ARAŞTIRMA / RESEARCH The Assessment of Depression in Siblings of Children with Cancer: A Pilot Study

Kanserli Çocukların Kardeşlerinde Depresyonun Değerlendirilmesi: Bir Pilot Çalışma

İbrahim EKER¹© Özge VURAL²©, Hamide Nur ÇEVİK ÖZDEMİR³©, Elif Bilge KELEBEK⁴©, Nihan ÇAKALOĞULLARI⁵ @ Naci GÜLTEKİN⁵©, Özge KAYA⁵(), Esma KURAL⁵(), Bilge MUMYAKMAZ⁵(), Orçun ÖZTÜRK⁵(), Nevzat SAKARYA⁵()

¹Afyonkarahisar Health Sciences University, Faculty of Medicine, Department of Pediatric Hematology, Afyonkarahisar, Turkey ²Gazi University, Faculty of Medicine, Department of Child Health and Diseases, Ankara, Turkey ³Afyonkarahisar Health Sciences University, Faculty of Health Science, Department of Child Health and Diseases Nursing, Afyonkarahisar, Turkey ⁴Afyonkarahisar Health Sciences University, Faculty of Medicine, Department of Child Health and Diseases, Afyonkarahisar, Turkey ⁵Afyonkarahisar Health Sciences University, Faculty of Medicine, Department of Mental Health and Illnesses, Afyonkarahisar, Turkey ⁵Afyonkarahisar Health Sciences University, Faculty of Medicine, Department of Mental Health and Illnesses, Afyonkarahisar, Turkey

⁶Afyonkarahisar Health Sciences University, Faculty of Medicine, Medicine student, Afyonkarahisar, Turkey

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Sorumlu Yazar/Corresponding Author:

Hamide Nur ÇEVİK ÖZDEMİR, Dr. Öğr. Üyesi Department of Nursing, Faculty of Health Science, Afyonkarahisar Health Sciences University, Afyonkarahisar, Turkey. E-posta: hamidenur43@hotmail.com ORCID: 0000-0002-1199-8801

İbrahim EKER, Doç. Dr. ORCID: 0000-0002-1880-546X

Özge VURAL, Dr. Öğr. Üyesi ORCID: 0000-0001-7523-7553

Elif Bilge KELEBEK, Asistan Dr. ORCID: 0000-0003-4445-2669

Nihan ÇAKALOĞULLARI, Asistan Dr. ORCID: 0000-0002-1762-1335

Naci GÜLTEKİN, Öğr. ORCID: 0000-0002-0141-581X

Özge KAYA, Öğr. ORCID: 0000-0002-5907-304X

Esra KURAL; Öğr. ORCID: 0000-0002-5380-2176

Bilge MUMYAKMAZ; Öğr. ORCID: 0000-0001-7808-7693

Orçun ÖZTÜRK; Öğr. ORCID: 0000-0001-8611-2625

Nevzat SAKARYA; Öğr. ORCID: 0000-0001-7211-2456

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Abstract

Objective: When compared to other siblings, siblings of cancer patients have a reduced quality of life, impaired emotional functionality, and post-traumatic stress symptoms. The present study aimed to determine the depression levels of the siblings of children with cancer.

Material and Method: The present study is descriptive and cross-sectional. Thirty healthy siblings of children with cancer who were followed up in the pediatric hematology-oncology service of a university hospital were included in the study. Descriptive information form and the Child Depression Inventory (CDI) was applied to the siblings.

Results: It was found that 33.3% of the siblings had depression. When they were first informed about their siblings' illness, 60% of the participants stated that they experienced fear and approximately 34% experienced sadness. All the siblings stated that the financial situation of their families was affected during the illness. There was no significant difference between the siblings' depression scores and their gender or age.

Conclusion: Siblings of children with cancer experience depression and psychological reactions associated with cancer. There is a need to improve siblings' cancer-related problems with family-based psychosocial interventions. In future studies, empirical, intervention studies with larger samples are needed on the subject.

