

Difficulties and Advantages Experienced by Mothers of Pediatric Oncology Patients During the COVID-19 Pandemic

Pediatric Onkoloji Hastalarının Annelerinin COVID-19 Pandemisi Sırasında Yaşadığı Zorluklar ve Avantajlar

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Abstract

Introduction: This study addressed the difficulties and advantages experienced by the mothers of pediatric oncology patients during the COVID-19 pandemic.

Materials and Methods: Descriptive and cross-sectional study, the sample consisted of 300 mothers of children treated in the pediatric oncology and hematology clinic of a university hospital in Türkiye. The study was approved by an ethics committee. Permission was obtained from the hospital. Informed consent was obtained from participants. Data were collected using a questionnaire. The data were analyzed using descriptive statistics and the Chi-square test.

Results: Most participants regarded COVID-19 as a risk factor for their children with cancer (96.7%). More than a quarter of the participants worried that their children with cancer would not survive COVID-19 (38.7%). More than half of the participants experienced extra stress during the COVID-19 pandemic (68%). Only one in ten participants stated that they needed psychological support during the COVID-19 pandemic (12.3%). The diagnosis, gender (child), and economic status did not significantly affect the participants' extra stress during the COVID-19 pandemic ($p>0.05$). Most participants noted that the COVID-19 pandemic helped them isolate their children with cancer (84.3%), wear masks (94%), understand the importance of masks during cancer treatment (90.7%), and relieve disease management (83.0%).

Conclusion: Although the COVID-19 pandemic exacerbated the current situation for mothers of pediatric oncology patients, it contributed to the isolation process and disease management.

Öz

Giriş: Bu çalışmada, pediatrik onkoloji hastalarının annelerinin COVID-19 salgını sırasında yaşadığı zorluklar ve avantajlar ele alınmıştır.

Gereç ve Yöntem: Tanımlayıcı ve kesitsel tipte olan araştırmanın örneklemini, Türkiye'de bir üniversite hastanesinin Çocuk Onkoloji/Hematoloji Kliniği'nde tedavi gören çocukların anneleri oluşturmuştur (n=300). Etik kurul, kurum ve annelerin onamı alınan çalışmada veriler, anket formu ile toplanmış, değerlendirilmesi bilgisayar ortamında tanımlayıcı istatistikler ve ki-kare testi kullanılarak yapılmıştır.

Bulgular: Araştırmaya katılan annelerin çoğunluğu (%96.7) Covid-19'u, kanser tedavisi alan çocukları için riskli bulduklarını, %38.7'si çocuğunun Covid'e yakalanması durumunda iyileşemeyeceğinden endişe ettiğini, %68.0'i pandemi sürecinde ekstra stres yaşadığını, %12.3'ü bu süreçte psikolojik destek almak

Keywords

Mothers, COVID-19, pandemics, Lymphoblastic Leukemia

Anahtar kelimeler

Anneler, COVID-19, pandemi, Lenfoblastik Lösemi

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durumunda kaldıklarını belirtmişlerdir. Annelerin pandemi sürecinde ekstra stres yaşamalarında, çocuğun tanısı, cinsiyeti ve ailenin ekonomik durumunun etkili olmadığı ($p>0.05$) bulunmuştur. Yanısıra anneler pandemi sürecinin; kanser tedavisi alan çocuklarının izolasyon sürecine yardımcı olduğunu (%84.3), maske kullanımına kolaylık sağladığını (%94.0), kanser tedavi sürecinde ‘neden maske kullanıldığının’ bireyler tarafından daha rahat anlaşıldığını (%90.7) ve hastalık yönetimini rahatlattığını (%83.0) düşündüklerini ifade etmişlerdir.

Sonuç: Çalışma sonucunda pandemi sürecinin, kanser tedavisi alan çocukların annelerinin varolan zorlu ve stresli yaşam koşullarına yenilerinin eklenmesine neden olmakla birlikte, izolasyon süreci ve hastalık yönetimine de olumlu katkısının olduğu bulunmuştur.

Introduction

The novel coronavirus disease (COVID-19) shook the whole world in the first months of 2020. The rapid spread of the virus led to a global alarm (1-3). On March 11, 2020, the World Health Organization (WHO) declared the situation a pandemic (4). The COVID-19 pandemic caused financial, psychological, and sociological problems taking a toll on everybody (5-7).

