The Effect of Home Education Provided to Caregivers of Children with Cancer on Caregiving Burden, Depression and Life Satisfaction[*]

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Abstract

Aim: In this study; It was aimed to reduce the care burden, decrease depression levels and increase life satisfaction by providing training to the caregivers of children with cancer.

Method: The research was designed as pre-test post-test, single group and semi-experimental. The target population of the study consisted of family members who give care for children with cancer patients. The study was conducted with 30 family members between May 2017 and September 2018, without using the sampling method, who met the criteria for participation in the study. "Information Forms Describing Patients and Caregivers, Caregiving Burden Scale, Beck Depression Scale and Life Satisfaction Scale" were used in data collection. In analysis the data; percent distribution and t test in

independent groups was used.

Results: In the study, the caregivers' total mean score on the Caregiving Burden Scale was found to be 53.63±11.67 before the training and 44.76±6.99 after the training. Beck Depression Scale total score average before 13.23±5.01 and after training It was found to be 9.03±3.66. The mean total score of the Life Satisfaction Scale was found to be 20.16±7.01 before the training and 25.23±5.22 after the training. These differences between the average scores were determined to be statistically significant ($p<0.01$).

Conclusion: It has been found that education given to caregivers of children with cancer is effective in reducing the burden on caregivers, decreasing their depression levels, and increasing their life satisfaction.

Keywords: Cancer, depression, education.

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[*] This study is derived from the doctoral thesis, the details of which are given below: Author: Ela VAROL. Title: "Kanser hastası olan çocukların bakım vericilerine evde yapılan eğitimin bakım yükü depresyon ve yaşam doyumuna etkisi / The effects of home education on caregiver care burden depression and life satisfaction for caregivers of children with cancer patients" Ataturk University, Institute of Health Sciences, Department of Public Health Nursing. Advisor: Dr. Öğr. Üyesi Nazli HACIALİOĞLU ; A part of this study was presented as an oral presentation at the Palandöken International Nursing Education Congress, 24-26 October 2019, Erzurum, Turkey.

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ETHICAL STATEMENT: Before the study was conducted, ethics approval was obtained from Atatürk University Ethics Committee (dated 13/05/2015 -13 Protocol No), and written permission was obtained from Atatürk University Health Application and Research Center. Before data was collected, participants were informed about the study and stated that participation was voluntary. The research was carried out in accordance with the rules of the Declaration of Helsinki.

Kanserli Çocuklara Bakım Veren Bireylere Evde Verilen Eğitimin Bakım Yükü Depresyon ve Yaşam Doyumu Üzerine Etkisi

Öz

Amaç: Bu çalışmada; kanserli çocuklara bakım verenlere eğitim verilerek bakım yükünün azaltılması, depresyon düzeylerinin düşürülmesi ve yaşam doyumunun artırılması hedeflendi.

Yöntem: Araştırma ön test son test, tek grup ve yarı deneysel olarak tasarlanmıştır. Araştırmanın evrenini kanser hastası çocuklara bakım veren aile bireyleri oluşturmaktadır. Araştırma, Mayıs 2017-Eylül 2018 tarihleri arasında, örnekleme yöntemi kullanılmadan, araştırmaya katılma ölçütlerini karşılayan 30 aile üyesi ile yürütüldü. Verilerin toplanmasında "Hasta ve Bakım Verenleri Tanımlayan Bilgi Formu, Bakım Yükü Ölçeği, Beck Depresyon Ölçeği ve Yaşam Doyumu Ölçeği" kullanıldı. Verilerin analizinde; bağımsız gruplarda yüzde dağılımı ve t testi kullanıldı.

Bulgular: Araştırmada bakım verenlerin Bakım Verme Yükü Ölçeği toplam puan ortalamasının, eğitim öncesi 53,63±11,67 ve eğitim sonrası 44,76±6,99 olarak bulundu. Beck Depresyon Ölçeği toplam puan ortalamasının eğitim öncesi 13,23±5,01 ve eğitim sonrası 9,03±3,66 olduğu tespit edildi. Yaşam Doyumu Ölçeği toplam puan ortalamasının, eğitim öncesi 20,16±7,01 ve eğitim sonrası 25,23±5,22 olarak bulundu. Ortalama puanlar arasındaki bu farkların istatistiksel olarak anlamlı olduğu belirlendi ($p<0,01$).

Sonuç: Kanserli çocuklara bakım verenlere verilen eğitimin bakım verenlerin yükünü azaltmada, depresyon düzeylerini düşürmede ve yaşam doyumlarını artırmada etkili olduğu bulundu.