Keywords: Depression, siblings, children with cancer.

Öz

Amaç: Kanserli çocukların kardeşleri, diğer kardeşlere göre daha düşük yaşam kalitesi, zayıf duygusal işlevsellik ve travma sonrası stres belirtileri göstermektedir. Bu çalışmanın amacı kanserli çocukların kardeşlerinin depresyon düzeylerini belirlemektir.

Gereç ve Yöntem: Tanımlayıcı, kesitsel tipte bir çalışmadır. Çalışmaya bir üniversite hastanesinin çocuk hematoloji-onkoloji servisinde takip edilen kanserli çocukların sağlıklı 30 kardeşi alındı. Kardeşlere tanımlayıcı bilgi formu ve Çocuk Depresyon Envanteri (ÇDE) uygulandı.

Bulgular: Kardeşlerin %33,3'ünde depresyon olduğu saptandı. Kardeşlerinin hastalıklarını ilk duyduklarında katılımcıların %60'ı korku, yaklaşık %34'ü üzüntü yaşadığını bildirdi. Kardeşlerin tamamı hastalık sürecinde ailelerin maddi durumlarının etkilendiğini belirtti. Kardeşlerin cinsiyet ve yaşları ile depresyon skorları arasında anlamlı farklılık saptanmadı.

Sonuç: Kanserli çocukların kardeşleri kanserle ilişki depresyon ve psikolojik reaksiyonlar yaşamaktadır. Kardeşlerin kanserle ilgili sıkıntılarını aile temelli psikososyal müdahalelerle iyileştirmeye ihtiyaç vardır. Gelecekteki çalışmalarda konu ile ilgili daha geniş örneklemli ampirik çalışmalara ihtiyaç vardır.

Anahtar Kelimeler: Depresyon, kardeş, kanserli çocuk.

1. Introduction

Cancer, one of the chronic diseases, is among the most important health problems seen in childhood in the world and in our country (1-3). Cancer affects not only the patient but also the family and relatives (2, 4). The diagnosis of cancer in a family member may cause changes in family dynamics and deepens the effects of cancer in the family (1, 5, 6). Having cancer during childhood and its treatment can have a major effect on the psychosocial adaptation of the child, parents, and siblings (7,8). While some of the siblings adapt well to this process, others may show symptoms of anxiety and depression (9, 10).

The effects of cancer on the child and family have been studied for a long time. However, little attention is paid to healthy siblings in family systems, and the psychosocial adaptation of siblings to childhood cancer is not well understood (10). There is currently a growing perception in the healthcare field that the psychosocial needs of siblings of children with cancer get less attention than other family members, and their needs are not adequately met (11). Some researchers describe siblings of children with chronic diseases as the most vulnerable group to be overlooked. In previous studies, it was stated that siblings of children with cancer are sensitive to several adaptation problems such as depression, anger, anxiety, withdrawal, and social isolation (11).

It might be difficult to be the sibling of a cancer patient (7, 12). The treatment process affects the social and emotional worlds of siblings. This is because their interaction with their parents and sick siblings decreases. Changes can occur in usual social and recreational activities (12-14). Siblings of children with cancer may have different experiences during the treatment process because some families have more than one child. Having to take care of a sick child can interrupt the time spent with other children. Long hospitalizations and routine check-ups can cause problems between parents and siblings. Oftentimes, having insufficient knowledge about cancer can also result in uncertainty and anxiety in siblings. Sometimes, parents may not be available, which requires siblings to take on caregiver roles. Therefore, childhood cancer affects the functioning of siblings in many areas (10, 12).

