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Investigation of time and effort required for care activities among parents of children with cancer in pediatric educational treatment center

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ABSTRACT

Caring for children with chronic diseases, such as cancer, can impose lots of responsibilities on parents. The present study aimed to investigate time and effort required for care activities among parents of children with cancer in pediatric educational treatment center, Tabriz, Iran. In this descriptive comparative study, parents of 150 children with cancer who were under treatment in pediatric educational treatment center, Tabriz were selected through convenience sampling. Care of My Child with Cancer questionnaire was used to measure the time and effort spent on taking care of children. The data were analyzed using descriptive (frequency, percentage, mean, and standard deviation) and inferential (Friedman test) statistics. The most difficult and time-consuming tasks were physical care activities and usual care for the ill child and other children for the mothers, but emotional factors, information, communication needs, and maintaining family performance while facing disease and treatment for the fathers. The study findings emphasized the effect of childhood cancer on families. While taking care of patients physically, mothers can be provided with information about the disease, treatment, and child care so as to reduce a part of their care burden. Besides, supportive interventions can be used to decrease the fathers' emotional care burden.

Keywords: Childhood cancer, Caregiving burden, Care, Parents

INTRODUCTION

Childhood cancer, as a life-threatening factor, is considered as a serious health concern [1]. This disease causes a large number of disorders in children and imposes new responsibilities on parents [2]. Children receive a great part of their treatment at home, which imposes even more responsibilities on parents, including controlling drug consumption and communication with the treatment team [3]. Moreover, caring for such children changes the parents' normal life process, resulting in short- and long-term changes in family function. During treatment, parents have close contact with healthcare specialists [4, 5]. Caregivers of patients with cancer may also face physical, social, and economic problems during treatment and their marital life, occupation, health, and social life may be negatively affected by the burden of the disease [6]. This reduces the quality of care and caregiver's life, eventually influencing patient's life quality [7]. Evidence has indicated that having a child with cancer can result in emotional instability, uncertainty, and tension among family members, particularly parents [8, 9]. Parents should care for other family members, including other children, as well [10, 11]. Thus, the process of moving from hospital care toward home care for these patients imposes a great burden on families [12]. This can be considered as the time and effort required for supplying others' needs and includes problems related to financial costs, familial relations, social performance [13], caregiver's distress, and emotional and behavioral problems [14, 15].

Nowadays that most medical cares are shifting towards home and outpatient care, parents and other caregivers are expected to accept more responsibilities regarding medical care, related complications, and child's conditions. Therefore, performing studies in this respect can be a basis for increasing families' caring role in cancer [3]. In addition, timely identification of time and difficulties of caregivers' care activities can play a major role in improving their health [16], because caring can have an impact on caregivers' quality of life and there is a direct relationship between mother's and child's life quality [17]. Hence, timely identification of these pressures among caregivers is of great importance in improving the life of children with cancer. According to a previous research, mothers reported high care burden and low life quality among their children with schizophrenia [18]. Studies have also demonstrated that long-term care for individuals suffering from chronic diseases, such as Alzheimer, and psychological disorders had a great impact on caregivers' health [19]. Additionally, ill children's care demands have impacts on their own and their family caregivers' quality of life [20].

By describing the present status of care activities in parents of children with cancer, the present study can help nurses, instructors, educational planners, and nursing managers have access to a proper model for providing care appropriated to families' conditions and needs. In this way, nursing care can be improved and such patients' satisfaction and life quality can be enhanced, which can be of great importance in taking a step towards progress of nursing profession. Having holistic care approach in this regard, emotional care behaviors should be valued in addition to physical care. Since no studies have been conducted on care activities of parents of children with cancer in Iran, this study aims to determine the time and effort required for care activities of parents with such children in pediatric educational treatment center, Tabriz, Iran.

MATERIALS AND METHODS

Based on a pilot study on 30 families, a 135-subject sample size was determined for this descriptive comparative study. Thus, the study was conducted on 150 parents with 8-16-year-old children suffering from cancer. The samples were selected through convenience sampling from the individuals referring to clinic and hematology department of the pediatric hospital affiliated to Tabriz University of Medical Sciences from May to September 2013. The inclusion criteria of the study were passage of at least 3 months from definite diagnosis of the disease, lack of mental disorders in parents, parents living with children, at least one discharge since disease diagnosis, and being willing to participate in the research. At first, permission for performing the study was gained from the Research Vice-chancellor of Tabriz University of Medical Sciences and dean of the pediatric hospital. Also, the study was approved by the Ethics Committee of Tabriz University of Medical Sciences. Before completing the questionnaires, the study objectives and procedures were explained to the parents and their written informed consents were obtained. After that, the study questionnaires were separately completed by the parents through interview in the hospital.

The study data were collected using a questionnaire containing two sections. The first section was a socio-demographic form, including parents' age, education level, and occupation, child's age and sex, and type of cancer. The second part was Care of My Child with Cancer questionnaire developed by D Keegan-Wells for measuring parents' care activities. This questionnaire includes 28 items assessing time and effort for care responsibilities. At first, the validity of the translated version of this questionnaire was determined through content validity method by 13 nursing and oncology professors. In so doing, the questionnaire was given to the experts to evaluate its content validity. The modified version of the questionnaire measured time and effort required for care responsibilities in 1 week through 25 items. The three omitted items were related to care with ports and catheters that was not done in the study hospital in the study period. Each item of this questionnaire was responded through a 5-point Likert scale. In the time section, the scores ranged from 1 (none) to 5 (more than 5 hours a week). In the effort section also, the scores ranged from 1 (none) to 5 (too much effort).

