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The effect of education training intervention on the caregiver burden among mothers of children with leukemia: a quasi-experimental study

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ABSTRACT

Introduction. Leukemia is a broad term that refers to a group of malignant diseases of the bone marrow and lymphatic system. Caregiver burden is one of the issues that are faced by primary caregivers, and this role is played by mothers in most cases. In addition to these problems, mothers experience frustration in performing tasks, isolation and failure due to inadequate education about the disease and inadequate information support. The aim of the present study was to determine the effect of education on the caregiver burden (CB) among mothers of children with leukemia.

Material and methods. The present quasi-experimental study was performed on mothers of children with leukemia in the Hematology Ward of Ali ibn Abi Talib Hospital of Zahedan in 2019. Convenience sampling was used to select eligible mothers. At the baseline, the control group was selected according to the inclusion criteria (this method was to prevent the effect of the intervention on the control group). Then, a questionnaire including demographic information, and caregiver burden inventory (CBI) were completed in two stages: pre-test and post-test. To this end, after completing the questionnaire, the first training session was held in the hematology department individually for 30 to 45 minutes with a specific content. Also, after completing three training sessions, phone follow-up was performed weekly for 4 weeks to ensure that the intervention was implemented. The questionnaires were redistributed and recompleted by intervention and control groups again four weeks after the intervention.

Results. The mean pre-intervention CB score in the intervention and control groups was 19.97 ± 5.25 and 18.97 ± 10.03, respectively. The mean post-intervention CB score was also 17.17 ± 4.78 and 19.18 ± 9.93, respectively. Intervention significantly reduced CB score in the intervention group ($p < 0.001$).

Conclusions. The findings showed that training was effective in reducing the CB score among mothers of children with leukemia. Therefore, it is recommended to use training as a non-pharmacological and appropriate method in reducing CB among mothers of children with leukemia.

Key words: educational intervention; caregiver burden; leukemia; mothers

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Introduction

Leukemia is the most common and well-known childhood cancer worldwide, and also the third leading cause of death in children aged 1 to 4 years [1]. In 2016, out of every 380 children aged under 15 years, 10 were diagnosed with cancer [2]. A total of 4% of children aged under 5 years and 13% of children aged 5 to 15 years died of cancer in Iran in 2010; while the youth (age less than 15 years) makes up 25% of the country's population [3]. Cancer is a disease that seriously undermines the physical and mental health of the patient and family members [4]. Caregiver burden (CB) is one of the issues facing primary caregivers, mainly moth-