The psychological impact of cancer on siblings has been investigated in both qualitative and quantitative studies (8, 12, 15). Most of these studies are descriptive and tend to examine differences between siblings based on sociodemographic characteristics and treatment factors (16, 17). In the content analysis results of the interviews with siblings, obscurity, stress, change, fear of death, as well as themes such as anxiety and social isolation have been reported to emerge (18). Other studies have found that siblings of children with cancer have a lower quality of life, poor emotional functionality, and post-traumatic stress symptoms when compared to other siblings. It is also reported that they experience more depression, anxiety, or behavioral problems (7, 10, 15).

In the light of this information, it is necessary to evaluate the presence of depression in siblings of children with cancer in order to determine the psychosocial adjustment problems and risks that may occur in siblings in the future. Based on this, this study evaluated the depression levels of siblings of children with cancer.

The study focused on the following essential questions;

What is the depression score of the siblings of children with cancer?

Do depression scores of children with cancer and their siblings differ significantly with their socio-demographic (gender, age, socioeconomic status, disease diagnosis, etc.) characteristics?

2. Material and Methods

2.1. Study Design

This is a descriptive and cross-sectional pilot study to determine the depression levels of siblings of children with cancer.

2.2. Participants

Participants were chosen from the pediatric hematology and oncology service of a university hospital in Afyonkarahisar province in Turkey. Participants included in the study were 3–18-year-old siblings of children with malignancies, who were treated or not treated in the pediatric hematology and oncology service between 2016 and 2019 and received follow-up care. Study included 30 siblings, one from each family. The siblings of children with cancer whose parents were separated, who lost a family member recently, who received palliative care, and siblings with a chronic and psychological disorder were excluded from the study. One of the researchers carried out the patient follow-up in the polyclinic and the service. Of the 50 siblings interviewed by the researcher, 40 consented to the interview. Following the researcher's communication, five siblings refused to participate in the study, and five did not complete the questionnaire. Incomplete and incorrect questionnaires were not included in the study. Other socio-demographic and treatment-related data were not recorded for the non-participants due to the regulations regarding the protection of patient data in the hospital.

2.3. Data Collection and Instruments

The siblings of children with cancer were individually interviewed for the study. A descriptive information form and the Children's Depression Inventory (CDI) were used in data collection.

Instruments;

Descriptive Information Form

Descriptive information form, in line with the relevant literature (8, 19), was prepared by the researchers. This form included ten questions regarding the sociodemographic characteristics of the siblings of children with cancer, such as gender, age, number of siblings, family type, and income level. In addition, in this form, there were four questions related to the sociodemographic characteristics (age, gender, disease diagnosis, duration of diagnosis, etc.) of the child with cancer.

Children's Depression Inventory (CDI)

Kovacs (1981) developed the Children's Depression Inventory based on the Beck Depression Scale (20). It is a self-report scale applied to children aged between 6 and 17. The child completed the scale by reading or having it read to him or her. The scale consists of 27 items, and there are three answer options for each item. The child is asked to choose the most relatable sentence for himself/herself for the last two weeks. E.g: 1 I feel sad every now and then. 2.I often feel sad. 3. I feel sad all the time. Each item gets 0, 1, or 2 points depending on the severity of the symptom. The maximum score is 54. The higher the score, the heavier the depression. The cut-off score of the scale is 19. The reliability and validity study of the scale was done by Öy (21) in Turkey and the cutoff point was identified as 19 points. Öy (21) reported the test-retest reliability of the depression scale for children as 0.70 and the internal consistency as 0.80 in his study.

A researcher in the clinical care team examined the computer records of pediatric cancer patients to identify siblings of children with cancer who met the initial inclusion criteria. They informed the children, their parents, and siblings about the purpose of the study and obtained their verbal and written consent. If the patient had a large number of gualified siblings, the patient's closest age sibling was invited to participate in the study. The date, time, and place were set to fill the study questionnaires with siblings who agreed to participate in the study. These interviews took place in the meeting room at the polyclinic by an expert researcher of the research team. Each meeting was held individually with siblings. The meeting and forms took about 15 minutes to complete. The siblings who met the inclusion criteria waited in the waiting room until the meeting time, accompanied by the other researcher.