The first 13 items of the questionnaire were related to meeting emotional needs, information, meeting communication needs, and maintaining family performance while facing disease and treatment. The next 7 items dealt with responsibilities related to physical care since disease diagnosis. Besides, 2 items were allocated to caring for children, including the ill child and his/her brothers and sisters. Finally, 3 items involved intramuscular and intravenous injections and going to hospital for treatment.

After getting the opinions, the writing modifications were applied. The reliability of the questionnaire was confirmed by Cronbach's alpha of 0.8 for the whole scale and 0.7 for different dimensions. After all, the data were entered into the SPSS statistical software, version 13 and were analyzed using descriptive (frequency, percentage, mean, and standard deviation) and inferential (Friedman test) statistics.

RESULTS

According to the results, the mean age of mothers and fathers was 35.29±5.99 and 40.68±6.50 years, respectively. Besides, most of the parents did not have academic education and were self-employed. The mean age of the children was 10.21±2.38 years and most of them were male. Type of cancer was classified into leukemia (61.3%), lymphoma (10.6%), and other (28.1%) categories.

Based on Friedman test, parents' care activities were prioritized according to difficulty and time-consumption. The results indicated that the most difficult and time-consuming tasks were physical care activities and usual care for the ill child and other children for the mothers, but emotional factors, information, communication needs, and maintaining family performance while facing disease and treatment for the fathers (Table 1).

Table 1. Prioritization of care activities based on difficulty and time-consumption according to the parents' viewpoints (results of Friedman test)

Time (time-consumption)					
Mother	Prioritization	Mean rank	Father	Prioritization	Mean rank
	Care dimension	3.31		Care dimension	3.14
	Physical dimension	2.71		Emotional dimension	2.96
	Emotional dimension	2.41		Physical dimension	2.35
	Transportation dimension	1.58		Transportation dimension	1.56
Effort (difficulty)					
Mother	Prioritization	Mean rank	Father	Prioritization	Mean rank
	Care dimension	3.21		Care dimension	3.07
	Physical dimension	2.74		Emotional dimension	2.94
	Emotional dimension	2.48		Physical dimension	2.42
	Transportation dimension	1.57		Transportation dimension	1.57

DISCUSSION

Cancer has a serious impact on patients as well as their families and friends. Such patients require long-term home care, which leads to a change in normal life process. Most mothers also have to change their lifestyle due to hospitalization of their children with cancer and caring for them at home. In the absence of mothers, fathers continue working and take care of the family and other healthy children. In comparison to mothers, fathers live a more normal life, but are affected by the disease, as well [21].

The findings of the present study indicated that parents' caregiving burden was far beyond the average level. This was in line with the results of other studies, emphasizing that caregivers of patients with cancer tolerate a great caregiving burden that mostly results from their care responsibilities [22]. These caregivers have to spend a lot of time and energy to care for children with cancer [23].

In the current study, the most difficult and time-consuming tasks were physical care related to the disease and usual care for the ill child as well as other children for the mothers, but emotional factors, information, communication needs, and maintaining family performance while facing disease and treatment for the fathers.In most studies, mothers were introduced as children's caregivers and fathers' role was neglected. In these studies, the most time-consuming activities for caregivers (mostly mothers) were emotional support, transportation to treatment centers, and monitoring the symptoms. Also, the most difficult tasks were emotional support, behavior management, monitoring the symptoms, and doing household chores [24]. In the study entitled "Care of My Child with Cancer" performed by D Keegan-Wells in 2002, the highest time and effort were related to the statements about emotional support, pain relief, supplying child's tranquility, and welfare facilities [3]. Similarly, Jerita Taydol conducted a study on caregivers of children with Acute Lymphocytic Leukemia (ALL) in 2008 and revealed that parents spent great time and energy on care [25].

In the present study, managing the house and providing personal care for children with cancer created many difficulties for the mothers. For fathers, on the other hand, working out of the house and caring for the child simultaneously and providing one's wife with emotional support were among the difficult and time-consuming tasks.This difference might be attributed to cultural differences. In the previous studies, caregiving burden was not investigated separately among fathers and mothers. For instance, ErlaColborn conducted a study on 26 parents with below-18-year-old children suffering from cancer between 1999 and 2001. The results of that study showed that children's cancer had long-term effects on families and that emotional support was the most difficult and time-consuming task for mothers and fathers [26]. Overall, it can be concluded that family caregivers of patients with cancer may be encountered with various physical, social, and economic problems through the treatment process. Therefore, being aware of parents' role in taking care of children with cancer is important for healthcare specialists, because caring for children can be considerably affected by caregivers, increase of time and difficulty of care can have negative effects on parents' life, and reduction of caregivers' life quality can have an impact on quality of care and patients' quality of life [27]. Further studies are recommended to assess the effect of demographic variables on this issue, such families' demands, and the relationship between parents' caregiving activities and life quality of caregivers and children. Furthermore, supportive interventions are necessary for elimination or reduction of time and difficulty of care activities among parents.

CONCLUSION

Based on the data collected from this study, emphasized that the effect of childhood cancer on families. While taking care of patients physically, mothers can be provided with information about the disease, treatment, and child care so as to reduce a part of their care burden. Besides, supportive interventions can be used to decrease the fathers' emotional care burden.

Clinical application of the research findings

The results of the present study can be the basis of further researches for providing patients with effective care or family-centered care. Using these results, a proper model can be proposed for provision of nursing care appropriated to families' expectations and needs. In our study, the parents experienced high caregiving burden for increasing their children's quality of life. Hence, nurses are required to be accessible to patients to respond to their needs. They also have to pay due attention to training the parents.

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