

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

Naiire Salmani <sup>1,\*</sup>, Robab Sheikhpour <sup>2,3</sup>, Azam Hashemi <sup>1</sup>, Mahnaz MirakhorAli <sup>4</sup>

1. Assistant professor, Department of Nursing and Midwifery, Shahid Sadoughi University of Medical Science, Yazd, Iran

2. Department of Physical activity and Sport Science, Taft Branch, Islamic Azad University, Taft, Iran

3. Hematology and Oncology Research Center, Shahid Sadoughi University of Medical Science, Yazd, Iran

4. Department of Pediatrics, Shahid Sadoughi University of Medical Science, Yazd, Iran.

\*Corresponding author: Naiire Salmani. Assistant professor, Department of Nursing and Midwifery, Shahid Sadoughi University of Medical Science, Yazd, Iran. E-mail: n.salmani@sbmu.ac.ir.

Received: 15 April 2016

Accepted: 10 August 2016

### 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  $47.5 \pm 8.54$  and  $5.3 \pm 3.2$  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 be 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 5 scopes. 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  $47.5 \pm 8.54$  and  $5.3 \pm 3.2$  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
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 $\pm$ SD (burden care)	Groups	p-value
Financial level	59.04 $\pm$ 8.8	Weak	0.006
	54.72 $\pm$ 10.7	Moderate	
	42.40 $\pm$ 13.7	Well	
Received aid from state institutions	50.43 $\pm$ 11.1	Yes	0.02
	56.85 $\pm$ 10.6	No	
take care of sick child lonely	56.78 $\pm$ 10.2	Yes	0.03
	50.31 $\pm$ 10.2	No	
Special disease of mothers	61.30 $\pm$ 11	Yes	0.05
	53.91 $\pm$ 0.60	No	
Child surgery due to illness	59.16 $\pm$ 10.10	Yes	0.02
	52.81 $\pm$ 11	No	

## Discussion

The result of this study showed that in cancer treatment process, majority of mothers of children experienced moderate to severe 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 care which can be due to factors including complications of the disease, concern of the 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 and low educational level experienced severe burden of care (22). Other researchers like Lee et al., in Thailand, Zahid et al, 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). Agren et 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 care was 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 between income and burden of care (22). Lee and Carlo reported that people without sufficient income endure extra burden of care (23, 27), but Zahid et 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-cultural factors and per capita income families. Another result of this study showed a significant difference between burden of care in mothers who took care of affected child alone and mothers who took care of her child with someone else. Abbas et al., and Hanzawa et al., demonstrated caregiver can help mothers in reducing the burden of care (28, 29), because care of patients causes mother spend all their time and don't have the opportunity to meet their own needs. Therefore, burden of care is increased (30). In addition, it was found that the mothers' kind of disease may play an important role in burden of care. Abbas et 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 not covered 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 mothers so 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 institution reduced 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 sample size who was gathered from one center in Yazd. Further studies are recommended with larger sample size.

## Acknowledgments

This study is the result of approved project by the Hematology and Oncology Research Center of Shahid Sadoughi University of Medical Sciences. We are thankful of the staff in pediatric Oncology Ward of Shahid Sadoughi Hospital for their kind cooperation in this study. We also acknowledge the sincere cooperation of all mothers of children with cancer who participated in this study.

## References

1. Michaud P-A, Suris J-C, Viner R. The adolescent with a chronic condition: epidemiology, developmental issues and health care provision. 2007.
2. Rubira EA, Marcon SR, Belasco AGS, Gaiva MAM, Espinosa MM. Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer. *Acta Paul Enferm* 2012;25(4):567-73.
3. Ortiz MCA, Lima RAGd. Experiences of families with children and adolescents after completing a cancer treatment: support for the nursing care. *Latino-Am. Enfermagem* 2007;15(3):411-7.
4. Moreira PL, Angelo M. Becoming a mother of a child with cancer: building motherhood. *Latino-Am. Enfermagem* 2008;16(3):355-61.
5. Elcigil A, Conk Z. Determining the burden of mothers with children who have cancer. *DEUHYO ED* 2010, 3(4), 175-181
6. Chiou CJ, Chang H-Y, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Arch Gerontol Geriatr*. 2009;48(3):419-24.
7. Smith BA, Kaye DL. Treating Parents of Children With Chronic Health Conditions: The Role of the General Psychiatrist. *Focus* 2012;10(3):255-65.
8. Rahimi S, Fadakar Soghe K, Tabari R, Kazem Nejad Lili E. Relationship between Mother's General Health Status with Quality of Life of Child with Cancer. *hayat* 2013;19(2):93-108.
9. Ferro MA, Boyle MH. The impact of chronic physical illness, maternal depressive symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *J Abnorm Child Psychol* 2015;43(1):177-87.
10. Graziano S, Rossi A, Spano B, Petrocchi M, Biondi G, Ammaniti M. Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-

