Original Article

Caregiver burden and related factors in Iranian mothers of children with Attention-Deficit Hyperactivity Disorder

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Background: Literature indicates high levels of burden in primary caregivers of children with attention-deficit hyperactivity disorder (ADHD). Identifying the related factors might help in planning the interventions to reduce it. **Objective:** This study aimed to identify the caregiver burden and its related factors in Iranian mothers with children suffering from ADHD. Methods: In this correlational study, 246 mothers with children and adolescents suffering from ADHD referred to psychiatric clinics of Tabriz University of Medical Sciences were included through a convenient sampling method. Data were collected using a demographic information form, Zarit Burden Interview, Swanson Nolan and Pelham Parent Rating Scale-IV, and the Kiddie Schedule for Affective Disorders and Schizophrenia-present and lifetime version. Data were analyzed using descriptive statistics, t-test, Pearson's correlation coefficient, analysis of variance, and multiple linear regression analysis. **Results:** A majority of children (66%) were in the combined subtype. The mean of the disorder severity was 1.91 ± 0.79 , 1.76 ± 0.70 , and 1.81 ± 0.61 in impulsive, inattentive, and combined subtypes, respectively. The mean of mothers' caregiver burden was 40.43 ± 1.38 . A significant relationship was found between the mean severity of the disorder subtypes and caregiver burden. The correlation coefficient was 0.36, 0.29, and 0.29 for the impulsive, inattentive, and combined subtypes, respectively. The mother's age, existence of ADHD in the child's brother, family member's cooperation in caregiving, and the child's birth rank could significantly predict the caregiver burden. Conclusion: Given the role of family-related factors in the burden of care in mothers of children with ADHD, family-centered care and home visits are recommended to assist mothers of these children.

Keywords: Attention-deficit hyperactivity disorder, Burden of illness, Caregiver, Mother

INTRODUCTION

Attention-deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder with a global prevalence of 5.3–7.1%.^[1] It is mainly characterized by inattention, hyperactivity, and impulsivity.^[2] This disorder not only affects the individual but also influences the immediate social environment, especially the school and family.^[3]

Parents of children with ADHD endure worse economic, social, and health conditions than parents who have

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Quick Response Code:	Website: www.nmsjournal.com	
	DOI: 10.4103/nms.nms_83_19	

healthy children. The probability of having a psychiatric diagnosis in mothers of children with ADHD is twice greater than that of others. In addition, these mothers experience 7%–13% less chance to be employed in the

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For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com Submitted: 10-Oct-2019 Accepted: 03-Mar-2020 Published: 17-Jul-2020

How to cite this article: Mostafavi M, Namdar Areshtanab H, Ebrahimi H, Vahidi M, Amiri S, Norouzi S. Caregiver burden and related factors in Iranian mothers of children with attention-deficit hyperactivity disorder. Nurs Midwifery Stud 2020;9:149-56.

labor market.^[4] The chronic nature of ADHD increases the amount of pressure on family members and deteriorates the caregivers' health.^[1]

A study in Nigeria found that, respectively, 26.4%, 36.2%, and 31.9% of caregivers of children with ADHD experienced severe, moderate, and mild burden, while only 7.3% reported no burden.^[5] Another study reported that the majority of parents of children with ADHD experienced no burden, however, higher levels of caregiver burden were associated with the behavioral problems presented by the children.^[6]

Compared to fathers, mothers have more responsibility in caring for children with ADHD; have more interactions with health-care providers, teachers, and school staff;^[7] and therefore experience more burden^[5,8] and emotional pressure. Studies show that these mothers experience more depression, fatigue, and feelings of hopelessness, guilt, and embarrassment,^[9] which consequently decrease their well-being,^[10] physical health,^[11] and quality of life^[12] and increase their fear of future.^[13] Such conditions not only diminish mothers' adaptation^[9] but also the quality of care they provide for their child.^[14]

of studies examined А number have the sociodemographic factors affecting the caregiving burden.^[15,16] Others highlighted the effect of support systems^[16] and factors associated with the child such as the severity of symptoms and the disease duration.^[17] Most of these studies have been conducted in Western countries. In a study of children with cerebral palsy, child behavior, experiential avoidance, and parental coping style were the main predictors of caregiver burden experienced by parents.^[18] In another study, the perceived caregiver burden was different in various subtypes of the disorder.^[15] A study on mothers of children with ADHD and some comorbid disorders also reported that these mothers experienced the highest levels of depression, stress, and caregiver burden than mothers whose children did not have comorbid conditions.^[16]

