Original Article

Factors Related to Fatigue among Mothers of Children with Cancer Undergoing Chemotherapy in Ho Chi Minh City Oncology Hospital

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Background: Having a child with cancer is a crisis for parents. In Vietnam, study examining the psychological problem of mothers having children with cancer is limited.

Objective: To determine level of fatigue in mothers of children with cancer undergoing chemotherapy and some factors related to fatigue of mothers.

Materials and Methods: A cross-sectional study was conducted in 185 mothers of cancer children undergoing chemotherapy at the Ho Chi Minh City Oncology Hospital from February 2018 to May 2018. Using the questionaire to colect data.

Results: The mean age of the mothers was 33.7±6.6 years. The average sleep time was 4.9±1.4 hours/day. 64.3% mothers had moderate fatigue, and 35.7% had severe fatigue. Marital status and average sleep per day, stress and social support were factors related to fatigue of mothers. However, age of mother was not related to fatigue of mothers.

Conclusion: 100% mothers had moderate to high level of fatigue. Therefore, nurses have to aware this issue to assess and provide support to them.

Keywords: Fatigue, Mothers, Childhood cancer, Social support, Stress

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Fatigue is a universal symptom that affects both physical and mental activity, but it is rarely discussed or treated[1,2]. According to North American Nursing Diagnoses Association, fatigue is considered to be a feeling of long-term exhaustion which reduces the ability to function physically and mentally[3]. Some studies have shown that fatigue is one of the commonest symptoms in people with chronic diseases such as cancer, multiple sclerosis, pregnant women and breastfeeding women, mothers with young children[4-6].

Having a child suffering from cancer is a crisis event for families especially the mothers. In addition to anxiety about curing, mothers must increase the role of caring for these children, including taking children to the hospital, monitoring symptoms and drug side effects, getting information about children's illness, make a decision to treatmen, caring for the child with cancer and taking care of other healthy children in the family. The parents of the child also face their own psychological changes such as anger, depression, stress. These problems can lead to severe fatigue. According to Kong et al (2013), high levels of maternal fatigue can significantly reduce their ability to fulfill the role of caregiver, leading to the failure of the care for young. The fatigue that mothers experience is believed to affect hospitalized children and their families, as well as themselves[7]. Maternal fatigue has a negative impact on parenting behavior and relationships among family members that indirectly negatively affect the health of the child[8].

According to Jensen's study (1991), a survey about fatigue levels of 248 cancer patients caregivers showed that 111 caregivers (45%) had mild fatigue levels, 63 caregivers (25 %) had average fatigue and 68 people (28%) had severe fatigue. A study in Korea showed that fatigue in mothers with hospitalized children correlated with physiological factors (including maternal age, age of the child, mother's sleeping hours), psychological factors (anxiety, children's adaptation to hospitalization) and situational factors (employment status, supported in housework)[9].

The fatigue of caregivers for cancer patients has been studied in many parts of the world. However in Vietnam, there have been no studies of fatigue in mothers of children with cancer. The authors hope that the present study will initially help the nurses to acknowledge the presence of

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maternal fatigue in order to develop mental support intervention programs for mothers in the future, therefore increase quality of nursing care.

Objective

Determine level of fatigue in mothers of children with cancer undergoing chemotherapy.

Determine relationships between some factors with the fatigue in mothers of children with cancer undergoing chemotherapy.

Theorical framework

The theory of unpleasant symptoms (TOUS) was developed by Lenz, Suppe, Gift et al (1995) to explain individuals' experiences of "unpleasant symptoms" such as fatigue and dyspnea. According to the TOUS, there are three categories of factors that affect symptoms including physiological, psychological, and situational factors. The physiological factors include the functioning of organs in the body, genetic factors, age, ethnicity, pathology, sleep quality, and energy levels of an individual. The psychological factors include: mental state of the individual (stress, anxiety…), emotional response to illness, knowledge of symptoms. The situational factors include social and physical environment factors such as employment status, marital and family status, social support, access to health care resources, personal factors such as lifestyle behaviors include diet and exercise[10].

