Pediatr Pract Res 2022; 10(3): 123-130
DOI: 10.21765/pprjournal.1192793

ORIGINAL ARTICLE
ORİJİNAL ARAŞTIRMA

Evaluation of the Opinions of the Pediatric Palliative Care Patients' Families Regarding the COVID-19 Pandemic: A Cross-Sectional Study

Pediatrik Palyatif Bakım Hasta Ailelerinin COVID-19 Pandemisine İlişkin Görüşlerinin Değerlendirilmesi: Kesitsel Bir Çalışma

Nilgün Harputluoğlu[1], Duygu Çubukçu[2], Sibel Durak[3], Tanju Çelik[1]

[1]Izmir Dr Behçet Uz Children's Hospital, Pediatric Palliative Care Center, Izmir, Turkey
[2]Izmir Dr Behçet Uz Children's Hospital, Department of Physical Medicine and Rehabilitation, İzmir, Turkey
[3]Izmir Dr Behçet Uz Children's Hospital, Department of Child Psychiatry, Izmir, Turkey

Abstract

Aim: While many countries around the world have faced similar challenges in pediatric palliative care as COVID-19, there have also been challenges that vary from country to country. In this study, it was aimed to evaluate the difficulties and opinions of families receiving pediatric palliative care in our country during the pandemic process.

Materials and Method: The study is a cross-sectional survey applied to families followed in the pediatric palliative care service between 01.12.2018 and 01.12.2020. In the study, caring parents were asked to share their experiences and opinions in the last year.

Results: Of the 175 families followed, 112 were included in the study. In the first year of the pandemic, it was determined that 42% of the families had no change in their lives, 16.1% had psychological problems, 35.7% had social (quarantine and restrictions) problems and 6.3% had economic problems. When the family order and endurance of those who stated that there were significant changes in their lives in the first year of the pandemic were examined, it was found that these individuals were bored with their families and had difficulty staying at home (2.482; p=0.013).

Conclusion: The COVID-19 pandemic process in pediatric palliative care has been milder and has a better prognosis than expected. Psychosocial difficulties are the most prominent areas of distress.

Keywords: COVID-19, pandemic, pediatric palliative care

Öz

Amaç: Dünya çapında birçok ülke pediatrik palyatif bakımda COVID-19 ile benzer zorluklar yaşarken, ülkeden ülkeye değişen zorluklar da olmuştur. Bu çalışmada pandemi sürecinde ülkemizdeki pediatrik palyatif bakım alan ailelerin yaşadıkları güçlüklerin ve görüşlerinin değerlendirilmesi amaçlanmıştır.

Gereç ve Yöntem: Araştırma, 01.12.2018 ile 01.12.2020 tarihleri arasında pediyatrik palyatif bakım servisinde takip edilen ailelere uygulanan kesitsel bir anket çalışmasıdır. Araştırmada bakım veren ebeveynlerden son bir yıldaki deneyimlerini ve görüşlerini paylaşmaları istenmiştir.

Bulgular: Takip edilen 175 aileden 112'si çalışmaya dahil edildi. Pandeminin ilk yılında ailelerin %42'sinin hayatında bir değişiklik olmadığı, %16,1'inin psikolojik, %35,7'sinin sosyal (karantina ve kısıtlamalar) ve %6,3'ünün ekonomik sorunları olduğu belirlendi. Pandeminin ilk yılında hayatlarında önemli değişiklikler olduğunu belirtenlerin aile düzeni ve tahammülleri incelendiğinde bu bireylerin ailelerinden sıkıldıkları ve evde kalmakta zorlandıkları saptandı (2.482; p= 0.013).

Sonuç: Pediatrik palyatif bakımda COVID-19 pandemi süreci beklenenden daha hafif ve daha iyi prognozlu seyretmiştir. Psikososyal zorluklar, en belirgin sıkıntı alanlarıdır.