A number of studies in Iran have investigated the burden of care among caregivers of adults with mental disorders,^[19] spinal injuries,^[20] and children with chronic disorders^[17,21] and cancer.^[22] However, no Iranian studies are available on the burden of care among parents of children with ADHD. Due to the prevalence of ADHD, the association between the quality of care and health concerns of parents, and due to the effects of caregivers' culture on how they experience caring,^[23,24] it is crucial to conduct studies to assess the burden of care and its associated factors in caregivers of children with ADHD.

Identifying the severity of caregiver burden and its associated factors in any cultural context increases the sensitivity of health-care providers, especially nurses, and helps them provide better and individualized support for the caregivers of children with ADHD. Then, the caregivers and especially mothers of children with ADHD would be able to do their best in caring for their children with ADHD.

Objectives

This study aimed to identify the caregiver burden and relating factors among Iranian mothers with children suffering from ADHD.

Methods

Study design and participants

This descriptive correlational study was conducted from December 2017 to March 2018 on mothers of children with ADHD, who referred to Razi, Sheikh-o-Raees, and Asad Abadi psychiatric clinics of Tabriz University of Medical Sciences, Tabriz, Iran.

The sample size was calculated using the results of a former study,^[25] in which the mean \pm standard deviation (SD) of caregiver burden in the caregivers of children with ADHD was 63.64 \pm 6.88. Then, with a SD of 6.88, a type I error of 0.05, and a measurement precision (*d*) of 1.0 score, the needed sample size was estimated at 183. However, we recruited all the available individuals with inclusion criteria (*n* = 246) to increase the validity of the study.

Inclusion criteria for the children and adolescents included passing at least 6 months from medical diagnosis of ADHD and being in the age range of 6–18 years. Inclusion criteria for the mothers were caring for a child with ADHD at least for 6 months. Mothers of children with severe mental retardation (intelligent quotient of 70 or lower), visual and hearing disorders, cerebral palsy, convulsive and autistic disorders, and a history of brain trauma (based on the child's medical profile) and mothers with a seriously stressful event (such as losing a beloved one and divorce) in the last 6 months and those who suffered from a diagnosed mental disorder or chronic physical disease were not included in the study.

Instruments

A four-part instrument was used in this study. The first part included a sociodemographic information form consisting of questions addressing the mother's and the child's characteristics such as the mother's marital status, education level, job, losing job or abandoning job due to caregiving, husband's job, family income, spouse's and other family members' cooperation in caregiving, having access to supportive sources, the child's sex, birth rank, education level, subtype of disorder, receiving medication and psychological interventions, and history of mental disorder or ADHD in other family members.

The Persian version of Kiddie Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version (K-SADS-PL); Zarit Burden Interview (ZBI); and Swanson, Nolan, and Pelham Rating Scale-IV (SNAP-IV Parent Rating) were used as the second to the firth parts of the instrument.

The K-SADS-PL is a semi-structured psychiatric interview designed based on the DSM-IV criteria and can help the diagnosis of disruptive behavioral disorders including ADHD and other affective and psychotic disorders. The reliability coefficient of the Persian version of this scale has been reported as 0.81.^[26] In the present study, a pediatric psychiatrist completed the K-SADS-PL for the diagnosis of ADHD in the children.

The 22-item ZBI is an inventory for measuring the caregiver's perceived burden in providing family care. All items are scored on a 5-point Likert scale ranging from 0 (never) to 4 (almost always 4). The level of burden can then be categorized into four levels of no burden (0–20), mild (21–40), medium (41–60), and severe burden (61–88). The test–retest reliability coefficient of the Persian translation of ZBI was reported as 0.94.^[19]