To determine the factors related to mothers' fatigue, the authors built a hypothesis based on the TOUS and some related research. Our research model consists of three main factors: physiological, psychological and situational factors (these are independent variables) that affect the fatigue in mothers of children with cancer undergoing chemotherapy (dependent variable). Physiological factors: include mother's age, chronic disease of mother and average number of hour sleeping per day. Psychological factors: include maternal stress. Situational factors: include employment status, marital status, difficulty about treatment cost and social support (from medical staff, family and friends). Besides, we also collected some variables about the demographic characteristics of mother and child.

Materials and Methods

Participants

Mothers of children with cancer who are receiving inpatient and outpatient chemotherapy at Department of Internal medicine No. 3. Mother is the primary caregiver of the child since the child is sick (direct care of the child, responsible for the treatment and monitoring of the child). Mothers have the ability to communicate in Vietnamese, without neurological disorders such as epilepsy, depression. Mother agreed to participate in the study. The authors excluded mothers do not complete the interview. There were 187 mothers participating in the present study, however 2 mothers did not answer all the questions and were excluded. The final sample was 185 participants.

Design

This is a descriptive cross-sectional study. Using a convenient sampling method. Data collection is done at the end of the morning hours (10.30 AM to 12.00 AM) on Mondays to Fridays on mothers who meet the inclusion criteria. Mothers were interviewed with available questions in the child's play room for a period of approximately 20 minutes.

Measure

Demographic characteristics: there are 8 questions about the characteristics of the mothers (age, education level, marital status, employment, chronic illness, average hours per day, treatment cost difficulties).

PedsQL Multidimensional Fatigue Scale: was developed by Varni (2002). This questionnaire consists of 18 items about general fatigue (6 items), sleep/rest fatigue (6 items) and cognitive fatigue (6 items)[11]. However, after conducting a trial interview and consulting with a specialist, we dropped one item about sleep/rest fatigue (You spend a lot of time in bed). The answer to each item is based on five levels (never, almost never, sometimes, often and almost always). The answer will then be converted into scores from 0 to 100 (with Never = 0, Almost never = 25, Sometimes = 50, Often = 75, Almost always = 100). Fatigue scores are averages of 17 items. It ranged from 0 to 100, the higher score indicated the higher level of fatigue. This variable is then divided into three levels: low fatigue (from 0 to 33.3 points), moderate fatigue (from 33.4 to 66.7 points), severe fatigue (from 66.8 to 100 score). The reliability coefficient (Cronbach's alpha) of this scale in the present study was 0.83.

Perceived Stress Scale 10: was developed by Cohen (1988) and consisted of 10 items with Cronbach alpha was 0.86[12]. The responses for each items were 0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often. There are 4 reversing items on the items number C4, C5, C7 and C8 (with 0 = 4, 1 = 3, 2 = 2, 3 = 1 vα 4 = 0). The total score was calculated by sum of each items score in the scale. It range from 0 to 40, the higher score indicated the higher level of stress . The questionnaire was translated into Vietnamese by Dao - Tran with Cronbach's alpha was 0.8[13]. In the present study, Cronbach's alpha of PSS-10 was 0.7.

Social support scale: Support care need of parent (SCNP) was developed by 9 Kerr (2007), which included 45 items concerning support from informational, emotional, psychosocial, practical, spiritual and physical[14]. However, the authors only used 9 items to assess support from medical staffs: e.g., were informed about the success of the treatment, were fully explained about the tests. Each question is answered on a five-point Likert scale from 0: never to 4: almost always. The score of social support from medical staffs is the sum of 9 items, range from 0 to 36, the higher the score, the more supportive the support is. This scale has been translated into Vietnamese by Dang Thi Thu Tram and is undergoing a study at the Ho Chi Minh City Oncology Hospital. The authors also used 2 out of 3 questions from the Perceived

Support Scale (De Caroli) to assess the level of social support received by mothers from family and friends[15]. The answer to each question is also based on a five-point Likert scale from 0 to 4.