Older adults, people with chronic diseases, immunocompromised patient groups, and those receiving immunosuppressive therapy were the top risk groups due to the severe course of the COVID-19 infection (8,9). Research has shown that children present with milder symptoms than adults (10,11). However, some children and their parents began the pandemic at a disadvantage and remained disadvantaged throughout the course of the process. Pediatric cancer patients constitute a high-risk group for the coronavirus for several reasons. First, they are vulnerable to infections due to reduced immunological competence. Second, they receive cancer treatment, which can cause additional physical and mental stress. Third, they visit hospitals frequently. Fourth, they are in constant contact with healthcare professionals (12,13). For all these reasons, these children have been placed at the top of the risky and disadvantaged groups during the pandemic (14,15).

Mothering a child who is being treated for cancer is one of the most challenging ordeals a mother can face. During treatment, the mother provides help and support that affects both the child’s treatment outcome and the health of all family members. However, the addition of the COVID-19 pandemic to this process has increased the challenges. The COVID-19 pandemic affected children with cancer and their parents and caregivers (12,16,17). Mothers of children with cancer already feel fear, anxiety, and uncertainty. However,

the COVID-19 pandemic exacerbated the situation as it caused additional financial, psychological, and social problems (18-20).

Healthcare professionals should determine the difficulties experienced by children with cancer and their parents to plan and provide healthcare services to them. They should also provide mothers with early psychosocial support. Therefore, this study investigated the challenges and advantages experienced by the mothers of pediatric oncology patients during the COVID-19 pandemic.

Material and Methods

Research Design and Population

This descriptive and cross-sectional study was conducted in the Pediatric Oncology and Hematology Clinic (Jacie accredited) of a university hospital in the Central Anatolia Region of Türkiye between March and September 2021. The study population consisted of all mothers of pediatric oncology patients in the university hospital. Mothers were the sample of choice because they undertake more duties than fathers in providing care during their children’s treatment process and accompanying them in the hospital. The sample consisted of 300 participants. The inclusion criteria for children with cancer were (1) not being in the terminal stage and (2) not being in the stage of bone marrow transplantation preparation. The inclusion criterion for mothers was (1) volunteering (Figure 1). The information form was based on a literature review conducted by the researchers. It had 54 items and two parts. The first part consisted of 20 items on sociodemographic characteristics (age, education, employment status, family type, etc.). The second part consisted of 34 items on mothers’ opinions, exposure, and difficulties regarding the COVID-19 pandemic (diagnosis and treatment, information about

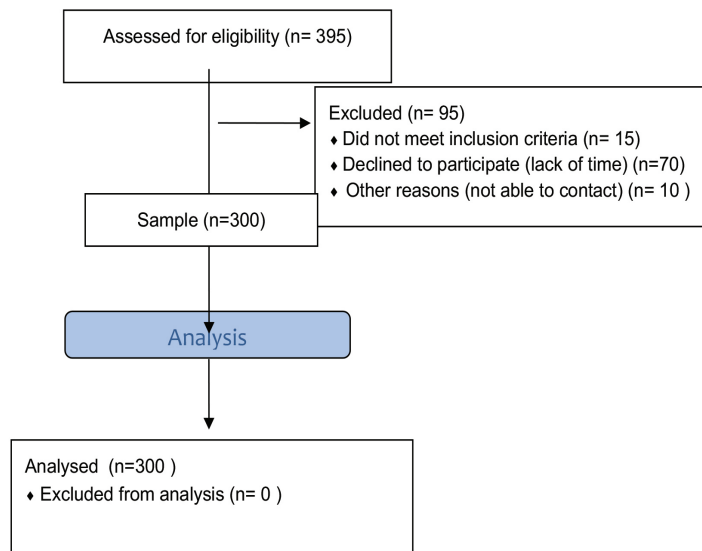


Figure 1. Flow Diagram

the disease, the impact of COVID-19 on the family and the child, the effect of COVID-19 on the cancer treatment process, etc.). The study was approved by the non-invasive ethics committee (date: 19.02.2021, approval number: 2021.03.71/2100005762). Written permission was obtained from the university hospital. All mothers were briefed about the research purpose and procedure. Informed consent was obtained from those who agreed to participate.