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ers. Caregivers are people who accompany the patient in the treatment process and help him/her to adapt with the disease [5]. These caregivers not only play an important role in the physical care dimension such as nutrition, personal hygiene, movement and mobility, but also provide emotional and social support to the patient in the psychological dimension [6]. Therefore, while caring for patients with chronic diseases such as cancer, both the patient and his/her primary caregivers are exposed to a variety of physical and psychological crises, and these caregivers may feel a heavy burden of responsibility because they have to play an important role in supporting the patient. In this regard, caregivers need more social support [7]. For this reason, paying attention to caregivers as part of their disease is a top priority. Numerous studies have emphasized that cancer challenges caregivers by affecting various aspects of their lives and affects their quality of life [8]. In the meantime, mothers play a very prominent role because in addition to providing physical care alone in many cases, they suffer from psychological consequences and subsequent stress, anxiety, and fatigue due to the condition of the sick child, worries about the future of the disease, and the consequences of the disease. Studies on families of cancer children showed that when a child becomes ill, the mother becomes more involved in care and treatment process than the father, and the father tends to do other things and attempts to ensure the peace of other family members, which in turn causes mothers to experience a lot of change in their life. Moreover, mothers lose their job and social position and work few hours because of caring for the child [9]. In a study of quality of life of parents of children with leukemia and related factors, Khanjari et al. [10] found that the quality of life of mothers of children with leukemia is very inadequate and it is necessary to educate families, especially caregivers in the field of child care and know how to adapt to improve the living conditions of caregivers. With regard to psychological problems of mothers of children with leukemia, studies have shown that caregivers experience different problems in different communities [11]. Studies show that mothers of children with leukemia admitted to the oncology wards experience more CB than other caregivers due to their low chance of recovery and high dependence on caregivers in daily activities, worsening of the patient's conditions as the disease progresses, and treatment non-response [12]. While providing care to cancer patients, caregivers are themselves exposed to a variety of stressful situations, which is called caregiver burden (CB) in nursing resources [13]. CB refers to the stress that a caregiver feels as a result of caring for the patient and has physical, psychological and social dimensions. Moreover, increasing CB levels will lead to several consequences such as inadequate patient care, patient abandonment, and disruption of family and social relationships [14]. Studies on quality of life of cancer patients' family have shown that cancer has significant effects on the physical, psychological, social and economic dimensions of the patient's family [15]. The family has also been introduced as the best source of care for patients with leukemia. Unfortunately, there are poor support services for caregivers in Iran [16]. Considering the limited role of mothers in the family and doing chores, they pay less attention to their health in most cases, now if, in addition to the relevant chores, they play the role of the main caregiver of a sick child, they will spend more time dealing with the above matters, and in practice, these issues lead to CB in the long run. For this reason, it is necessary to consider both variables according to the fundamental role of mothers in the family. Therefore, determining the CB level and then planning to reduce it and increase support for the family and caregivers of cancer patients can play an important role in improvement of symptoms. Despite the high prevalence of cancer and the potential risk of CB in caregivers, physicians have paid less attention to this issue in Iran [17]. Safaeian et al. (2016) found that more than half of caregivers of cancer patients experience severe and very severe CB levels. They also confirmed that it seems necessary to evaluate primary caregivers by members of the treatment team and develop family-centered rehabilitation programs [18]. Therefore, it is necessary for mothers to have a good mood in order to be able to adequately adapt to the disease. One of the effective factors helping children adapt with chronic diseases such as leukemia is the role of their mothers who are their main supporter during treatment programs and play the main role in promoting the quality of health and adaptation to the disease. This role is affected by the patient's problems and to provide care along the care path is different. Therefore, it is necessary to teach mothers of these patients some appropriate solutions to cope with the disease. The aim of the present study was to investigate the education training intervention on caregiver burden among mothers of children with leukemia.

Material and methods

Design

This quasi-experimental pre-test-post-test study was performed on 90 mothers of children with leukemia hospitalized in Ali ibn Abi Talib Hospital of Zahedan located in southeastern Iran from February 10, 2019 to March 1, 2020. Participants were selected from among eligible mothers of hospitalized children with leukemia using convenience sampling method. The sample size was determined 37 people in each group using the results of the previous study.

$$n = \frac{(Z_1 - \frac{\alpha}{2} + Z_1 - \beta)^2 (S_1{}^2 + S_2{}^2)}{(d)^2} = \text{٣٦/٥٢}$$

$$Z_1 - \frac{\alpha}{2} = \text{١/٩٦} \quad S_1 - \text{٣/٦٨} \quad Z_{1-\beta} = \text{٤/٢٢} \quad d = \text{٣}$$

Data collection

After the research project was approved by the Ethics Committee and coordination was made with the management of hospital, the researchers referred to the head nurse of the pediatric ward. First, after getting acquainted with the children and mothers and gaining their informed consent, the researchers explained the purpose and method of the intervention to them. Also, sufficient explanations were given to them regarding the safety of participating in this study. The mothers were assured that their personal information would be kept confidential and that they could withdraw from the study at any time. At the baseline, the control group was selected according to the inclusion criteria (this method was used to prevent the effect of the intervention on individuals in the control group). Demographic information questionnaire and caregiver burden inventory (CBI) were completed in two stages, namely pre-test and post-test. Then the samples of the intervention group were selected. To this end, after filling out the questionnaires, the first training session covering a specific content was held in the hematology department for 30 to 45 minutes with each individual. The second and third training sessions were held in the same way one week later. After completing three training sessions, phone follow-up was performed weekly for 4 consecutive weeks to perform the provided trainings. Questionnaires were redistributed and recompleted by the intervention and control groups at the end of the intervention. In order to observe the ethical principles, the control group only received the routine ward care, and the training booklet was given to this group after the intervention.