- threatening chronic disease A pilot study. *J Child Health Care* 2016;20(2):174-84.
11. Ayfer Elcigil, Zeynep Conk. Determining the Burden of Mothers with Children Who Have Cancer. *DEUHYO ED* 2010, 3(4), 175-181.
  12. Zarit SH. Family care and burden at the end of life. *CMAJ*. 2004;170(12):1811-2.
  13. Lu L, Wang L, Yang X, Feng Q. Zarit Caregiver Burden Interview: development, reliability and validity of the Chinese version. *Psychiatry and Clinical Neurosciences* 2009;63(6):730-4.
  14. Wells DK, James K, Stewart JL, Moore IMK, Kelly KP, Moore B, et al. The care of my child with cancer: A new instrument to measure caregiving demand in parents of children with cancer. *J Pediatr Nurs* 2002;17(3):201-10.
  15. Abbasi A, Ashrafrezaee N, Asayesh H, Shariati A, Rahmani H, Mollaei E, et al. THE RELATIONSHIP BETWEEN CARING BURDEN AND COPING STRATEGIES IN HEMODIALYSIS PATIENTS CAREGIVERS. *J Urmia Nurs Midwifery Fac* 2012;10(4):532-539.
  16. Kazak AE, Boeving CA, Alderfer MA, Hwang W-T, Reilly A. Posttraumatic stress symptoms during treatment in parents of children with cancer. *J Clin Oncol.* 2005;23(30):7405-10.
  17. Moreira PL, Angelo M. Tornar-se mãe de criança com câncer: construindo a parentalidade. *Rev. Latino-Am. Enfermagem* 2008.16(3):355-361.
  18. Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of physical medicine and rehabilitation* 1996;77(2):177-82.
  19. Valizadeh L, Joonbakhsh F, Pashaei S. Determinants of care giving burden in parents of child with cancer at Tabriz children medical and training center. *J Clin Nurs Midwifery*. 2014;3(2):13-20.
  20. Yamazaki S, Sokejima S, Mizoue T, Eboshida A, Fukuhara S. Health-related quality of life of mothers of children with leukemia in Japan. *Qual Life Res* 2005;14(4):1079-85.
  21. Salvador A, Crespo C, Martins AR, Santos S, Canavarro MC. Parents' perceptions about their child's illness in pediatric cancer: Links with caregiving burden and quality of life. *Journal of Child and Family Studies* 2015;24(4):1129-40.
  22. Mashayekhi F, Rafati S, RAFATI F, Pilehvarzadeh M, MOHAMMADI SM. A study of caregiver burden in mothers with thalassemia children in Jiroft. *Mod Care J* 2014, 11(3): 229-235
  23. Lee SJ, Li L, Jiraphongsa C, Rotheram-Borus MJ. Caregiver burden of family members of persons living with HIV in Thailand. *Int J Nurs Pract* 2010;16(1):57-63.
  24. Zahid MA, Ohaeri JU. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC psychiatry* 2010;10(1):1.
  25. Adeosun II. Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophrenia research and treatment* 2013;2013:1-8.
  26. Ågren S, Evangelista L, Strömberg A. Do partners of patients with chronic heart failure experience caregiver burden? *Eur J Cardiovasc Nurs* 2010;9(4):254-62.
  27. Garlo K, O'Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. *J Am Geriatr Soc* 2010;58(12):2315-22.
  28. 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. *IJPN* 2013;1(3):62-71.
  29. Hanzawa S, Tanaka G, Inadomi H, Urata M, Ohta Y. Burden and coping strategies in mothers of patients with



schizophrenia in Japan. *Psychiatry Clin Neurosci* 2008;62(3):256-63.

30. Chang H-Y, Chiou C-J, Chen N-S. Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriatr* 2010;50(3):267-71.

31. Warner EL, Kirchhoff AC, Nam GE, Fluchel M. Financial burden of pediatric cancer for patients and their families. *JOP* 2014;155(98):1-7.

32. Ramsey S, Blough D, Kirchhoff A, Kreizenbeck K, Fedorenko C, Snell K, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)* 2013;32(6):1143-52.

33. Amir Z, Wilson K, Hennings J, Young A. The meaning of cancer: implications for family finances and consequent impact on lifestyle, activities, roles and relationships. *Psycho-Oncology* 2012;21(11):1167-74.

34. Baldwin LM, Cai Y, Larson EH, Dobie SA, Wright GE, Goodman DC, et al. Access to cancer services for rural colorectal cancer patients. *J Rural Health* 2008;24(4):390-9.

35. Bartolo M, De Luca D, Serrao M, Sinforiani E, Zucchella C, Sandrini G. Caregiver burden and needs in community neurorehabilitation. *J Rehabil Med* 2010;42(9):818-22.