2.4. Statistical Analysis

SPSS 21.0 for Windows (SPSS Inc., Chicago, Illinois, USA) package program was used to analyze the study data. Descriptive statistics were used to characterize children with cancer and their siblings. Frequencies and percentages were used for categorical variables. Median (minimum-maximum) values were used for continuous variables. For the presence of depression, as a result of the evaluation of the scale, the cut-off score of which was recommended as 19, the difference between the percentages of the answers of the participants (with depression detected or not) to the questions in the data form and the questionnaire was evaluated using McNemar tests for dependent variables while chi-square tests were used for independent variables. All statistical evaluations were done bilaterally, and a p <0.05 value was accepted as the level of significance.

3. Results

Some individual characteristics of children with cancer and their siblings are presented in Table 1. The ages of siblings of children with cancer range from 7 to 18 years and the average age was 13.00 ± 3.20 (X±SD). The ages of children with cancer range from 4 to 19 years and the average age was 11.30 ± 4.48 (X±SD). Of the siblings, 56.7% were females. While ALL (Acute Lymphoblastic Leukemia) constituted 50% of the medical diagnoses of the children, 6.7% were rhabdomyosarcoma. The time elapsed since the children were diagnosed ranged from 2 to 48 months, and the mean was 18.07 (2 \pm 48) months (Table 1).

Table 1. Individual Characteristics of Children with Cancer and Their Siblings (N = 30)

Variables	Groups	f	%
Siblings Characteristics			
Gender	Female	17	56.7
	Male	13	43.3
Age	13.00 ± 3.20		
Number of Siblings	2	8	26.7
	3	17	56.7
	4	5	16.6
Sibling rank	1st	9	30.0
	2nd	17	56.7
	3rd	4	13.3
Feelings when they first learned about the disease	Fear	18	60.0
	Sadness	10	33.3
	Uneasiness / stress	2	6.7
Characteristics of Children with Cancer			
Gender	Female	12	40.0
	Male	18	60.0
Age	11.30 ± 4.48		
Diagnosis	Acute Lymphoblastic Leukemia	15	50.0
	Acute lymphoblastic Leukemia	3	10.0
	Hodgkin lymphoma	4	13.3
	Rhabdomyosarcoma	2	6.7
	Solid tumors	6	20.0
Duration of diagnosis/month	2 ± 48		
Family income	≤ 2.000 TL	10	33.3
	2.000 -5.000 TL	17	56.7
	≥ 5. 000 TL	3	10.0
Marital status of parents	Married	28	93.3
	Single	2	6.7

The mean depression score of the participants was found to be 12 (1-25) points. According to the cut-off score of the depression scale of 19, 33.3% of the siblings of children with cancer were found to have depression (Figure 1). The siblings with depression were equal in terms of gender distribution. Of the siblings, 80% had a diagnosis of ALL and 20% had a diagnosis of HL (Hodgkin's Lymphoma). Of the participants, 60% stated that they experienced fear after learning about their sibling's illness. None of the siblings received professional psychological support. All the siblings reported that the financial situation of their families was affected during the illness. No statistically significant relationship was found between the time elapsed since the diagnosis of the disease and the depression score. In terms of depression scores and demographic characteristics, no statistically significant difference was identified between participants who were found to have depression and those who were not.





4. Discussion

In this study, depression levels of siblings of children with cancer were investigated. Study findings showed that a guarter of the siblings had depression. The presence of depression was equally distributed among siblings according to gender. These findings show that siblings of children with cancer may be psychologically vulnerable during treatment process. Similar to our study findings, Alderfer et al. (7) reported that only 5% of the siblings of children with cancer initially showed high depression symptoms, which was 9% lower than the children's previous depression scores. Kaplan et al. (15) stated in their study that more than half of the siblings (60%) experienced moderate to severe cancer-related post-traumatic stress, and approximately a quarter (22%) met the criteria for posttraumatic stress disorder. Besides, siblings with cancer-related post-traumatic stress disorder reported more anxiety and depression than others (15). These figures reveal that siblings may experience cancer-related distress and adjustment problems.