Anahtar Sözcükler: Depresyon, eğitim, kanser.

Introduction

Although the incidence of cancer varies from country to country, it is gradually increasing, and cancer continues to be an important public health problem. Although the cancer incidence rate in children is lower than in adults, it is one of the leading causes of childhood death[1]. The most common types of cancer diagnosed in children aged 0-14 around the world are leukemia, lymphoma, and central nervous system tumors. Similarly, the most common childhood cancers are leukemia and lymphoma in Turkey[2].

Chemotherapy, radiotherapy, surgery, stem cell transplantation, complementary and alternative treatment methods are used in the treatment of childhood cancers. These methods are applied alone or in combination according to the patient's diagnosis and disease status. Increasing treatment possibilities in cancer and increasing the quality of care have decreased mortality rates and prolonged survival time. For this reason, cancer has become one of the chronic diseases that require long-term care. Therefore, home care after hospitalization has become necessary in cancer, as in other chronic diseases[3].

Caregiving is an experience that can be perceived by caregivers in a multidimensional way. Conditions such as the psychology of the child, treatment costs, exacerbation and recurrence of symptoms, inadequate symptom management, deterioration in social relations and difficulties in daily life can strain the caregivers physiologically and psychologically. Especially primary caregivers may experience problems such as stress, depression, social isolation, fatigue and exhaustion[4,5].

In Turkish culture, as in some societies, women are primarily responsible for household affairs and taking care of children. Caring for a sick child is perceived as a task that a woman must fulfill. In addition, it is known in our society that women are more compassionate and sensitive, and they can cope better with the difficulties they face in providing care than men. For this reason, mothers are more involved in the care of children with cancer than other family members. This situation can negatively affect the psychological and social status of mothers. Consequently, care burdens increase even more[6]. In the literature, there are studies showing that women participate more in the care of cancer patients and their care burden is higher than men[6,7].

The increased care burden causes lifestyle changes and adaptation problems in the caregiver. In time, caregivers start to have psychological difficulties, and situations such as anger, anxiety, and sleep disorders may occur. When these situations are not dealt with, depression may develop[8]. When depression in caregivers cannot be prevented or treated with early diagnosis, symptoms of depression become progressively worse. There is a decrease in the caregiver's quality of life and life expectancy. This situation causes the life satisfaction of the caregiver to be negatively affected over time[9].

Increased care burden, increased depression level, and decreased life satisfaction negatively affect the physical and mental health of caregivers. Caregivers' adaptation to the disease process, their ability to overcome problems and to apply the necessary care is directly proportional to their own good health. Therefore, evaluating and supporting the physical and mental distress of caregivers during the stressful cancer process is extremely important for quality care and a successful treatment process[10].

With good home care in cancer, many risks are prevented, treatment is adapted, hospitalizations are reduced, and the recovery rate increases. For this, it is essential to plan good care in-home care so that the child and caregivers do not have problems[11].

The most important attempt to ensure the correct home care of a child with cancer is to educate caregivers at all stages of the disease and to provide them with knowledge, attitude, and skills regarding care. With the training, a new perspective can be gained in caregivers to solve their problems, the care burden they feel can be reduced, depression can be reduced, and their life satisfaction can be increased. At this point, it is necessary to train caregivers about what the disease is, treatment and side effects, expected symptoms, nutrition, coping mechanisms, physiological needs, maintaining a normal family life, and encouraging the patient[12]. This study was conducted to decrease the care burden, decreasing the depression levels, and increase the life satisfaction with education given to the caregivers of children with cancer.

Hypotheses of the Research;

H1: Educating caregivers of children with cancer reduces the care burden.

H2: Educating caregivers of children with cancer reduces the level of depression.

H3: Educating caregivers of children with cancer increases life satisfaction.

Material and Methods

Purpose and Type of the Study

In this study, it was aimed at reducing the burden of care, reducing depression levels, and increasing life satisfaction by providing education to caregivers of children with cancer. The research was designed as a pre-test post-test quasi-experimental design without a control group.

Sampling and Participant

The universe in the research; consists of individuals who care for a child between the ages of 6 and 12 who has lymphoma or leukemia and is receiving treatment at Atatürk University Health Research and Application Center. The treatment process for lymphoma and leukemia cancers is similar. Symptoms and complications of treatment are similar. The effect of treatment on care burden is the same. For this reason, only caregivers of children with acute lymphoblastic leukemia (ALL) and lymphoma were included in the study. As a result of the power analysis, it was determined that 30 participants were needed with a 95% confidence interval between pre-test and post-test and an effect size of 0.8. Non-probability sample selection was made in the research. Between the relevant dates, 34 caregivers who met the inclusion criteria and agreed to participate in the study were included in the study. 4 caregivers left the study, and the research was completed with 30 caregivers.