Overall, there have 11 items determine about information, emotional and financial support that mothers have received from medical staff (9 items), family (1 item) and friends (1 item) since the child had cancer. The total score of social support was sum of 11 items score, which score from 0 to 44. High scores indicate that mothers receive more support.

Ethical consideration

The contents of the present study were approved by the Ethics Council of the University of Medicine and Pharmacy in Ho Chi Minh City and Ho Chi Minh City Oncology Hospital. Mothers participating in this study were given a clear explanation of the purpose, benefit, and research process. Mothers have the right to agree or refuse to participate in the present study. If they agree to participate, they will sign a informed consent. All information relating to study participants is kept confidential and only used for research purposes.

Data analyses

Data were analyzed by using SPSS 18.0 software program. Descriptive statistics (mean, standard deviation, frequency, percentage) and statistical analysis (Pearson, Chi-square and Fisher) were used for data analysis. Pearson's correlation coefficients were used to determine the relationships between fatigue and mother's age, average hours of sleep per day, maternal stress and social support. Chi-square test: found the relationship between fatigue and employment status, chronic maternal disease and difficulty about treatment cost. Fisher's exact test is used to analyze the relationship between fatigue and marital status of mothers. The standard distribution hypothesis test was performed for each variable before the analysis of the relationship between the variables. Significance level $p<0.05$ was used to find significant differences.

Results

Mothers' characteristics

The participants' mean age was 33.7 (SD = 6.6) years. The average sleep time was 4.9 (SD = 1.4) hours per day. The majority of mothers reside in the provinces outside of Ho Chi Minh city (85.9%). The majority of mothers were married (89.2%), mainly occupational were workers, farmers and housewife. Educational level was mainly secondary school (45.9%). There were 11.9% of mothers with chronic disease. 84.3% of mothers had problems about the cost of treating of their children. Details were shown in Table 1.

Level of fatigue among mothers with cancer children undergoing chemotherapy

The study found that 100% mothers had moderate to high level of fatigue. Specifically, 64.3% of mothers had moderate fatigue and 35.7% had severe fatigue, as shown in Figure 1.

Mean of total score of maternal fatigue was 60.7 (SD = 12.8). The highest mean score was general fatigue (M = 63.3, SD = 14.7), followed by sleep/rest fatigue (M = 59.7, SD = 16.1), the lowest was cognitive fatigue score (M = 58.8, SD = 19.4) (Table 2).

Mean of score of maternal stress and social support for mothers

Table 3 results showed that mean of total score of maternal stress was 25.2 (SD = 4.6). Mean of total score of social support received by the mother was 24.5 (SD = 6.5), the support from the medical staff is the highest, followed by the family and the lowest is the support from friends.

Table 1. Mothers' characteristics (n = 185)

Characteristics	Frequency	%
Mother's age (years) (m, SD)	(33.7, 6.6)	
Hours of sleeping per day	(4.9, 1.4)	
Resident		
HCMC	26	14.1
Other provinces	169	85.9
Marital status		
Single	3	1.6
Married/ Living together	165	89.2
Divorced/ Widowed	17	9.2
Employment status		
Worker	54	29.2
Farmer	44	23.7
Housewife	39	21.1
Officer	14	7.6
Other occupations	34	18.4
Educational level		
Illiterate	3	1.6
Primary school	40	21.6
Secondary school	86	46.5
High school	38	20.5
College/ University	18	9.7
Chronic disease		
Yes	22	11.9
Difficulty about treatment cost		
Yes	156	84.3

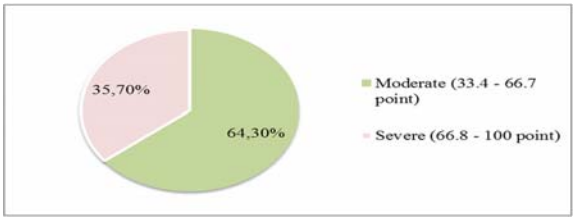

Figure 1. Level of fatigue of mothers.