Statistical Analysis

The data were analyzed using the Statistical Package for Social Sciences (SPSS, IBM, version 18.0) at a significance level of 0.05. Numbers and percentages were used for descriptive statistics. The Chi-square test was used to compare categorical data.

Result

Less than half of the participants were 31 to 40 years of age (41.7%; n=125). Most participants were housewives (80%; n=240). More than half of the participants had a negative income (income < expense) (74%; n=222). Children with cancer had a mean age of 5.81 ± 2.88 years. More than half of the children were girls (56%; n=168) diagnosed with leukemia (68.7%; n=206) (Table 1). More than a quarter of the participants viewed COVID-19 as a “fatal disease” (30%; n=90). Most participants considered COVID-19

risky for their children treated for cancer (96.7%; n=290) (Table 2).

More than a quarter of the participants stated that the COVID-19 pandemic adversely affected their financial well-being (28.7%; n=86). Less than a quarter of the participants noted that they or their spouses had to find new jobs during the COVID-19 pandemic (18.7%; n=56). Moreover, participants reported that they experienced additional stress during the COVID-19 pandemic (68.0%; n=204) as they were concerned about their healthy children catching the coronavirus (67.3%; n=202) or their children with cancer not surviving COVID-19 (38.7%; n=116). Less than a quarter of the participants also noted that the COVID-19 pandemic changed their sleep (16.3%; n=49) and dietary patterns (11.7%; n=35) (Table 3).

Most participants remarked that the COVID-19 pandemic helped them isolate their children with cancer (84.3%; n=249), wear masks (94%; n=282), and understand the reasons for using masks in the cancer treatment process (90.7%; n=272). They also noted that they believed that the COVID-19 pandemic relieved disease management (83.0%; n=249) (Table 3).

Less than a quarter of the participants stated they needed psychological support during the COVID-19 pandemic (12.3%; n=37) (Table 3). Diagnosis, gender (child), and income did not significantly affect the additional stress that all participants experienced during the COVID-19 pandemic ($p > 0.05$) (Table 4).

Discussion

The COVID-19 pandemic changed the daily lives, habits, and routines of families, paving the way for a “new normal,” which was a great challenge for parents (21). The lives of parents of children with chronic diseases, which are already distinct and challenging compared to those of other families even in ordinary circumstances, became even more arduous during the pandemic (22,23). Parents of children with chronic diseases have more challenging living conditions and lower quality of life than parents with healthy children (24-26). Mothers of children with chronic diseases in general, and mothers of children with cancer in particular, have a very low quality of life (27,28).

Pediatric cancer treatment and follow-up affect all family members (12). Like other types of cancer, pediatric cancers require special conditions for disease follow-up and treatment. Parents have to shift their roles and assume new responsibilities to provide those special conditions (12,29). As suggested Kadan, G. (30), the COVID-19 pandemic adversely affected the lives of children and their families. The COVID-19 pandemic had numerous direct and indirect effects on children with cancer and their family members (31,32). During the COVID-19 pandemic, they faced economic difficulties, changed their daily routines, and experienced sleep and dietary problems (33-35).

Table 1. Sociodemographic characteristics

Sociodemographic Characteristics	n	%
Child's age (year)		
2-4	107	35.7
5-7	125	41.7
≥8	68	22.6
Diagnosis		
Leukemia	206	68.7
Other malign	94	31.3
Gender		
Girl	168	56.0
Boy	132	44.0
Mother's age (year)		
20-30	28	9.3
31-40	125	41.7
41-50	94	31.3
51-60	53	17.7
Mother's education (degree)		
Literate	179	59.7
Primary school	121	40.3
Mother's working status		
Not working/Housewife	240	80.0
Working	60	20.0
Family's income status		
Negative (income < expense)	222	74.0
Neutral (income = expense)	52	17.3
Positive (income > expense)	26	8.7
Family type		
Nuclear	262	87.3
Extended	38	12.7
Total	300	100.0

Information and opinions	n	%
What kind of disease is COVID-19?		
A mild disease that is easily treated	193	64.3
A deadly disease	90	30.0
A long-term disease	11	3.7
An incurable disease	6	2.0
Where do you get your information about COVID-19?		
TV	248	82.7
Health personnel	34	11.3
Friend/Relative	18	6.0
Has any of your family members tested positive for COVID-19?		
Yes	16	5.3
No	284	94.7
Do you consider COVID-19 risky for your children with cancer?		
Yes	290	96.7
No	10	3.3
Total	300	100.0