Anahtar kelimeler: COVID-19, pandemi, pediatrik palyatif bakım

Corresponding Author: Nilgün Harputluoğlu
Address: Pediatric Palliative Care Center; Dr. Behçet Uz Children's Hospital, İsmet Kaptan Region, Sezer Doğan Street, No:11, Alsancak, Konak, 35210, İzmir, Turkey
E-mail: nilgunharputluoglu@yahoo.com.tr

Başvuru Tarihi/Received: 21.10.2022
Kabul Tarihi/Accepted: 31.12.2022

INTRODUCTION

Coronavirus disease-2019 (COVID-19) is a disease that emerged in the city of Hubei Province-Wuhan in China in December 2019 and affected the whole world (1-3). The World Health Organization (WHO) has announced that the number of confirmed cases to date is 121,969,223 and deaths as 2,694,094 (4). For Turkey, T.R. The Ministry of Health reported a total number of 2,992,694 cases and 29,959 deaths so far (5). The COVID-19 pandemic mostly affects those with advanced age and chronic diseases (6). Despite this, these terrifying figures have caused various restrictions, significant changes in the way of life, especially social isolation, worldwide. Thus, behavioral and social changes occured (7). The comorbidities of children with life-limiting or threatening diseases such as primary disease and/or chronic lung disease constitute a risk factor for COVID-19 (8,9). Although the difficulties experienced in the process related to COVID-19 in pediatric palliative care (PPC) in many countries of the world show similarities, the differences in the health system and practices have led to varying difficulties from country to country (10). This study aimed to evaluate the difficulties patients and their families who received pediatric palliative care during the pandemic process and the effect of the pandemic.

MATERIAL AND METHOD

Organization of PPC Unit

Izmir Dr. Behcet Uz Pediatric Diseases and Surgery Training and Research Hospital is a tertiary hospital, and the PPC center started to serve in November 2018. It is the only center in the Aegean Region. Our PPC center has 12 beds and is an example of teamwork consisting of three doctors, eight nurses, four staff, one psychologist, one dietician, one social worker, one physiotherapist, one religious worker, one secretary. To our PPC center, children whose treatment is possible but unsuccessful (cancer, complex cyanotic congenital heart disease), with potentially progressive conditions (cystic fibrosis, severe immunodeficiency), without therapeutic options (trisomy 13, trisomy 18, osteogenesis imperfecta), children with non-progressive but irreversible disease (cerebral palsy) are admitted.

Study Design

The study was a cross-sectional questionnaire study planned to be applied to the parents of all patients followed up the PPC center between December 01, 2018 and December 01, 2020. The families were reached by phone, and after they were informed, they were asked to answer the questionnaire by asking the prepared questions. Parents whose children died, parents who could not speak Turkish, parents whose telephone records were not available, and parents who refused to participate in the study excluded. Only one of the parents (mother or father) was included in the study. Sociodemographic data, whether they had COVID-19 infection, social media use, family life, what the pandemic changed in families' lives, the experiences of the sick child and parents, their future hopes and expectations from the palliative care team were investigated. A total of 39 questions were asked, and 21 subgroup options were opened one by one for multiple-choice questions (**Figure 1**).

Ethics

The study was carried out with the permission of Izmir Dr Behçet Uz Children's Hospital Clinical Researches Ethics Committee (Date: 25.03.2021, Meeting Number: 540, Decision Number: 2021/06-05). This study was performed as per the Declaration of Helsinki. Verbal consent was obtained from the parents who agreed to participate in the study by making the necessary explanations during the phone call to the parents.

Statistical Analysis

SPSS (Statistical Package for Social Sciences) package program version 15.0 was used for statistical analysis to evaluate the data obtained in the study. In addition to descriptive statistical methods (e.g., mean, standard deviation, frequency, percentage.), Chi-square test or Fisher's exact test for categorical variables, Student T-test or Mann Whitney U test for continuous variables were used to cpmpare two groups. Results were evaluated a 95% confidence interval and $p < 0.05$ significance level.

RESULTS

A total of 175 caregiver parents whose children were followed up by the PPC center were enrolled in the study. However, only 112 of these caregiver parents were included in the study. Twenty-six parents were excluded from the study because of the death of their children, 24 parents because they did not have a telephone record or could not be reached, five parents could not speak the language, six parents were nursing home caregivers, and two parents did not want to participate in the study. Only one of the parents (mother or father) was included in the study.

