Disappointment	12.49± 3.12
Loneliness	8.46± 2.74
Emotional factor	6.24± 2.55
Environmental factor	8.31± 2.02

Table IV: Burden of care comparison in mothers of children with cancer.

Variable	Mean ±SD (burden care)	Groups	p-value
Financial level	59.04± 8.8	Weak	0.006
	54.72± 10.7	Moderate	
	42.40±13.7	Well	
Received aidfrom state institutions	50.43± 11.1	Yes	0.02
	56.85±10.6	No	
take care of sick child lonely	56.78±10.2	Yes	0.03
	50.31±10.2	No	
Special disease of mothers	61.30±11	Yes	0.05
	53.91±0.60	No	
Child surgery due to illness	59.16± 10.10	Yes	0.02
	52.81± 11	No	

Discussion

The result of this study showed that in cancer treatment process, majority of mothers of childrenexperiencedmoderate tosevere burden of care. Valizadeh et al, reported that severe burden of care was observed in parents of children with cancer (19). Yamazaki et al reported that mothers of children with leukemia had low quality of life and didn't have psychological and social performance (20). Salvador et al, in their study showed that parents of children with cancer have severe burden of care (21).The results of literature review revealed that parents of children with cancer in different society have similar status and endure severe burden of carewhichcan be due to factors including complications of the disease, concernofthe disease process and recovery.

In the current study, the relationship between demographic variables with burden of care showed an inverse relation between education levels and emotional burden of care.Mashayekhi et al., in their study reported that mothers of children with thalassemia andlow educational level experienced severe burden of care (22). Other researchers like lee et al., in Thailand, Zahidetal, in kuwait, Adeosun et al., in Nigeria showed that parents with low level of education experienced severe burden of care (23-25).

The relationship between demographic variables with burden of care represented an inverse relationship between emotional burden of care with age, but the result of other studies are different.for instance, Mashayekhi et al reported that increased age of mothers of children with thalassemia is associated with severe burden of care and hold that this can be due to heredity of disease at birth (22).

However, in a study by Zahid et al., an inverse relation between age and burden of care in caregivers of patients with AIDS was observed (24). Agrenet al.,have not observed any relation between age and burden of care in patients with heart failure (26). It seems that these differences can be due to disease condition including acute and chronic disease, caregiver's age, patient's age, and burden of care.

In this study, only emotional burden of carewas related to age of mothers.In fact, with increased age, mothers felt fewer shame, embarrassment, and anger for disease of their child.This may be due to gradual adaptation of mothers with disease condition.

Moreover, there was significant difference regarding burden of care between mothers with high financial status and low financial status in a way that the latter experienced higher burden of care.Mashayekhi et al, reported an inverse relation betweenincome and burden of care (22). Lee and Carlo reported that people without sufficient income endure extra burden of care (23, 27),butzahidet al.,have not observed a relation between income and burden of care among caregivers(24). It seems that these differences are due to different socio-cultura factors and per capita income families.Another result of this study showed a significant difference between burden of care in mothers who took care ofaffectedchild aloneandmothers who took care her child with someone else.Abbasiet al., and Hanzawaet al., demonstrated caregiver can help mothersin reducing the burden of care (28, 29), because care of patients causesmother spend all their time and don't have the opportunityto meet their own needs. Therefore, burden of care is increased (30).

In addition, it was found that the mothers' kind of disease mayplay an important role in burden of care.. Abbasiet al.,reported that disease in the caregiver is considered as a risk factor for increased burden of care(28).

Assistance from government institution is considered as another variable which affects the burden of care. On the other hand, financial support from friends and family can help parents' adjustment to financial stress and burden of care (31). Lack of support can lead to financial weakness (32) and stress in family

relationship (33). These events caused increased burden of care, especially in families who was notcovered by insurance(34).

Moreover, mothers of children with surgery had increased burden of care.Abbasi et al., reported that patient's dependence to personal activities can be effective in burden of care (28). Bartolo et al, revealed an inverse relation between patient's functional independence and quality of life with burden of care in caregivers (35).Actually, it seems that child surgery during the process of disease as a medical method can lead to increased dependence sick child to motherso that mothers experience increased burden of care.

Conclusion

Given that the large majority of mothers experienced moderate to severe burden of care, it is essential that health caregivers provide care for affected children. Also, identification of vulnerable women including mothers with low education, mothers who alone bear the burden of care and mothers who do not receive aid from any institutionreduced the burden of care on mothers. Realization of this issue requires full cooperation among health care providers including physicians,nurses, psychologists, and social workers.

One of the limitations of this study can be related to small samplesize who was gathered from one center in Yazd. Further studiesare recommended with larger sample size.

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