



# Economic and psychosocial problems experienced by pediatric with cancer patients and their families during the treatment and follow-up process

Çocukluk çağı kanser hastaları ile ailelerinin tedavi ve izlem sürecinde yaşadığı ekonomik ve psikososyal sorunlar

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**Cite this article as:** Bozkurt C, Uğurlu Z, Tanyıldız HG, et al. Economic and psychosocial problems experienced by pediatric with cancer patients and their families during the treatment and follow-up process. *Turk Pediatri Ars* 2019; 54(1): 35-9.

## Abstract

**Aim:** To identify the psychosocial and economic problems of the pediatric patients with cancer who were treated at the Dr. Sami Ulus Obstetrics and Gynecology and Child Health and Diseases Training and Research Hospital's Pediatric Oncology Department and their relatives during this process.

**Material and Methods:** We interviewed a total of 100 patients who were treated at Dr. Sami Ulus Obstetrics and Gynecology and Child Health and Diseases Hospital's Pediatric Oncology Department between 1996 and 2015, and were now followed up without treatment and their relatives using survey questions on the psychosocial and economic problems they experienced.

**Results:** Most of patients were from provinces outside Ankara. The average monthly income was below the level that would meet the family needs in 80% of the families and only 16% had extra income. Additional economic support had been received by 93% of the families in the patient group. Twenty-five families (25%) had been forced to sell property during the treatment. Forty-nine (49%) families had borrowed money from acquaintances and relatives or had taken out a bank loan. Serious psychological problems were experienced during and after the treatment by 46% of the mothers; 41% of the families had used religious procedures more commonly during the treatment period to cope with the psychological problems. Education was subject to a 1-2 year pause in 83% of the patients.

**Conclusion:** Childhood-age patients with cancer and their families experience significant psychosocial and economic problems during and after the treatment process. Providing medical treatment and psychosocial support in harmony is an important factor that increases the success of cancer treatment. The patient and the family will require psychosocial support mechanisms throughout life, starting from the moment they face the disease. Developing national social support programs and legal regulations to form a basis for such programs are required in our country.

**Keywords:** Childhood age cancers, psychosocial problems, social support

## Öz

**Amaç:** Dr. Sami Ulus Kadın Doğum ve Çocuk Sağlığı ve Hastalıkları Eğitim ve Araştırma Hastanesi Çocuk Onkoloji Kliniği'nde tedavi edilmiş kanserli çocuk hastaların ve yakınlarının bu süreçte karşılaştıkları psikososyal ve ekonomik sorunları belirlemek.

**Gereç ve Yöntemler:** Dr. Sami Ulus Çocuk Sağlığı ve Hastalıkları Hastanesi Çocuk Onkoloji Kliniği'nde 1996-2015 yılları arasında tedavi görmüş ve şu anda hastalısız olarak izlemde olan toplam 100 hasta ve yakını ile görüşülerek yaşadıkları psikososyal ve ekonomik sorunlara ilişkin anket soruları yönlendirildi.

**Bulgular:** Hastalarımızın çoğu Ankara dışı illerden gelmekte idi. Hasta ailelerinin %80'inin ortalama aylık gelirinin ailenin gereksinimlerini karşılama düzeyinin altında olduğu ve sadece %16'sının ek geliri olduğu saptandı. Hasta grubunda ailelerimizin %93'ü ek ekonomik destek almışlardı. Yirmi beş aile (%25) tedavi süresince sahip oldukları bazı mal varlıklarını satmak zorunda kalmıştı. Kırk dokuz (%49) aile tanıdık ve akrabalarından borç almıştı ya da bankadan kredi çekmişti. Annelerin %43'ünün tedavi sırasında ve sonrası ciddi psikolojik sorunlar yaşadığı, psikolojik sorunlarla başa çıkabilmek için ailelerin %40'unda tedavi döneminde dini ibadetlere eğilimde artış olduğu gözlemlendi. Hastalarımızın %83'ünün eğitimlerinde 1-2 yıl gibi bir kayıp yaşandığı görüldü.

**Çıkarımlar:** Çocukluk çağı kanser hastaları ve aileleri tedavi sürecinde ve sonrasında önemli oranda psikososyal ve ekonomik sorunlar yaşamaktadır. Kanserde, tıbbi tedavi ile psikososyal desteğin bir uyum içerisinde yürütülmesi tedavi başarısını artıran önemli bir etmendir. Hastanın ve ailesinin hastalıkla tanıştığı ilk andan başlayarak tüm hayat boyunca psikososyal destek mekanizmalarına gereksinim vardır. Ülkemizde ulusal olarak bu yönde geliştirilecek sosyal destek programları ve bu programın yürütüleceği zemini oluşturacak yasal düzenlemelere gereksinim vardır.