The mean age of the parents in the study group was 35.6 ± 6.8 year (24-54), and 79 (70.5%) were female. The rate of caregiver parents who had COVID-19 infection was 7.1% (n=8), and the rate of COVID-19 in children who received the care was 1.7% (n=2). The rate of those who had COVID-19 in their first degree relatives and/or friends were 33.9% (n=38), while those who lost their first degree relatives and/or friends due to COVID-19 were 7.1% (n=8).

General information					
Name:					
Gender:					
Age:					
Have you had COVID-19?					
Do you have a relative with COVID?					
Have you lost a loved one due to COVID-19?					
Do you have any health problems?					
Has your use of social media and internet increased?					
Has your palliative care relationship with social media increased?					
Have the apps you use changed?					
Has your mode of transport changed?					
What has been the most important thing that has changed in your life?					
Part 1. Family routine and endurance					
1. We feel calm and peaceful as a family	1	2	3	4	5
2. Sometimes we get bored as a family or have trouble staying at home	1	2	3	4	5
3. We try to find positive aspects, we are hopeful	1	2	3	4	5
4. We enjoy family time we didn't have before	1	2	3	4	5
5. We are already used to change and uncertainty	1	2	3	4	5
6. Tired of not having the help I received before (eg personal assistant, babysitter, grandma)	1	2	3	4	5
7. I miss contact with my friends and relatives	1	2	3	4	5
8. I have many practical and economic concerns	1	2	3	4	5
Part 2. Changes in child and caregiver life					
1. My family feels calm and peaceful	1	2	3	4	5
2. Sometimes my family gets bored or has trouble staying at home	1	2	3	4	5
3. My child's routine remains the same despite limitations	1	2	3	4	5
4. As a family, we set our new routine to find mental balance	1	2	3	4	5
5. I dedicate myself to unresolved problems and jobs that I can't find time for	1	2	3	4	5
6. I rediscover outdoor environments such as a garden or terrace	1	2	3	4	5
7. I am resting, having a comfortable time	1	2	3	4	5
8. I don't have free time; I always have something to do	1	2	3	4	5
9. I let my son break some rules	1	2	3	4	5
Part 3. Top concern for caregiver					
Health of family and friends					
Possible COVID-19 infection in your child					
Possible COVID-19 infection of the caregiver or other cohabiting family members long term future					
Part 4. Wishes and plans for the future after COVID-19					
Specific outdoor activity					
"Going to the beach"					
"Going to the Mountains"					
"Go shopping"					
"Relaxing on the grass"					
"Going on vacation"					
"Going out to dinner"					
"Go to cinema"					
Social relations					
"Seeing grandma"					
"Seeing the rest of the family"					
"Getting together with friends and relatives"					
"Rediscovering the taste of sociality"					
Health problems					
"Going swimming to do physiotherapy"					
"Restarting Physiotherapy"					
"Going to hospital checkups"					
Sports					
"Riding a horse"					
"To swim"					
"To do sport"					
Others					
"Embrace Everyone"					
"Moving to a new home"					
"Going to the hairdresser"					
"Wearing heels"					
Part 5. Perception of support from the PPB team					
Is there anything palliative care can do for you during this period? Yes No					
Comments: _____					