The SNAP-IV Parent Rating was used to identify the severity of the disorder and its subtypes. The Persian version of this tool consists of 18 items for measuring attention-deficit disorder (9 items) and hyperactivity-impulsivity (9 items). It can measure the three subtypes of ADHD including "inattentive," "hyperactive," and "compound." All items are responded on a 4-point Likert scale ranging from 0 (never) to 3 (a lot). The cutoff points for the diagnosis of severe conditions are 1.57, 1.45, and 1.9 SDs from the mean scores of the total scale, attention-deficit, and hyperactivity-impulsivity subscales, respectively. The cutoff point of ≤ 1 is considered as a response to the treatment or successful treatment and indicates less severity of clinical symptoms.^[27] Sadrosadat et al. reported the Cronbach's alpha coefficient of the scale as 0.90.^[28] In the present study, ten faculty experts at Tabriz University of Medical Sciences confirmed the content validity of the study instrument. Moreover, the study instrument was responded by ten mothers who were chosen randomly, and the Cronbach's alpha of ZBI and SNAP-IV was calculated as 0.85 and 0.86, respectively.

Procedures

The researcher attended the hospitals in every morning and evening shifts after obtaining permission from the chairman of the hospitals and clinics. After the approval of the diagnosis by the psychiatrist, the researcher met mothers and assessed their inclusion criteria and if they were qualified, they were allowed to complete the questionnaires through individual structured interviews. To this end, the researcher read them the questionnaire items and recorded their answers in the questionnaire. All the interviews took place in a private and comfortable room in the clinic setting. Among 246 mothers, five decided to withdraw from the study during the interviews, and therefore were excluded.

Ethical considerations

The present study was of a research project approved by the institutional review board and the ethics committee of Tabriz University of Medical Sciences (IR.Tbzmed. Rec. 1396.730). The participants were provided with a thorough explanation about the study aim, the methods, confidentiality of the data, and filling up of the questionnaire. All the questionnaires were anonymous. In addition, all the patients were informed that their participation is voluntary and signed the written informed consent before participation.

Data analysis

Data analysis was performed using SPSS software (version 13; SPSS Inc., Chicago, IL, USA). Descriptive statistics such as mean, SD, and absolute and relative frequencies were used to describe the participants' characteristics and the scores of the questionnaires. The t-test and analysis of variance were used to compare the mean burden scores according to the mothers' and their children's characteristics. The Pearson's correlation coefficient was used to examine the correlation between burden scores and the participants' characteristics. All variables with P < 0.20 from univariate analyses were entered into the multiple linear regression analyses. In multiple regression analysis, the step-wise method was used in order to arrive at the final model of determinants of the outcome variables. The independent variables in this study were a mixture of continuous and categorical variables. Then, in multiple regression analysis, the categorical variables with more than two categories were coded as "dummy variables." P < 0.05 (two sided) was used to indicate statistical significance. The regression coefficient and 95% confidence intervals were reported to consider the strength of association.

RESULTS

Of all mothers, five ones did not return their questionnaires, therefore, 241 questionnaires were

analyzed. The mean of the mothers' and children's age was 35.86 ± 5.93 and 8.99 ± 2.75 years, respectively. Most of the mothers were married, homemakers, and had a high school education [Table 1]. Most of the children were boys [Table 2].

The results of the psychiatrist's diagnostic interviews K-SADS-PL showed that using 117 children (40.69%) suffered from comorbid psychiatric disorders (i.e., 6 children [2.5%] from bipolar disorder; 47 children [19.5%] from anxiety disorder; 16 children [6.6%] from elimination disorders; 19 children [7.9%] from tic disorder; 54 children [22.4%] from defiant, impulsivity, and conduct disorders; and 13 children from [5.4%] obsessive-compulsive disorder).

The mean caregiver burden was 40.43 ± 1.38 . Among all mothers, respectively, 6.6%, 42.7%, and 43.2% showed severe, medium, and mild burden, while 7.5% possessed a score showing no caregiver burden.

The mean SNAP scores were 1.91 ± 0.79 , 1.76 ± 0.70 , and 1.81 ± 0.61 in impulsive, inattentive, and combined subtypes, respectively. Based on the classification of the children's symptoms from mothers' point of view, 159 children (66%) were in the combined subtype, 19 children (7.9%) were in the inattentive subtype, four children (1.7%) were in impulsive subtype, but 59 children (24.5%) had no symptom.

Using the Pearson's correlation coefficient, a significant association was found between the score of each subtype and the caregiver burden score (i.e., in inattentive subtype, r = 0.36, P < 0.01; in impulsive subtype, r = 0.29, P < 0.01; and in combined subtype, r = 0.29, P < 0.01).