Table 2. Mean of scores of fatigue in mothers

Items	Mean	SD
General fatigue	63.3	14.7
Feeling tired	69.2	21.3
Feeling physically weak	71.5	19.2
Feeling too tired to do things that she likes to do	63.5	25.8
Feeling too tired to spend time with her friends	60.1	25.6
Trouble starting things	58.9	21.4
Trouble finishing things	56.6	23.9
Sleep/rest fatigue	59.7	16.1
Sleeping very little	57.8	27.6
Difficulty sleeping through the night	71.9	22.0
Feeling tired when she gets up in the morning	60.8	24.4
Resting a little	53.6	30.2
Taking a lot of naps	54.3	26.4
Cognitive fatigue	58.8	19.4
Difficulty keeping her attention on things	59.2	22.0
Difficulty remembering what people tell her	62.2	24.8
Difficulty remembering what she just heard	58.5	27.4
Difficulty thinking quickly	56.8	23.8
Trouble remembering what she was just thinking	57.0	27.6
Trouble remembering more than one thing at a time	59.6	25.4
Total fatigue score	60.7	12.8

Table 3. Mean of score of maternal stress and social support for mothers

Variables	Mean	Standard deviation	Range
Stress	25.2	4.6	0 to 40
Social support	24.5	6.5	0 to 44
From medical staff	21.5	5.7	0 to 36
From family	1.6	0.9	0 to 4
From friend	1.2	0.8	0 to 4

Relationships between some factors and fatigue in mothers of children with cancer undergoing chemotherapy

There was a statistically significant association between maternal fatigue and marital status, $p = 0.012$.

Of the 156 mothers who have difficulty about treatment costs, 60.9% had moderate fatigue and 39.1% had a high fatigue level. This difference was statistically significant ($X^2 = 5.093$; $p<0.05$).

There were negative correlations between fatigue and social support total score ($r = -0.8$; $p<0.001$), hours of sleep during the day ($r = -0.4$; $p<0.001$). There was a positively significant relationship between fatigue and maternal stress score ($r = 0.3$; $p<0.001$). There is no correlation between fatigue and mother's age.

There were no relationships between fatigue and employment status and chronic disease of mothers.

Discussion

Level of fatigue in mothers of children with cancer undergoing chemotherapy

The results from Chart 1 showed that 64.3% of mothers had moderate fatigue and 35.7% had severe fatigue. The mean of total fatigue score was 60.7±12.8. This result is higher than that of Jensen (1993), Gelady-Duff (2006) and Zupanec (2010)[6,16,17].

Jensen (1991) conducted a study on 248 caregivers of cancer patients in the United States, showed that 45% of caregivers had mild fatigue; 25% had moderate fatigue and 28% had severe fatigue[17]. Our results differ from Jensen, possibly because the two studies were conducted at different times, in two different locations, with significant differences about time, culture, religion, and habitat between Vietnam and one country in the Americas. In addition, Jensen's study mainly determine the fatigue of caregivers of adult cancer patients (mean's age of patients is 59.1, SD = 12.3), so the difference here is reasonable.

Our mean of fatigue scores were higher than those of Zupanec (40.6±24.6) and Gelady-Duff (45±12.5). These two studies have determined the level of fatigue of parents and children with leukemia who are receiving outpatient chemotherapy at home. In our study, most of children were also treated as outpatients (but in the hospital). Moreover, most of the maternal and child residence were in the provinces

Table 4. Relationships between fatigue and marital status

Level of fatigue	Marital status		Fisher's exact test (p)*
	Single/Divorced, Widowed	Married	
Moderate	18 (90%)	101 (61.2%)	0.012
Severe	2 (10%)	64 (38.8%)	

* The relationship between the two variables was analyzed by Chi-square test. However, the number of cells in the table with expected results <5 accounted for 25%. The Fisher's exact test was performed

Table 5. Relationships between fatigue and difficulty about treatment cost

Level of fatigue	Difficulty about treatment cost		Total	PX^2
	Yes	No		
Moderate, n (%)	95 (60.9)	24 (82.8)	119 (64.3)	p = 0.024
Severe, n (%)	61 (39.1)	5 (17.2)	66 (35.7)	$X^2 = 5.093$
Total	156 (100)	29 (100)	185 (100)	

outside of Ho Chi Minh City (85,9%), so majority of mothers stayed in the hospital (all night) during chemotherapy time. Because inpatient beds are not arranged, mothers and child often sleep along the corridors outside the inpatient rooms, some of which are located underneath the inpatient beds. Difficulty in living, eating, resting, and the environment in the hospital may have increased the mean score of fatigue among these mothers.