Impact of pandemic	Yes		No	
	n	%	n	%
The adverse impact of the pandemic on family life				
The adverse impact of the pandemic on family economy	86	28.7	214	71.3
Either parent had to change jobs	56	18.7	244	81.3
The adverse impact of the pandemic on mother's life				
Extra stress	204	68.0	96	32.0
Increased anxiety about healthy children catching COVID-19	202	67.3	98	32.7
Worrying that the child with cancer would not survive COVID-19	116	38.7	184	61.3
The ability to contribute to the online education of healthy children	78	26.0	222	74.0
The adverse impact of the pandemic on sleep patterns	49	16.3	251	83.7
Receiving psychological support	37	12.3	263	87.7
Being adversely affected by the diet	35	11.7	265	88.3
The child receiving cancer treatment and its effects on the management of the disease				
Thinking that it is useful to wear masks	282	94.0	18	6.0
Thinking that people understand why masks are necessary during cancer treatment	272	90.7	28	9.3
Thinking that it is easier to understand why it is necessary to be protected from infections during treatment.	271	90.3	29	9.7
Thinking that the pandemic helps with isolation	253	84.3	47	15.7
Thinking that the pandemic makes it easier to manage the disease	249	83.0	51	17.0
Disruption in treatment due to restrictions	29	9.7	271	90.3
Having difficulty accessing healthcare institutions for the treatment of the child with cancer due to restrictions	23	7.7	277	92.3

Table 4. Characteristics of mothers and children and mothers' extra stress during the pandemic

Characteristics	Mothers experiencing extra stress				
	Yes	No	Total	χ^2	p-value
Child's gender					
Girl	111 (66.1)	57 (33.9)	168 (100.0)	0.653	0.419
Boy	93 (70.5)	39 (29.5)	132 (100.0)		
Diagnosis					
Leukemia	142 (68.9)	64 (31.1)	206 (100.0)	0.262	0.608
Other malign	62 (66.0)	32 (34.0)	94 (100.0)		
Family income					
Positive (income > expense)	20 (76.9)	6 (23.1)	26 (100.0)	2.858	0.240
Neutral (income = expense)	39 (75.0)	13 (25.0)	52 (100.0)		
Negative (income < expense)	145 (65.3)	77 (34.7)	222 (100.0)		

Less than a quarter of our participants reported sleep problems (16.3%) and changes in their diets (11.7%) (Table 3). Most participants had a negative income (74%) (Table 1). Those participants stated that they faced additional challenges during the COVID-19 pandemic. More than a quarter of our participants reported that their financial situation worsened during the COVID-19 pandemic (28.7%). Less than a quarter of our participants stated that they or their spouses or both had to find new jobs during the COVID-19 pandemic (18.7%) (Table 3). These results suggest that the COVID-19 pandemic brought new challenges for children with cancer and their parents, who already went through a tough time during cancer follow-up and treatment, causing them to experience more stress and anxiety. Mothers experienced anxiety, fear, and stress during the COVID-19 pandemic. Mothers assume the care and responsibility of family members in every culture. Therefore, the fact that mothers experience anxiety, fear, and stress is not surprising. However, mothers of children with cancer experienced high levels of stress and anxiety even before the pandemic (17,28,36,37). During the pandemic, every mother in every corner of the world experienced a similar fear of losing her child. However, children with cancer fought hard and difficult battles for life even before the pandemic (18). Some children with cancer even came face to face with death. Considering all these, we can argue that the anxiety and fear experienced by mothers of healthy children and those of children with cancer during the pandemic cannot be the same.

Research shows that parents of children with cancer experience high levels of stress and anxiety (17,28,36-37). Some of the most significant stressors for mothers are the risk of losing their sick child, enduring the difficulties caused by diagnosis and treatment, and a lack of maternal support for healthy children at home (17,28,36-37). More than half of our participants reported additional stress due to the COVID-19 pandemic for various reasons (Table 3). First, the more they knew about the pandemic, the more stress they might have experienced. Second, they were afraid of being exposed to infection. Third, preventive measures and fear of the unknown put a greater burden on their shoulders. Fourth, their children are disadvantaged. Fifth, people who come into contact with children have only recently begun to be vaccinated. However, diagnosis, gender (child), and income had no significant impact on their additional stress during the COVID-19 pandemic ($p>0.05$) (Table 4). In addition, less than a quarter of our participants stated that they needed psychological support during the COVID-19 pandemic (Table 3). These findings suggest that mothers of children with cancer need help and support during the COVID-19 pandemic but might be unable to receive social support due to social isolation.