Among all mothers' and children's characteristics, only the mothers' and her spouse's education level (P < 0.01and P = 0.04) and the families' income (P = 0.007) could significantly affect the mean caregiver burden [Tables 1 and 2]. The results of the multivariate regression analysis showed that among all variables entered into the model, only the mother's age, the cooperation of family members in caregiving, having a brother with mental disorder, and the child's birth rank (i.e., first, second, and third ranks) could predict the mother's burden score (P = 0.002, F = 1.69). These variables predicted 55.7% of the mothers' caregiver burden ($R^2 = 0.563$, adjusted $r^2 = 0.22$, and r = 0.750) [Table 3].

DISCUSSION

The majority of mothers in the present study had a mild level of burden. Caring for a child who is usually inattentive, hyperactive, or impulsive is difficult and can exert considerable pressure on the family caregivers, especially on mothers. However, the mean caregiver

burden according to the mothers' characteristics				
Mothers' characteristics	n (%)	Caregiver burden	Р	
		(mean ± SD)		
Marital status				
Married	234 (97.1)	36.75 ± 8.42	0.81	
Divorced or widowed	7 (2.9)	42.33 ± 25.72		
Education level				
Illiterate	9 (3.7)	37.73 ± 13.92	0.01	
Elementary	31 (12.9)	38.92 ± 14.10		
Secondary	41 (17)	43.09 ± 13.90		
High school	99 (41.1)	43.61 ± 11.13		
University	61 (25.3)	52.22 ± 10.94		
Occupational status				
Homemaker	209 (86.7)	45.31 ± 12.42	0.49	
Employed	31 (12.9)	40.24 ± 13.97		
Retired	1 (0.4)	44.00 ± 0		
Losing a work				
Yes	1 (0.4)	44.00 ± 0	0.62	
No	60 (24.9)	41.88 ± 14.22		
Irrelevant	180 (74.7)			
Leaving the job	()			
Yes	14 (5.8)	39.96 ± 13.77	0.59	
No	47 (19.5)	41.88 ± 14.22	0.09	
Irrelevant	180 (74.7)	39.93 ± 13.77		
Husband's occupational	100 (//)	07.00 - 10.17		
status				
Employed	215 (89.2)	40.27 ± 13.80	0.43	
Retired	6 (2.5)	35.50 ± 12.01		
Unemployed	13 (5.4)	45.76 ± 13.15		
Died	7 (2.9)	39.57 ± 17.97		
Husband's education level	/ (=.))	0,0,0, - 1,0,1		
Illiterate	9 (3.7)	48.22 ± 17.26	0.04	
Elementary	42 (17.4)	43.97 ± 12.44	0.0.	
Secondary	49 (20.3)	41.89 ± 13.09		
High school	60 (24.9)	40.10 ± 12.92		
University	74 (30.8)	36.86 ± 14.41		
Died	7 (2.9)	39.57 ± 17.97		
Cooperation of family in	7 (2.7)	57.57 - 17.57		
caregiving				
Little	171 (71)	41.77 ± 13.45	0.059	
Moderately	35 (14.5)	36.51 ± 15.21	0.00)	
Greatly	35 (14.5)	37.82 ± 13.65		
Income	55 (11.5)	57.02 - 15.05		
Less than expenditures	105 (43.6)	43.40 ± 13.26	0.007	
Equal to expenditures	103 (45.0)	38.75 ± 14.08	0.007	
More than expenditures	24 (10)	35.29 ± 12.96		
History of mental disorder or	24 (10)	33.29 ± 12.90		
ADHD in family members				
Yes	46 (19.1)	43.62 ± 12.88	0.08	
No	40 (19.1) 195 (80.9)	43.02 ± 12.08 39.70 ± 13.99	0.00	
Type of the disease in	195 (00.9)	JJ. 10 ± 13.77		
family members				
ADHD	37 (15.4)	43.48 ± 13.61	0.16	
Depression		43.48 ± 13.01 43.71 ± 12.36	0.10	
Depression	6 (2.5)	+J./1 = 12.30		