**Anahtar sözcükler:** Çocuk çağı kanserleri, psikososyal sorunlar, sosyal destek

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**Received / Geliş Tarihi:** 24.12.2018 **Accepted / Kabul Tarihi:** 11.02.2019

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DOI: 10.14744/TurkPediatriArs.2019.11129

## Introduction

In Turkey, recovery rates reaching 70% have generally been obtained in pediatric cancers (1). With these recovery rates, pediatric cancers have many psychosocial and economic influences on patients, families, and the community throughout the whole treatment process from the time of diagnosis. In pediatric cancers, the disease process may lead to problems that could negatively affect the patient, including disruption in the treatment process, psychological problems and lack of social support, in addition to the problems experienced by the family. Therefore, providing psychosocial and economic support to patients and families besides medical treatment and harmonization of these interventions are important in cancer treatment. In this study, our aim was to investigate the psychosocial problems experienced by pediatric patients with cancer during the treatment processes, interventions to overcome these problems, and how these problems influenced the patients' treatment processes and health states.

## Material and Methods

One hundred patients who were treated at Dr. Sami Ulus Obstetrics and Gynecology and Child Health and Diseases Hospital's Pediatric Oncology Department between 1996 and 2015 and who were currently being followed up disease-free, and their relatives were interviewed. Face-to-face interviews were conducted by social workers at the settings preferred by the participants, considering the principles of volunteering. Standard questions related to economic status, social security, occupation, wealth and loss of property, support from relatives, psychological exhaustion, supporting individuals, problems experienced by siblings and methods used to lessen the extent during this process were asked to the patients and their relatives.

When the subtitles were examined in detail, property holding during and after the treatment process, monthly income in Turkish Lira, social security, additional income resources, the individuals and social institutions from whom they received support and economic losses during and after the treatment process were asked to the patients' families.

Related to psychological problems, the families and patients were asked about the psychological problems they experienced during and after the treatment process, if they consulted any psychiatrist or psychologist for these problems, and if they used any psychiatric drugs or substances in this process or which methods they used to overcome these problems.

This study was approved by Ankara Pediatrics and Hematology and Oncology Education and Research Hospital Ethics Committee (Approval number: 2018/127). In addition, the study was designed in accordance with the Declaration of Helsinki and informed consent was obtained from the patients or the patient's families.

## Results

Thirty-three of the patients were female and 67 were male. The mean age at the time of diagnosis was found as 6 (range, 1–15) years. The diagnoses of our subjects who were being followed up without treatment were as follows: acute lymphoblastic leukemia (n=23), Hodgkin lymphoma (n=25), Wilms tumor (n=10), Burkitt lymphoma (n=10), non-Hodgkin lymphoma (n=10), rhabdomyosarcoma (n=6), acute myelocytic leukemia (n=4), colon cancer (n=1), germ cell tumor (n=5), Langerhans cell histiocytosis (n=1), optic glioma (n=1), Ewing sarcoma (n=1), neuroblastoma (n=1), medulloblastoma (n=1), and hemangioendothelioma (n=1). The median treatment time of the patients was found as 3 years (range, 6 months to 6 years).

Most of our patients came from provinces outside of Ankara and the provinces were predominantly located in Central Anatolia Region (n=51), Central Anatolia Region (n=27), Black Sea Region (n=14), Eastern Anatolia Region (n=6), and Mediterranean Region (n=2). The clinical and demographic properties of the patients are shown in Table 1.

## Economic Losses

It was found that the average monthly income was below the level to meet the family's requirements in 80% of the families and only 16% had a side income. Only 9 families (9%) had economic opportunities at a level that did not necessitate additional support or economic aid. The families spent 200–500 Lira/monthly on an average as travelling money for transportation (bus, shared taxi, airplane) throughout the treatment period. Charities including Kançoder, Lösev, Governorship and District Governorship Aid Foundations gave 62 families (62%) financial support for travel expenses. Twenty-five families (25%) had to sell their possessions (house, car, estate, shop, cropland, gold, small cattle and cattle) during the treatment process. Forty-nine (49%) families borrowed from acquaintances and relatives or obtained a loan. Job change was reported in the fathers of 35 (35%) patients because of financial difficulties or problems experienced at the workplace. It was found that nine mothers (9%) began to work for financial support.