Instruments

Data collection instruments include a questionnaire consists of two sections. The first section includes demographic characteristics of mothers (age, mother's education level, mother's employment status, number of children, presence of disease symptoms in the mother, child's sex, birth rank of the child). The second section includes the standard caregiver burden inventory (CBI). CBI was developed to assess the perceived burden in caregivers [18]. CBI consists of 24 items and the participant must determine how much he/she experiences each situation on a five-point Likert scale. This questionnaire measures CB in following five dimensions: Time-dependent burden (phrases 1–5): This subscale indicates the time constraint created for the caregiver following the addition of the care tasks to his or her previous tasks. Developmental burden (phrases 6–10): This subscale examines whether the caregiver feels that he or she is lagging behind less than his or her peers due to caring for the patient. Physical burden (phrases 11–14): This subscale describes the caregiver's feelings about threats or physical harm. Social burden (phrases 15–19): This subscale measures role conflict in the caregiver. Emotional burden (phrases 20–24): This subscale measures the negative feelings of the caregiver towards the person caring for him/her. The possible score range is 0 to 120 and higher scores indicate the higher negative effect of patient care on various aspects of caregiver's life. Cronbach's alpha coefficient of each suable and the whole questionnaire has been reported 0.68–0.78 and 0.78, respectively. Cronbach's alpha coefficient of the Persian version of this questionnaire has been reported 0.90.

Ethical considerations

The present study has been approved by the Ethics Committee of Zahedan University of Medical Sciences with the ethics code: IR.ZAUMS.REC.1398.340. Written and oral consent was received from all participants in the study. Participants were assured that their information will remain confidential.

Data analysis

Statistical analysis was carried out using SPSS ver. 21. To describe individual characteristics, descriptive statistics were used to determine central indicators and dispersion such as minimum, maximum, range of changes, mean, standard deviation, percentage and frequency. Paired t-test was used to compare the mean in each group before and after intervention. Independent t-test was also used to compare the mean of the two groups. Chi-square test was used to compare the frequency of qualitative variables of the two groups. Finally, analysis of covariance (ANCOVA) was used to determine the effectiveness of the intervention by simultaneously controlling some confounding variables. P-value 0.05 was considered as the significance level. Shapiro-Wilk test was used to test the normality of the distribution of observations.

Results

Based on the findings, the mean and standard deviation of children's age in the intervention and control groups was 9.61 ± 2.84 and 9.65 ± 2.28 years, respectively. The duration of cancer in the intervention and control groups was 2.10 ± 1.69 and 2.50 ± 1.85 years,

Table 1. Content of training sessions in reducing caregiver burden

First session	Definition of cancer, symptoms of complications, educational interventions	30–45 minutes
Second session	Reviewing the content of previous session, crisis management in cancer, spiritual methods of controlling stress and anxiety based on religious teachings	30–45 minutes
Third session	Reviewing the contents of previous sessions, solutions to control fatigue, distraction and energy conservation and relaxation strategies and teaching adequate sleep and rest methods	30–45 minutes

Table 2. Comparison of mean and standard deviation of CB score among mothers of children with leukemia in intervention and control groups before and after training

	Before educational intervention	After educational intervention	Changes in mean value	p value
	Mean ± SD	Mean ± SD	Mean ± SD	
Intervention	70.62 ± 13.75	55.97 ± 7.16	14.65 ± 6.59	0.001
Control	71.28 ± 12.71	76.75 ± 13.93	5.47 ± 1.22	0.70

SD — standard deviation

respectively. There was no significant difference between the groups in terms of demographic and clinical symptoms. The mean and standard deviation of depression score in the intervention group was significantly reduced in the post-intervention phase (28.94 ± 15.21) as compared to the pre-intervention phase (99.13 ± 92.37) ($p < 0.001$).