Table 1: The mean and standard deviation of caregiver

burden according to the mothers' characteristics

Mostafavi, et al.: Caregiver burden and related factors

Table 1: Contd			
Mothers' characteristics	n (%)	Caregiver burden (mean ± SD)	Р
Anxiety	1 (0.4)	39.00 ± 0	
Autism	2 (0.8)	49.50 ± 14.84	
Access to supportive sources			
Yes	11 (4.6)	46 ± 11.57	0.33
No	230 (95.4)	40.16 ± 13.91	
Spouse's cooperation in caregiving			
Never to low	234 (97.1)	40.46 ± 17.76	0.867
Spouse died	7 (2.9)	39.57 ± 17.97	
Receiving psychotherapy interventions			
Yes	101 (41.9)	41.09 ± 14.24	0.676
No	140 (58.1)	39.95 ± 13.59	

SD: Standard deviation, ADHD: Attention-deficit hyperactivity disorder

burden in the present study was lower than the burden reported by Adeosun *et al.* in Nigeria^[5] and higher than that reported by Salas *et al.* in Spain.^[6] The differences might either be attributable to the differences in social and health-care resources available in different countries or to the fact that a quarter of mothers in our study had asymptomatic children while a quarter of the children in Adeosun *et al.*'s study suffered from an impulsive subtype of ADHD. Furthermore, the prevalence of comorbid disorders among the children in Adeosun *et al.*'s study was higher than that of ours. On the other hand, the participants in Salas *et al.*'s study were foster parents and responded to the questionnaires at home, which is more relaxing than the clinic setting, in which our study was conducted.

The present study showed that the mean burden was higher in the combined subtype. This finding was in agreement with earlier studies.[15,29] We also found a significant relationship between the severity of ADHD and caregiver burden. This finding was consistent with the studies carried out in this field.^[15,30,31] As expected, the more severe the symptoms, the greater the care needs of children. As a result, parents need to spend more financial and time resources, etc. The greater the severity of the disease, the greater the need for social support, but most participants in the study also complained of a lack of social support. Accordingly, due to the lack of enough supportive resources in Iran, caregiver burden would increase. Such a condition will increase the level of unmet needs of mothers and consequently increase their perceived caregiver burden.^[30]

In the present study, the mothers' age, the existence of ADHD in brother, family members' cooperation in

burden according to the children's characteristics				
Children's characteristics	n (%)	Caregiver burden (mean ± SD)		
Sex				
Male	176 (73)	40.72 ± 13.70	0.59	
Female	65 (27)	39.64 ± 14.32		
Birth rank				
First	145 (60.2)	41.37 ± 13.78	0.60	
Second	71 (29.5)	38.6 ± 13.83		
Third	22 (9.1)	40.90 ± 15.05		
Fourth	2 (0.8)	31.50 ± 0.70		
Sixth	1 (0.4)	42.00 ± 0		
Education level				
Preschool	38 (15.8)	39.71 ± 11.16	0.59	
Elementary	165 (69.7)	39.89 ± 14.02		
Secondary	17 (7.1)	42.52 ± 14.35		
High school	5 (2)	46.60 ± 13.61		
Preuniversity	2 (0.8)	36.00 ± 25.45		
Illiterate	11 (4.6)	40.43 ± 17.86		
Receiving a medication	()			

200 (83)

41 (17)

 40.26 ± 13.74

 41.29 ± 14.52

0.66

Table 2: The mean and standard deviation of caregiver

SD: Standard deviation

Yes

No

giving care, and the child's birth rank could significantly predict the caregiver burden. In some of the studies on caregivers of children with chronic physical^[21] and mental conditions,^[32-34] the age of caregiver could not predict the burden, however, a number of studies reported the mothers' age as an important factor affecting caregiver burden.^[3,14] Perhaps, as caregivers get older, they become more worn out, which reduces their ability to care for their ill children and increases their perceived burden.^[11] In addition, as time passes, the mother feels that she was not successful in changing her child's behavior and condition despite all her attempts. Consequently, she feels low self-confidence in her caregiving role.^[32] Furthermore, when people get older, their family size shrinks and the caregiver burden increases on the main caregiver.

The present study was in agreement with the previous studies, indicating that getting help and support from other family members is accompanied by the lower caregiver burden.^[5,16,35] It seems that family members' cooperation in giving care reduces the perception of the burden. The evidence shows that the perception of the burden is more related to the complicated social interactions inside the families and the social networks than the care – receivers' personal features.^[36,37] Nurses are responsible to encourage other family members to take more roles in caring for the children with ADHD, so that the level of burden on the main caregiver would decrease.