Our results also provided the same data for Weiss's study (2016)[18], mothers also have memory problems such as not remembering what people have said or forgotten, can not concentrate on what to do, can not remember many things at the same time.

In Vietnam, we have not found any study on fatigue in mothers of children with children undergoing chemotherapy. However, our results show an alarming situation. In pediatric care, doctors and nurses need to pay attention to the presence of fatigue on this mother to take timely interventions.

Relationships between some factors and fatigue in mothers of children with cancer undergoing chemotherapy

Marital status

According to the TOUS theory, there is a relationship between marital status and fatigue[10]. Our results were similar, indicating a relationship between marital status and fatigue (Table 6). However, we have not found any studies survey this association.

Mother's age

The results of the present study show no correlation between maternal fatigue scores and age. This finding is in line with Giallo, Cooklin on fatigue among Australian parents with young children[5,19]. This finding is similar to that studies by Jensen and Weiss. There is no correlation between fatigue of caregivers and their age[6,16,17]. However, according to the TOUS theory, age is one of the factors that directly affect fatigue[10]. Kim's study about the factors affecting fatigue of mothers with children hospitalized showed that maternal age had a weak correlation with maternal fatigue scores ($r = 0.15$, $p<0.05$)[6,16,17].

The published data have shown that the results are inconsistent in relation to age and fatigue. More research is needed to conclude. However, at any age, mothers face many difficulties and fatigue when their children have cancer so the medical staffs need to pay attention to the mother's psychological care to be able to support timely.

Difficulty about treatment cost

Results from Table 5 showed there was a relationship between maternal fatigue and the cost of treatment for the child. This results in a similarity to the TOUS theory[10], the affordability of health services is relate to fatigue. However, the authors have not yet found any study investigating this association in mothers of children with cancer for comparison.

Number of hours sleeping per day

The results from Table 6 showed that there is a moderate negative correlation between maternal fatigue scores and the average number of hours sleeping per day. This means that if the mother sleeps less, the higher the fatigue score, or the more sleep the mother has, the heavier the fatigue will be. Our results are similar to Giallo, Zupanec, Gelady-Duff and Meltzer (2007)[6,16,19,20]. Giallo and Zupanec's study also found a relationship between sleepiness's child and maternal fatigue and sleepiness's mothers. In the present study, we interviewed only one question about the average number of

Table 6. Relationships between fatigue and mother's age, hours of sleeping per day, maternal stress and social support for mothers

Variable	Fatigue score	
	R	*p*
Mother's age	0.1	0.092
Number of hours sleeping per day	-0.4	<0.001
Stress score	0.3	<0.001
Social support total score	-0.8	<0.001
Medical staff score	-0.7	<0.001
Family score	-0.5	<0.001
Friend score	-0.5	<0.001

hours of sleep in mothers, without comprehensive evaluation of the quality of the mother's sleep (standard questionnaire) and of the child sleep. Future studies should investigate further and more specifically on this problem.

The relationship between fatigue and insomnia is a two-way relationship. Specifically, according to research by Theobald (2004), fatigue and sleeplessness, if combined, will aggravate the consequences. Fatigue can lead to certain behaviors such as reduced mobility or drowsiness during the day, which makes it difficult to sleep at night. Insomnia, on the other hand, can lead to changes in the cytokines or stress hormones that make the person feel more fatigue[21]. These results suggest that interventions that improve the quality of sleep among mothers may contribute to lowering fatigue levels and vice versa, which is one of the tasks of the future research.