## Psychosocial Difficulties

When the social problems were examined, it was found that difficulties were experienced in the care of the other

**Table 1. Clinical and demographic characteristics of the patients**

Characteristics	n	%
Sex		
Male	67	67
Female	33	33
Median age at the time of diagnosis, (minimum–maximum) (months)	72 (12–180)	
Treatment period, median (minimum–maximum) (months)	36 (6–72)	
Diagnosis		
Leukemia	27	27
Lymphoma	45	47
Wilms tumor	10	10
Rhabdomyosarcoma	6	6
Other	12	12
Regions from which the patients originated		
Central Anatolia	51	51
Southeast Anatolia	27	27
Black Sea	14	14
Eastern Anatolia	6	6
Mediterranean	2	2

healthy siblings and support was received from relatives in 69% of the families. School success of the siblings was reduced because the parents' attention decreased. It was found that drug addiction and substance abuse developed in 14% of patients and psychological problems developed in 24%. It was noted that 43% of mothers experienced severe psychological problems during and after treatment and used medication because of excessive anxiety, crying episodes, and depression. This rate was 11% for the fathers. Twenty-seven mothers and 37 fathers started smoking following stress, though they never smoked before. Five fathers had to be treated for alcohol addiction. In contrast, three mothers and eight fathers quit smoking for financial reasons or because their awareness related to cancer increased. It was learned that the tendency to praying increased to overcome psychological problems during the treatment period in 40% of the families and the frequency of shrine visits increased.

A loss of 1–2 years occurred in education in 83% of our patients. Twelve percent of the patients currently have an active profession and the others still continue their school lives with delay. Thirty-eight of our patients (38%) stated that they were faced with reactions from their friends because they had hair loss or wore a wig, and therefore experienced difficulties in social relations. Two patients

**Table 2. Socioeconomic and psychosocial properties of the patients' families**

Properties	n	%
Income level		
Below average	80	80
Adequate	20	20
Additional economical support resources		
Benevolent associations and foundations	62	62
Sale of property	25	25
Taking loan	49	49
Job switches	44	44
Psychosocial difficulties		
Experiencing difficulties in taking care of the other healthy siblings	27	27
Development of drug and substance addiction	14	14
Psychological problems of patients	24	24
Psychological problems of parents	54	54
Initiation of religious practices	40	40
<b>Loss in the educational process</b>	<b>83</b>	<b>83</b>

(2%) stated that they were married and had 2 children, and 5 patients (5%) stated that they were engaged and their partners did not give negative reactions related to their disease. The socioeconomic and psychosocial properties of the families are shown in Table 2.

## Discussion

Although important advances have been made in the diagnosis and treatment of cancer, severe economic and psychosocial problems are experienced by patients with cancer and their close relatives because treatment is long lasting and expensive, may lead to organ loss, the disease may spread and may sometimes result in mortality. In the treatment of cancer, psychological aid, social support, and economic aid are very important in addition to medical treatment (2, 3). In a study conducted in this area, it was reported that 56.9% of the relatives of patients diagnosed as having cancer experienced economic problems and difficulties (4). In our patient group, 93% of our families received additional economic support. This high rate may be related to the fact that families mostly received treatment in a province other than the province in which they lived, though their healthcare expenses were completely met by the government, and expenses related to transport, accommodation, and personal needs increased in this process. In addition, a significant factor may be that an important portion of our patient group was composed of families who had lower socioeconomic status and health cards for uninsured people. Chino et al. (5) reported that

an important financial difficulty was observed in families who were diagnosed as having cancer and this resulted in negative psychological outcomes. They stated that depression was observed with a 3-fold higher frequency in subjects who experienced this stress. As seen, economic and psychological problems are actually associated with each other (6). One of the basic reasons for experiencing economic difficulties is the fact that cancer treatment centers are clustered in large cities, especially in Istanbul, Ankara, and Izmir. Patients and their relatives who go to these cities for treatment, experience accommodation and economic difficulties because of transportation expenses. Family members' loss of the chance to work at a former workplace in the prolonged treatment period and increased expenses related to drugs and nutrition, increase the difficulties further in this process. The same findings were also observed in our study. Relatives who observe physical and emotional changes in their loved ones become exhausted and unhappy as a result of putting in excessive effort to overcome economic problems.