Criteria for inclusion in the study;

- A person who cares for a child who has had lymphoma or leukemia for at least 3 months and at most 5 years.
- Person caring for a child who has been receiving chemotherapy treatment for at least 3 months
- A person who does not have a physical or mental illness
- Person without communication barriers

Collection of Data

The participants were met at the Atatürk University Health Research and Application Center Pediatric Hematology Polyclinic. The purpose of the research was explained, and permission was obtained from the participants. Afterwards, the caregivers were visited at their homes. Pretest data were collected at the first visit. Posttest data were collected at the last visit. Data were collected using a face-to-face interview technique. Data collection took approximately 20-30 minutes. Pre-test data were collected by applying "Information Forms Introducing Patients and Caregivers, Caregiving Burden Scale, Beck Depression Scale and Life Satisfaction Scale" to the caregivers. Later, a total of six home visits were made at two-week intervals. In other home visits; Trainings were given on cancer, treatment methods, basic care needs of the child, prevention of symptoms, what to do in emergencies, institutions providing social support, psychosocial needs, adaptation to treatment, coping with crisis, and ensuring correct communication within the family (via Power point presentation). A booklet containing the training given and prepared by scanning the literature was given. Additionally, the caregiver's questions were answered and feedback was received at each visit. Training was completed in the first five home visits. Each home visit lasted 40-50 minutes. Post test data are collected at the sixth home visit without training or feedback.

Data Collection Tools

Information Form Introducing the Patients: The form was developed by the researcher. The form was created from four questions. (age, gender, time of diagnosis and duration of treatment)

Information Form Introducing Caregivers: The form was developed by the researcher. The form was created from fifteen questions. In the form, nine questions measure sociodemographic characteristics, and six questions measure disease related information.

Care Burden Scale (CBS): It was developed by Zarit, Reever and Bach-Peterson (1980) to evaluate the difficulties experienced by caregivers[13]. It was adapted to Turkish by İnci and Erdem[14]. In the Turkish form of the scale, the Cronbach Alpha coefficient was found 0.87. The scale consists of 22 statements about the social and emotional domains that determine the impact of caregiving on an individual's life. A score between 0-88 can be obtained on a Likert type scale from 0 to 4. In scoring, 0-20 points: no care burden, 21-40 points: mild care burden, 41-60 points: medium care burden, and 61-88 points: heavy care burden[14]. In this study, the Cronbach alpha coefficient was found to be 0.80.

Beck Depression Scale (BDS): It was developed by Beck et al. to evaluate the severity of cognitive, emotional, somatic, and behavioral symptoms of depression[15]. It was adapted into Turkish by Hisli[16]. In the Turkish form of the scale, the Cronbach Alpha coefficient was found to be 0.74. The scale consists of 21 items that question how individuals over the age of 15 felt in the last week. Each item contains a four-grade self-assessment statement that identifies a behavior specific to depression. Scores between 0-63 can be obtained on the scale. Scores of 0-13 indicate absence of depression, scores between 14-24 indicate moderate depression, and scores above 25 indicate severe depression[16]. In this study, the Cronbach alpha coefficient was found to be 0.70.

Life Satisfaction Scale (LSS): It was developed by Diener et al. to evaluate the general life satisfaction of individuals[17]. The scale was adapted to Turkish by Yetim[18]. In the Turkish form of the scale, the Cronbach Alpha coefficient was found to be 0.86. The scale consists of 5 items. It is a 7-point Likert type and for each item, options such as "Strongly Disagree (1), Disagree (2), Partially Disagree (3), Undecided (4), Partially Agree (5), Agree (6), Strongly Agree (7)" were presented. Each item is scored between 1 - 7 and scores between 5 and 35 can be obtained from the scale. High scores indicate high life satisfaction[18]. In this study, the Cronbach alpha coefficient was found to be 0.90.

Statistical Analysis

The data were analyzed at a significance level of 0.01 using the statistical package program. Frequency, percentage, minimum, maximum, average and standard deviation values were used in the analysis of the data. A t test was used to compare the differences between pre- and post-test values. Kolmogrow-Sminov test was performed for normality test.