Children with cancer have compromised immune systems and are at particular risk for COVID-19, which puts mothers in a precarious situation where they feel more stress during the COVID-19 pandemic. More than a quarter of our participants considered COVID-19 a fatal disease (30%). Almost

all participants believed that COVID-19 posed a significant risk to their children with cancer (96.7%) (Table 2). This may have exacerbated their fear of losing their children and resulted in increased anxiety and stress levels. More than half of our participants were concerned that their healthy children might contract the coronavirus (67.3%). More than a quarter of the participants worried that their children with cancer might not survive COVID-19 (Table 3). These findings suggest that mothers of children with cancer experienced more anxiety and struggled to cope with it during the COVID-19 pandemic. Dolunay (17) and Akoğlu et al. (38) found that children of mothers with high anxiety or stress during the COVID-19 pandemic also had high anxiety or stress. This situation could adversely affect the way families experienced the disease process (17,39,40). Similarly, how mothers perceive and cope with the COVID-19 disease affects how their children with cancer perceive the disease (41,42). Children make sense of the COVID-19 pandemic through their mothers' reactions because they experience such a challenging process for the first time (17,39,40). Multidisciplinary teams, including pediatric nurses, should provide mothers with training and counseling to help them learn about COVID-19, conquer uncertainties, experience less anxiety and stress, and prevent their children from being adversely affected by the situation.

Although the COVID-19 pandemic took a significant toll on children with cancer and their parents, our results showed that it helped mothers manage the treatment process. Chemotherapy affects children's immune systems (28,37). Therefore, protecting pediatric oncology patients with weakened immune responses from infections is one of the main goals of treatment (43-45). This means they need to be isolated. However, social isolation in response to the COVID-19 pandemic made it easier for mothers to cope with the current treatment process. Since everyone was wearing masks, their children wore masks without feeling stigmatized.

Wearing masks is an essential measure for the protection of pediatric oncology patients from infections. Before the COVID-19 pandemic, only pediatric oncology patients and their parents wore masks. However, other people around those children have worn masks since the COVID-19 pandemic (4,46). Most of our participants believed that the

COVID-19 pandemic facilitated the use of masks (94%). They noted that the COVID-19 pandemic helped other people better understand why masks were integral to the cancer treatment process (90.7%). They also added that the COVID-19 pandemic relieved the disease management process (83.0%) (Table 3). We think that these are original findings that contribute to the literature. Our results showed that the COVID-19 pandemic had both positive and negative impacts on children with cancer and their parents.

Study Limitations

This study had several limitations. First, the sample size was small. Second, the results are sample-specific and cannot be generalized to all pediatric cancer patients. Third, the treatment stage of the disease (induction, maintenance, etc.) may have affected the results, but this study did not evaluate the findings by disease stage. However, this is one of the first studies to investigate the difficulties experienced by pediatric cancer children and their mothers during the COVID-19 pandemic. Moreover, our results also show that the COVID-19 pandemic made it easier for mothers to cope with the current treatment process and helped them manage it. We think this study will contribute to the literature and pave the way for further research on the impact of the COVID-19 pandemic on pediatric cancer patients and their parents.

Conclusion

Although the COVID-19 pandemic caused mothers of pediatric oncology patients to experience new stressors, it contributed to the isolation process and disease management. Multidisciplinary teams should adopt family- and child-centered care approaches and support mothers of pediatric oncology patients emotionally and psychologically to help them experience less stress and anxiety. Researchers should recruit larger samples and conduct multicenter qualitative and quantitative studies to investigate the impact of the COVID-19 pandemic on pediatric cancer patients and their parents.

Ethics

Ethics Committee Approval: The study was approved by the non-invasive ethics committee (date: 19.02.2021, approval number: 2021.03.71/2100005762). Written permission was

obtained from the university hospital. All mothers were briefed about the research purpose and procedure.

Footnotes

Conflict of Interest: No conflict of interest was declared by the authors.

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