Figure 1. Survey Form

In the first year of the pandemic, it was determined that 58% of the caregivers, who were asked whether there was a significant change in their lives, had a significant change in their lives, and 42% had no change in their lives. Among parents who have had significant changes in their lives due to the pandemic, it was determined that 16% had psychological issues, 35.7% had social issues (quarantine and restrictions), and 6.3% had economic problems. 35.7% (n=40) did not use public transportation, and 17.9% (n=20) accessed palliative care through applications such as WhatsApp. It was determined that the use of social media by 50.9% (n=57) of caregiving parents increased, and the social media applications used by 33% (n=37) changed. The relationship between parents, who stated that there were significant changes in their life in the first year of the pandemic, and the situation of having COVID-19 infection was examined. It was found that 78.9% of those whose first-degree relatives and/or friends had COVID-19 infection had significant changes in their lives (9.068; p=0.003). When the family routine and endurance of those who stated that there were significant changes in their lives in the first year of the pandemic were examined, these individuals were bored with their families and had difficulty staying at home (2.482; p=0.013). When the life of the child in need of care and the caregiver parent was examined during the pandemic, no difference was found between those who stated that there was a significant change in their lives and those who stated that there was no change in their lives (**Table 1**). Examining what caregivers were most concerned about in the first year of the pandemic, it was determined that they were concerned about the long-term future and the health of their first-degree relatives and friends. Sources of concern are presented in **Table 2**.

Table 1. Comparison of the scores of the study group on items related to "Changes in the life of the child and caregiver"

	(Mean-SD) Median (Q1-Q3)	Significant changes in life		p-value
		No (Mean-SD) Median (Q1-Q3)	Yes (Mean-SD) Median (Q1-Q3)	
My family feels calm and peaceful	3.5 (1.3) 3.0 (3.0-5.0)	3.7 (1.3) 4.0 (3.0-5.0)	3.3 (1.3) 3.0 (2.5-5.0)	1.618; 0.106
Sometimes my family is bored or has trouble staying home	3.0 (1.4) 3.0 (1.0-4.0)	3.0 (1.4) 3.0 (2.0-4.0)	2.9 (1.5) 3.0 (1.0-4.0)	0.182; 0.856
My child's routine remained the same despite the limitations	3.5 (1.4) 4.0 (3.0-5.0)	3.5 (1.4) 4.0 (2.0-5.0)	3.5 (1.3) 4.0 (3.0-5.0)	0.237; 0.812
As a family, we set our new routine to find mental balance	2.8 (1.3) 3.0 (2.0-4.0)	2.6 (1.3) 2.0 (1.0-3.0)	3.0 (1.3) 3.0 (2.0-4.0)	1.724; 0.085
I devoted myself to unsolved problems and work where I could not find time	3.2 (1.4) 3.0 (2.0-4.0)	3.1 (1.3) 3.0 (2.0-4.0)	3.2 (1.5) 3.0 (2.0-5.0)	0.485; 0.628
I rediscover outdoor environments such as gardens or terraces	2.7 (1.5) 3.0 (1.0-4.0)	2.7 (1.3) 3.0 (1.0-4.0)	2.7 (1.7) 3.0 (1.0-4.0)	0.006; 0.995
I am resting, having a comfortable time	3.1 (1.5) 3.0 (2.0-5.0)	3.1 (1.4) 3.0 (2.0-4.0)	3.0 (1.6) 3.0 (1.0-5.0)	0.416; 0.677
I do not have free time; I always have a job to do	3.6 (1.4) 4.0 (3.0-5.0)	3.8 (1.3) 4.0 (3.0-5.0)	3.5 (1.5) 4.0 (2.0-5.0)	1.100; 0.271
I let my boy break some rules	2.4 (1.3) 2.0 (1.0-3.0)	2.5 (1.3) 2.0 (1.0-3.0)	2.4 (1.3) 2.0 (1.0-3.0)	0.420; 0.974

Table 2 . Situations that are "a source of concern" due to COVID-19

Situations of concern due to COVID-19		Significant changes in life		p-value
		No	Yes	
Worrying about the health of family and friends	Yes	1 (6.3)	15 (93.8)	8.140; 0.004
	No	46 (47.9)	50 (52.1)	
Worrying about possible COVID-19 infection in their child	Yes	31 (42.5)	42 (57.5)	0.000; 1.000
	No	16 (41.0)	23 (59.0)	
Worrying about the caregiver and caregiver child's COVID-19 infection	Yes	20 (45.5)	24 (54.5)	0.165; 0.685
	No	27 (39.7)	41 (60.3)	
Worry about the long-term future	Yes	5 (20.8)	19 (79.2)	4.550; 0.033
	No	42 (47.7)	46 (52.3)	
Total		47 (42.0)	65 (58.0)	112 (100.0)