Ethical Aspect of Research

Before the study was conducted, ethics approval was obtained from Atatürk University Ethics Committee (dated 13/05/2015 -13 Protocol No), and written permission was obtained from Atatürk University Health Application and Research Center. Before data was collected, participants were informed about the study and stated that participation was voluntary. The research was carried out in accordance with the rules of the Declaration of Helsinki.

Results

According to the data obtained from the research, it was determined that 66.7% of children with cancer with an mean age of 8.66 ± 2.8 were boy, 90% of them were diagnosed with ALL, and the mean treatment duration was 12.93 ± 9.89 months (Table 1).

Table 1. Distribution of introductory characteristics of children with cancer

Specifications	**n**	**%**
Age	30	X± SD:8.66±2.8
Gender		
Male	20	66.7
Female	10	33.3
Diagnosis		
ALL	27	90.0
Lymphoma	3	10.0
When treatment was started	30	X± SD:12.93±9.89

SD: Standard deviation

All participants in the study are mother. It was found that 80% of the caregivers with an mean age of 36.13 ± 6.05 were nonworker, 40% had 1-2 children, 73.3% lived in the nuclear family, and 56.7% had difficulty in meeting their health expenses. 56.7% of the caregivers stated that they were responsible for the care of someone else, 56.7% stated that they did not receive assistance in care, 53.3% said that they received social support occasionally while providing care, and 70% thought they had enough knowledge about care (Table 2).

Table 2. Distribution of introductory features of caregivers

Specifications	**n**	**%**
Age	30	x±SD:36.13±6.05
Working status		
Worker	6	20.0
Nonworker	24	80.0
Number of children		
1-2	12	40.0
3-4	12	40.0
5 and +	6	20.0
Family type		
Nuclear family	22	73.3
Extended family	8	26.7
Difficulty in meeting health expenses		
Yes	13	43.3
No	17	56.7
Caregiver's state of caring for another individual		
Yes	17	56.7
No	13	43.3
Caregiver's state of getting help from someone else		
Yes	13	43.3
No	17	56.7
Caregiver's social support status		
Never	14	46.7
Sometimes	16	53.3
Status of having knowledge about Care requirements		
Knowledgeable	21	70.0
Partially knowledgeable	9	30.0

SD: Standard deviation

In this work means of caregivers before training from CBS 53.63±11.67, BDS 13.23±5.01, LSS 20.16±7.01 and means of caregivers after training from CBS 44.76±6.99, BDS 9.03±3.66, LSS 25.23±5.22 has been found (Table 3).

Table 3. Distribution of min-max points and means of caregivers before and after training from CBS, BDS, LSS

Measurement time	Scales	Min	Max	x± SD
Before Training	**CBS**	33	82	53.63±11.67
	BDS	4	27	13.23±5.01
	LSS	8	29	20.16±7.01
After Training	**CBS**	30	58	44.76±6.99
	BDS	4	19	9.03±3.66
	LSS	14	34	25.23±5.22

Min.: Minimum; Max.: Maximum, SD: Standard deviation, CBS: Caregiving Burden Scale, BDS: Beck Depression Scale, LSS:Life Satisfaction Scale

When the caregivers' mean scores obtained from the scales before and after the training were compared; It was seen that the care burden score which was 53.63±11.67 before the training fell to 44.76±6.99 after the training; The depression score which was 13.23±5.01 decreased to 9.03±3.66 after the education; the life satisfaction score which was 20.16±7.01 increased to 25.23±5.22 after the training. It was determined that these differences between the mean scores were statistically significant (p<0.01) (Table 4).

Table 4. Comparison of the mean scores of the caregivers before and after the training in CBS, BDS, LSS

Scales	Before Training	After Training	Test and p value
CBS	53.63±11.67	44.76±6.99	t=6.23, **p=0.0001***
BDS	13.23±5.01	9.03±3.66	t=9.21, **p=0.0001***
LSS	20.16±7.01	25.23±5.22	t=7.75, **p=0.0001***

*=p<0,01 CBS: Caregiving Burden Scale, BDS: Beck Depression Scale, LSS:Life Satisfaction Scale

Discussion

In this section, findings obtained from the study conducted to determine the effect of home education for caregivers of children with cancer on care burden, depression, and life satisfaction are discussed with similar study results. The caregivers' pre-test CBS mean scores were found to be moderate (Table 4). Situations such as changing roles in the family, having more than one person responsible for their care, insufficient income, not receiving social support, and not reaching resources cause an increase in the burden of care for caregivers[19,20]. In a study measuring the caregiving burden of parents of children with chronic diseases, the care burden of parents was found to be moderate[21]. In another study, the care burden of caregivers of children with cancer was found to be moderate[12]. The moderate level of care burden in this study was found to be consistent with the results of research conducted with different groups.