Depression symptom/presence may have a potential longterm impact on the psychological adjustment of siblings of children with cancer (22). Given the preliminary results from our study findings, mental health may not be a priority for families with difficulties, and their children's illness may be in the first place. Studies assume that it is important to determine the symptoms of depression and other psychological risks for siblings in families with this condition (18, 22).

We could not find a significant correlation between the gender and age of the siblings and their depression scores. Past research has shown that women whose siblings have cancer are more likely to experience traumatic stress reactions (23, 24). In our study, similar to the other study, although we had a wide age range, we could not reveal differences in depression scores depending on age or gender. This result may be related to the small sample size of the study. In addition, siblings selected for the study may not be the siblings most at risk for depression. These findings suggest that gender and age may not be markers of siblings with a greater risk of depression symptoms in subgroups. Different from those, it is possible that siblings tend to underreport emotional and adaptation problems related to the disease and not fully express themselves. These possible reasons may affect depression scores. In identifying siblings at risk of cancer-related depression symptoms, it is thought that more research is needed to examine potential predictors such as individual temperament (25), emotional characteristics (26), family factors, and communication models.

Unlike our findings, Barrera (8) stated in his intervention study on siblings of children with cancer that sisters had higher symptoms of depression than brothers. In the same study, it was reported that depression scores decreased significantly after the intervention in siblings (8). The stress and increased needs experienced by siblings associated with pediatric cancers may increase the tendency to depression and anxiety (10, 18). The results further support the need for developing psychological interventions to meet the special needs of siblings who experience stress related to cancer (22, 27).

Cancer continues to have long-term effects on children and their families. According to studies on the anxiety levels and psychiatric symptoms of children who lost their siblings to cancer, even 2-9 years after the loss of their siblings, they experienced higher anxiety, and more than half of the teenagers were still mourning (28, 29). These results reveal that the siblings experience depression, anxiety, and grief during and after the disease, especially after the death of siblings. The bond between siblings is thought to be one of the most important bonds in one's life, just as the bond between parents and children (29-31). Therefore, it can be difficult for young adolescents to face the loss of their siblings suffering from cancer.

Overall, our results show that siblings of children with cancer experience feelings of fear, sadness, and distress/ stress. Similarly, a study with siblings of children with cancer involved children's experiences associated with distress, a sense of exclusion, and having more than one stress at the same time (12). Our findings that siblings of children with cancer experience fear, sadness, and distress contribute to the growing evidence about sibling stress in this area. In the systematic review of Long et al., the anxiety, depression, and general adjustment levels of the siblings were similar to those in the comparison groups (10).

In our study, no moderator effect of income level on depression was found. Although the results did not reveal the effect of families' income on depression, siblings reported that lack of financial resources affected family processes. Economic and financial insufficiencies are important risk factors for mental health problems for families and caregivers. Families taking care of a child diagnosed with cancer have too many needs and demands and have trouble meeting them (32). When resources are insufficient in the family, there may be less interest in psychosocial services for siblings of children with cancer who may be thought to need less help, unlike the child with cancer. In a study conducted in the field of pediatric oncology, it was stated that families who are most at risk in terms of psychosocial difficulties do not have a workforce and have difficulty finding a job (33). In future field studies, a riskbased intervention approach can be adopted by targeting families with low socioeconomic levels. Long et al. (10) and Gerhardt et al. (14) consider that siblings of children with cancer need a strong support and that affected siblings should be systematically reviewed.