In recent years, institutions that give importance to treatment and quality of life of patients and try to solve the social, economic, and psychological problems of relatives, engage in activities with oncologic social service works directed to oncology patients and their relatives. Efficient support ensures that patients benefit from treatment in the best way. Our clinic is among the pediatric oncology clinics that give positive support to patients and their relatives, owing to social service experts who work in favor of this objective. This support helps patients to develop self-confidence throughout the treatment period and to cope with the disease. This need in the area of social service was also demonstrated previously with studies conducted with adult patients with cancer and their relatives. The lack or inadequacy of social service support may cause patients' relatives to fatigue to an even greater extent, especially in this stage and to turn towards different areas. It is known that patients' relatives have a restricted social life and experience despair, hopelessness, and anxiety because of their duty of caregiving (7). In this process, it is observed that relatives experience depression, exhaustion, and anxiety to a greater extent compared with patients. Riveara et al. (8) reported that patients' relatives experienced depression and related exhaustion, sleeplessness, and excessive sleeping and concentration problems. In particular, work losses experienced in the family increase economic difficulties and cause disturbance, despair, conflict, distress, and discomfort among family members. At this stage, family therapy is considerably valuable for patients with cancer and their families. Patients with cancer and their families have stated that family therapy is helpful in curing cancer (9).

Around the world and in our country, relatives of patients with cancer use prayer and religious practices extensively in order to alleviate their distress. The frequency of praying was reported as 61.4% in a study conducted in the United States of America and 71% in a study conducted in Istanbul (10, 11). In the literature, it has been reported that religious behaviors including praying, positively influenced the feelings of self-consciousness, confidence, and faith, coping with stress, and a hopeful and meaningful life (12). Some of these practices are performed with the objective of treatment (13). Although the way of praying, the place of worship, and the belief of a creative power vary by religions, these practices are considered a curative application in most communities. Studies have reported that praying decreases the frequency of depression, strengthens the immune system, and relaxes individuals in cases of anxiety and decreases pain (14). We also observed that praying increased in this process in our study. Behaviors including praying, visiting holy places, making vows, and consulting religious officials were the most frequent practices.

In conclusion, conducting medical treatment and psychosocial support in accord is an important factor that increases treatment success in cancer. Patients and their relatives need psychosocial support throughout their lives from the first moment they confront the disease. This support will improve the patient's self-confidence and help in coping with the disease throughout the treatment period. In our country, we need national social support programs to be improved in this direction and legal adjustments that will constitute the basis on which these programs will be conducted.

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**Ethics Committee Approval:** This study was approved by Ankara Pediatrics and Hematology and Oncology Education and Research Hospital Ethics Committee (Approval number: 2018/127).

**Informed Consent:** Informed consent was obtained from the patients or their families.

**Peer-review:** Externally peer-reviewed.

**Author Contributions:** Concept - C.B., Z.U., G.Ş., U.E.; Design - Z.U., H.K.; Supervision - C.B., G.Ş., U.E., N.Y.; References - Z.U., H.K., G.Ş.; Materials - Ş.T., Ş.Y.; Data Collection and/or Processing - C.B., N.Y., Ş.T., Ş.Y.; Analysis and/or Interpretation - H.K., Ş.T., G.Ş.; Literature Review - Ş.T., Ş.Y., Z.U.; Writing the Article - C.B., H.G.T., Ş.Y., U.E.; Critical Review - G.Ş., N.Y., U.E., H.G.T., H.K.

**Conflict of Interest:** The authors have no conflicts of interest to declare.



**Financial Disclosure:** The authors declared that this study has received no financial support.

**Etik Komite Onayı:** Bu çalışma Ankara Çocuk Sağlığı ve Hastalıkları ve Hematoloji ve Onkoloji Eğitim ve Araştırma Hastanesi Etik Kurulu tarafından onaylanmıştır (Onay numarası: 2018/127).

**Hasta Onamı:** Hasta ya da hasta ailelerinden aydınlatılmış onam alınmıştır.

**Hakem Değerlendirmesi:** Dış bağımsız.

**Yazar Katkıları:** Fikir - C.B., Z.U., G.Ş., U.E.; Tasarım - Z.U., H.K.; Denetleme - C.B., G.Ş., U.E., N.Y.; Kaynaklar - Z.U., H.K., G.Ş.; Malzemeler - Ş.T., Ş.Y.; Veri Toplanması ve/veya İşlemesi - C.B., N.Y., Ş.T., Ş.Y.; Analiz ve/veya Yorum - H.K., Ş.T., G.Ş.; Literatür Taraması - Ş.T., Ş.Y., Z.U.; Yazıyı Yazan - C.B., H.G.T., Ş.Y., U.E.; Eleştirel İnceleme - G.Ş., N.Y., U.E., H.G.T., H.K.

**Çıkar Çatışması:** Yazarlar çıkar çatışması bildirmemişlerdir.

**Mali Destek:** Yazarlar bu çalışma için mali destek almadıklarını beyan etmişlerdir.

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