When the posttest data were examined, it was determined that the care burden scores of the caregivers before the training, which was 53.63±11.67, decreased to 44.76±6.99 after the training and the difference was statistically significant ($p<0.01$) (Table 4). Lack of education and nonpreparation in meeting the physiological and psychological needs of the child increases the care burden felt by the caregiver. Informing the caregiver about care, knowing what is waiting for him/her, reduces the felt care burden[6]. In their study, Öğür et al. Applied a planned training program to individuals who care for bedridden patients at home and found a significant decrease in the care burden of caregivers after the training[22]. In their study, Belgacem et al. (2013) Provided training on nursing care and symptom management to individuals who care for cancer patients. They found a significant decrease in caregivers' care burden after training[23]. In another study conducted with the caregivers of individuals with breast cancer, it was found that psychosocial interventions and training (breast cancer and basic information, communication with the patient, symptom management, information about care) had an effect on the reduction of care burden[24]. The results of this study are similar to the literature.

When the BDS mean scores of caregivers before the training were examined, it was found that depression levels were low (Table 4). In the studies of Katende and Nakimera (2017), it was determined that the depression levels of caregivers were high[25]. Softa and Çelik found that the depression levels of patients' relatives who received chemotherapy were moderate[26]. In this study, the low mean scores of BDS of caregivers before the training may be due to the different demographic characteristics. The fact that their children were not hospitalized during the period of pre-test data collection and their condition was good, the data being collected at home and therefore the mothers felt more comfortable may have caused the depression results of the mothers to be low.

When the total BDS mean scores of the caregivers were compared before and after the training, it was found that the post-test mean score decreased and the difference was statistically significant (p <0.01) (Table 4). It is known that nursing care given to the caregivers of cancer patients for areas where care is difficult, prevents depression and reduces symptoms of depression[23,25]. However, when depression cannot be prevented or diagnosed early in caregivers, symptoms of depression increase and treatment becomes difficult[26]. Heckel et al. (2018) implemented a telephone training and counseling program for the caregivers of cancer patients for 6 months. At the end of the program, they found that education was effective in caregivers with depression risk[27]. In another study conducted with caregivers of elderly patients, it was observed that education and counseling with home visits reduced the risk of depression in caregivers[28]. This finding is consistent with the literature.

In this study, it was determined that LSS of caregivers before the training was moderate (Table 4). Caring for the sick child causes physical, economic and emotional difficulties in the caregiver. This situation increases the caregiver's stress, concern, and anxiety level and causes a decrease in the quality of life and life satisfaction[4]. Similar to this study, there are studies in the literature in which the life satisfaction of caregivers of individuals with chronic diseases was found to be moderate[29-31].

When the LSS total score means of caregivers of children with cancer were examined, it was found that the increase in life satisfaction level was statistically significant (p<0.01) (Table 4). When the training needs of caregivers on issues such as combating stress, social support, ensuring family adaptation, communication are met, when they can access social support resources, when their care burden is reduced, their quality of life can be increased by making them feel better. Thus, life satisfaction can be increased[4]. There are many studies in the literature that improve the quality of life of cancer patients' caregivers with training, counseling and therapies[12,24]. In some studies conducted with the aim of reducing stress and increasing life satisfaction in caregivers, it was found that the education given had an effect on increasing life satisfaction by reducing stress[32,33]. The finding of this study is in line with the literature finding.

Conclusion

As a result of this study, it was found that the care burden and life satisfaction of the individuals who cared for children with cancer were moderate and their depression levels were low. It has been found that the education provided reduces the care burden and depression levels of the caregivers and increases their life satisfaction. In line with these results, the recommendations are as follows: Individuals who care for children with cancer should be provided with nursing care, education and counseling after hospital treatment. This training should especially include coping with negative situations during the treatment process. Education should be continued in individuals' homes as much as possible. Training should be repeated at certain periods and supported by telephone and written literature. Caregivers should be supported by a multidisciplinary team. Training and counseling for caregivers should be increased in private and state institutions.

Limitations of Study

The limitations of this study are that the data of the study were collected only from the caregivers of patients enrolled in one hospital, and the control group was not used because there were not enough cases at the time of the study and 4 caregivers left the study. For these reasons, the results obtained from the research can only be generalized to this group.

Conflict of Interest

No conflict of interest has been declared by the authors.

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