Stress

The results of the present study showed a positive correlation between fatigue and stress scores of mothers. The present study has similar results with Maghout-Juratli and Cooklin, between fatigue and stress are positively correlated[5,22]. This means that if the mother has a high level of stress it can lead to severe fatigue and vice versa. The authors found the results to be appropriate because, according to Maghout-Juratli, when there is not enough resources to cope with stressful events, negative emotions such as stress, anxiety, fatigue and depression often appear at the same time, interactions that exacerbate physical and mental health[22].

The relationship between fatigue and stress has not been mentioned much in the study, especially do not know what is the cause, what is the result. Although our research initially only stops at identifying the correlation between fatigue and stress, it also shows a great significance. In pediatric health care, medical staff should not only consider fatigue in a single aspect but also look at it in relation to stress factors, insomnia, because these factors have a direct impact on maternal fatigue. There is a need to plan interventions on related factors that can reduce the level of fatigue for mothers.

Social support

Results showed a strong negative correlation between the general social support score and maternal fatigue score. This means that if the mother receives a lot of social support (high social support), the level of fatigue will be low (low fatigue). This result is consistent with the literature reviews[5,18,19].

Social support is one of the resources that helps parents cope better with their child's cancer. Providing social support is also one of the roles of health care that helps children and families cope with cancer. In fact, we recorded a strong correlation between fatigue scores and social support scores from health workers ($r = -0.7$, $p<0.001$). According to the interviews, the mothers received very good information from health care workers, so it is necessary to further promote this strength.

Results showed that there was a strong correlation between fatigue scores and social support scores from family and friends ($r = -0.5$, $p<0.001$). Beyond the medical staff, family and friends are the closest people that mothers can confide in and they can be a spiritual support for mothers. In the present study, the level of support received by mothers from family and friends was low, so the authors recommend that, in communication, emphasis should be placed on important roles of family and friends. For families with children cancer, they may be the spiritual support for the mother to overcome the crisis.

Conclusion

64.3% of mothers had moderate fatigue and 35.7% had severe fatigue. Mean of total score of maternal fatigue was 60.7 ± 12.8.

There were relationship between marital status, difficulty in treatment costs, average number of hours sleeping per day, stress, social support and maternal fatigue.

There were no relationships between fatigue and mother's age, employment status and chronic disease of mothers.

Recommendation

For medical staff: in pediatric health care, medical staff should be aware of the presence of fatigue in mothers who are directly caring for their children. Factors related to maternal fatigue such as insomnia, stress, and social support should be explored for effective and timely intervention methods.

For family and community: increased support for mothers to help them overcome the difficult times when a child is diagnosed with cancer.

Future research: More research is needed on the quality of maternal sleep, the relationship between the child's fatigue, the sleep state of the mother and the level of fatigue. It is important to understand the causal relationship between stress and fatigue of these mothers.

Limitations of study

The authors performed a cross-sectional study

describing the level of fatigue of mothers with cancer children undergoing chemotherapy at the Oncology Hospital and determine some factors related to fatigue. This sample of the present study was only a convenience sample, therefore it may limit generalization. Besides, fatigue has changed over time, but in the present study the authors did not track the change. Longitudinal study designs should be conducted to find changes in fatigue over time as well as other relevant factors to have guide future interventions.

What is already known on this topic?

Fatigue is a common symptom in mothers of children with cancer who are receiving chemotherapy besides some other psychological symptoms such as anxiety, depression. It is considered to be a feeling of long-term exhaustion which reduces the ability to function physically and mentally, but it is rarely discussed or treated.

What this study adds?

The results showed that 100% mothers had moderate to high level of fatigue. The number of hours of sleep per day, stress and social support are factors related to the fatigue of these mothers. Nurses have to aware this issue to assess and provide support to them. They should not only consider fatigue in a single aspect but also look at it in relation to stress factors, insomnia, because these factors have a direct impact on maternal fatigue.

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Potential conflicts of interest

The authors declare no conflict of interest.

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