The results showed that the mean age of mothers in the control and intervention groups was 33.73 and 35.95 years, respectively. The possible age range was 19 to 58 years. Approximately, 62.2% of mothers in the control group and 55.6% of them in the intervention group had under diploma education. Also, mothers in the control and intervention groups were housewives in 71.1% and 91.1% of cases, respectively. The duration of leukemia ranged from 2 months to 60 months. With regard to the sex variable, the majority of children in the intervention (57.8%) and control (73.3%) groups were boys. Concerning birth rank, they were the first child in the control and intervention groups in 40%. With regard to the ethnicity variable, the mothers of the control and intervention groups had Baloch ethnicity in 84.4% and 60% of cases, respectively.

Results also show a reduction in the mean and standard deviation of CB scores among mothers of children with leukemia in intervention and control groups from 70.62 ± 13.75 to 55.97 ± 7.16 ($p < 0.001$) and, the mean changes in the post-training CB score in the intervention group were statistically different ($p < 0.001$), but not in the control group ($p = 0.70$) (Tab. 2).

Comparison of the mean CB score among mothers of children with cancer in the intervention and control groups before and after training showed that training could effectively reduce CB among mothers of children with cancer ($p < 0.001$).

Discussion

Comparison of the mean CB scores among mothers of children with cancer in the intervention and control groups before and after training showed that intervention could effectively reduce CB scores among mothers of children with cancer. It seems that the face-to-face training program could significantly reduce CB levels among mothers participating in the present study. In a study of the effect of stress management training on improving the life of mothers with children with leukemia, Manzoomeh et al. [17] showed that stress management can increase the quality of life in the intervention group. In another similar study on the effectiveness of reality therapy on the resilience of mothers with children with cancer, the above researchers also showed that reality therapy training is effective on resilience of mothers with children with cancer [16]. In a study on caregiver burden and its related factors among caregivers in oncology patients, Salmani et al. showed the highest CB score among the spouses. They found that other factors such as low economic status and the disease progression affect CB score [19]. However, this issue has not been addressed in the present study, but it seems that other influential factors should also be addressed in order to manage and control CB. Considering the importance of having a son in Sistan and Baluchestan province, especially in Baloch population, it can be one of the influential factors on increasing CB score. In other words, factors such as ethnicity and sex of a baby as well as support resources and the caregiver age can affect the CB intensity. Therefore, it is necessary to investigate the factors affecting CB intensity taking into account the above variables according to the regional and cultural status of the mother, especially considering the fact that there are contradictions in some studies in this regard. For example, some studies reported high CB rate among young caregivers [19, 20] (Kim and Given, 2008), but some other studies have reported high CB rate among older caregivers [21]. According to the resources, mothers of cancer children suffer from high CB rate, which can be attributed to their increased responsibility and insufficient attention to caregivers by members of the caregiver team to meet their care needs [22]. The active participation of fathers in treatment programs and their cooperation with mothers in this path may be one of the effective factors that can reduce CB rate among mothers. Although the present study does not address it, the experiences of researchers and dealing with the community of mothers of children with cancer can demonstrate it very well. In the present study, almost all cancer children were cared for by their mothers and fathers played a weak role in this regard. Although the presence of fathers and participation in caring of a sick child may be effective in reducing CB of mothers, it seems that it is necessary to use training methods based on coherent programs that meet all the needs of caregivers. However, the authors could find studies that are inconsistent with the present study.

Limitations

The present intervention investigated the caregiver burden among mothers of children with leukemia. Considering the special conditions of these children, the results cannot be generalized to mothers with children suffering from other chronic diseases.

Conclusions

Considering the foregoing, it seems that it is necessary to use training methods based on coherent programs that meet all the needs of caregivers. In other words, by teaching crisis management strategies and training to control stress, anxiety and creating a sense of efficiency in mothers, their psychological condition can be improved and this process will ultimately lead to a reduction in their caregiver burden. Therefore, it is suggested to address participatory role of fathers in the caregiver burden of mothers in future studies. It is also recommended to address the factors affecting the caregiver burden according to regional conditions in further comprehensive research so that we may implement methods to reduce the caregiver burden of mothers by accurately recognizing and gaining a broader and more comprehensive view of these variables in future planning.

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Conflict of interest

The authors have declared no conflicts of interest.

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