Table 3: Results of multivariate regression model
analysis with enter method to predict caregiver burden
based on the mothers' and children's features

based on the mothers and children's leatures					
Variables	В	SE	ß	t	Р
Constant	-55.887	27.300		-2.047	0.043
Mothers' age	0.611	0.276	0.276	2.218	0.028
Cooperation of family in caregiving (very much)	-14.033	4.671	-0.212	-3.004	0.003
Having a brother with mental disorder	11.470	5.623	0.218	2.040	0.043
Being the first child of the family	56.488	19.240	2.000	2.936	0.004
Being the second child of the family	50.679	18.546	1.671	2.733	0.007
Being the third child of the family	44.005	17.294	0.917	2.544	0.012
SE: Standard error					

In this study, ADHD in the patients' brother was accompanied by an increased caregiver burden. In a study comparing caregiver burden of children with Autism Spectrum Disorder (ASD) to children with Attention-Deficit/Hyperactivity Disorder(ADHD), the results showed that the disease in the boy child increased caregiver burden in the mother.^[30] It might result from the belief that boys are the supportive sources for the parents when they get older,^[38] and thinking about losing this supportive source may increase the mothers' caregiver burden.

In the present study, the child's birth rank was a predictor of caregiver burden so that the illness of the first child induced the greatest burden on the mother. This finding could be associated with the increase in mothers' experience, ability, and the needed knowledge as the number of children increases in the family. However, in families with only one child, as the child is worthy for the parents, parents are more vulnerable if their child suffers from any disorder.^[39]

The difference in predictors is probably associated with factors such as using different psychometric tools, the differences in children's age, study settings, social structures, cultures, economic conditions, and available health-care services. Most predictors of caregiver burden are related to family and caregiver rather than the child's characteristics or disorder. This highlights the need for family-centered care and home visits to assess and meet the child's and caregivers' needs. Through home visits, psychiatric nurses, psychiatrists, and the health-care team can gather adequate information about the care provided by the caregiver and the caregivers' abilities and needs for supporting and caring for the children with ADHD. They not only can counsel, train, and empower them for suitable caring for the ill child and themselves, but also can make the caregivers aware of the social support organizations and introduce them to these supportive systems so that both children and their caregivers receive quality support and care. Psychiatric nurses can also form social networks and groups of caregivers to help them achieve what the best care can be. Hence, caregivers may also experience more support and less burden.

Most former studies used a self-report method to assess comorbid disorders. However, usage of semi-structured interviews by the psychiatrist was the strength of the present study.

Passing 6 months from diagnosis was among the inclusion criteria of this study. Therefore, the symptoms and, consequently, the level of caregiver burden might have been reduced because of starting the medication. Further studies with a longitudinal design starting from the medical diagnosis of ADHD are suggested. The studied mothers were selected from three different clinics and their children were monitored by different psychiatrists. Differences in treatment modalities, as well as the communication skills of physicians, might also affect the results of the study. Furthermore, as the findings were limited to the children aged 6–18, they were not generalizable to younger or older children. Further studies on mothers of children with different age groups are recommended.

CONCLUSION

This study showed that mothers of children with ADHD experience caregiver burden. The level of burden is higher in mothers of children with compound or severe symptoms. ADHD in brother, family members' cooperation in caring for the child with ADHD, and the child's birth rank could predict the caregiver burden. Therefore, psychiatric nurses and psychiatrists are recommended to assess the health and caregiver burden of mothers of children with ADHD when they bring their children to the clinic. Suitable caring and supportive interventions can be planned for high-risk mothers. Psychiatric nurses and other experts in this field are responsible for giving consultation to the mothers of children with ADHD to reduce their caregiver burden and increase their efficient adaptability. Home visits by psychiatric nurses and providing family-centered care can reduce mothers' concerns and meet their demands.

Acknowledgments

The authors would like to acknowledge the vice chancellor of research of Tabriz University of medical sciences for their support. We also are thankful of all patients' mothers who participated in this study.

Financial support and sponsorship

The research project was supported by the vice chancellor of research of Tabriz University of Medical Sciences.

Conflicts of interest

There are no conflicts of interest.

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