To summarize, the study findings will be able to contribute to the literature by revealing the depression levels of the siblings of children with cancer and raising awareness about focusing on the psychosocial needs of the siblings. Along with the research results in the literature (8, 10, 14) our study reveals the lack of psychological support services available for siblings of children with cancer and the need to establish evidence-based standards of care to help them.

5. Conclusion

As a result, siblings of children with cancer experienced disease-related depression. The siblings faced problems of fear, sadness, and stress along with depression. These symptoms were considered as long-term risk factors for siblings in terms of psychosocial adjustment problems.

Health professionals should be able to evaluate the child with cancer and their family as a whole and apply holistic care including siblings. At the same time, families of children with cancer, educators, and other people who may interact with siblings should be provided with information and awareness training on the impact of cancer on healthy siblings in the family. However, evidence from empirical studies is required to comprehensively identify and evaluate the depression symptoms of siblings. In line with this requirement, it is considered necessary to establish evidence-based standards of care to support siblings.

These recommendations can be difficult to implement, given the workload at most cancer centers, lack of budgets, and the fact that siblings may not be able to communicate with medical and psychosocial care teams regularly. Therefore, screening the siblings of children with cancer for factors such as anxiety, depression, and stress and referring them to a higher unit when necessary, should be an element of familybased pediatric cancer care. Siblings can benefit from schoolbased counseling by bolstering their current social networks.

In the future, qualitative and quantitative studies should be conducted in larger sample groups and in different regions to determine the depression symptoms of siblings of children with cancer. It is believed that there are potential and moderating factors affecting the presence of depression in siblings of children with cancer; these effects should be clarified. More research related to cancer, using a broader framework that is not limited, and research on the general significance of cancer in the lives of these siblings will be informative.

5.1. Limitations of the study

This study had several limitations. As a measure of the presence of depression, we used the Children's Depression Inventory (CDI), which is designed to assess the depression perceptions of siblings of children with cancer. Children completing this scale may not be able to fully interpret the questions appropriate to the nature of the clinical criteria to be evaluated in the scale. This scale may have yielded different results more generally and specifically than others (34) in determining children's depression. It is believed that these findings should be repeated with a different measurement tool in future studies. Results may not be generalized to siblings of children with other chronic diseases. Additionally, the small sample size may not be sufficient to adequately test some of the effects of important findings. A larger sample will allow more testing power in the statistical testing of these factors. Besides, although our study sample was relatively homogeneous compared to previous studies with siblings, there was heterogeneity in our sample in terms of treatment status. Some of the siblings in the sample had brothers or sisters still in treatment. This heterogeneity may, conceptually, be considered as a risk since depression symptoms can be seen while stressors related to the disease continue.

On the other hand, in those whose sibling's treatment is finished, the symptoms of depression may have decreased or may continue to act as a potential indicator. Finally, the study was conducted at a single center, although siblings of children with cancer who were treated in different facilities might be included in the study and extensively studied in subgroups of siblings.

6. Contribution to the Field

The study findings will contribute to the literature by revealing the depression levels of the siblings of children with cancer and raise awareness about focusing on the psychosocial needs of the siblings.

Ethical Aspect of the Research

The study received ethical approval from the university's Clinical Research Ethics Committee (IRB approval no: 2011-KAEK-2, 18.01.2019). Institutional permissions were obtained from the clinic where the study would be conducted. The participants provided informed consent. Additionally, informed consent was sought from the children's parents.

Conflict of Interest

This article did not receive any financial fund. There is no conflict of interest regarding any person and/or institution.

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Authorship Contribution

Concept: İE, ÖV, EBK, NÇ; Design: İE, ÖV, EBK; Supervision: İE, ÖV; Funding: İE; Materials: İE; Data Collection/Processing: İE, ÖK, NS, OÖ, BM, EK, NG; Analysis/Interpretation: İE, ÖV, EBK, NÇ; Literature Review: HNÇÖ, İE; Manuscript Writing: HNÇÖ, İE; Critical Review: HNÇÖ, İE.

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