What they wanted to do most when the pandemic process was over included going to the hospital (79.5%), meeting with friends and relatives (69.6%),and relaxing on the grass (65.2%). Considering the expectations of the groups with and without changes in their lives from the future, going on vacation (14.491; p = 0.000), seeing family elders (10.277; p = 0.001), seeing the rest of the family (6.913; p = 0.009), getting together with friends and distant relatives (6.735; p = 0.009), swimming (4.188; p = 0.041), and moving to a new house (4.675; p = 0.031) were determined as the most important requests and expectations (**Table 3**). It was determined that 20.5% (n=23) of the participants needed the support of the palliative care team, 47.8% (n=11) were related to psychological support, and 26% were related to drugs and materials.

Table 3. Comparison of "Planning for the future" in the study group

Wishes and plans for the future after COVID-19		n (%)	Significant changes in life		p-value
			No	Yes	
Going to the beach	Yes	22 (19.6)	6 (27.3) (12.8)	16 (72.7) (24.6)	1.734; 0.188
	No	90 (80.4)	41 (45.6) (87.2)	49 (54.4) (75.4)	
Going to the mountains	Yes	55 (49.1)	18 (32.7) (38.3)	37 (67.3) (56.9)	3.078; 0.079
	No	57 (50.9)	29 (50.9) (61.7)	28 (49.1) (43.1)	
Going shopping	Yes	60 (53.6)	27 (45.0) (57.4)	33 (55.0) (50.8)	0.257; 0.612
	No	52 (46.4)	20 (38.5) (42.6)	32 (61.5) (49.2)	
Relaxing in the grass	Yes	73 (65.2)	29 (39.7) (61.7)	44 (60.3) (67.7)	0.208; 0.649
	No	39 (34.8)	18 (46.2) (38.3)	21 (53.8) (32.3)	
Going on vacation	Yes	42 (37.5)	8 (19.0) (17.0)	34 (81.0) (52.3)	14.491; 0.000
	No	70 (62.5)	39 (55.7) (83.0)	31 (44.3) (47.7)	
Going out to dinner	Yes	31 (27.7)	10 (32.3) (21.3)	21 (67.7) (32.3)	1.153; 0.283
	No	81 (72.3)	37 (45.7) (78.7)	44 (54.3) (67.7)	
Going to cinema	Yes	29 (25.9)	8 (27.6) (17.0)	21 (72.4) (32.3)	2.573; 0.109
	No	83 (74.1)	39 (47.0) (83.0)	44 (53.0) (67.7)	
Seeing grandmother	Yes	28 (25.0)	4 (14.3) (8.5)	24 (85.7) (36.9)	10.277; 0.001
	No	84 (75.0)	43 (51.2) (91.5)	41 (48.8) (63.1)	
Seeing the rest of the family	Yes	65 (58.0)	20 (30.8) (42.6)	45 (69.2) (69.2)	6.913; 0.009
	No	47 (42.0)	27 (57.4) (57.4)	20 (42.6) (30.8)	
Getting together with friends and relatives	Yes	78 (69.6)	26 (33.3) (55.3)	52 (66.7) (80.0)	6.735; 0.009
	No	34 (30.4)	21 (61.8) (44.7)	13 (39.4) (20.0)	
Rediscovering the taste of sociability	Yes	53 (47.3)	18 (34.0) (38.3)	35 (66.0) (53.8)	2.058; 0.151
	No	59 (52.7)	29 (49.2) (61.7)	30 (50.8) (46.2)	
Going swimming to do physiotherapy	Yes	16 (14.3)	5 (31.3) (10.6)	11 (68.8) (53.8)	0.441; 0.506
	No	96 (85.7)	42 (43.2) (89.4)	54 (56.8) (46.2)	
Restarting physiotherapy	Yes	28 (25.0)	9 (32.1) (19.1)	19 (67.9) (29.2)	0.990; 0.320
	No	84 (75.0)	38 (45.2) (80.9)	46 (54.8) (70.8)	
Going to hospital checks	Yes	89 (79.5)	39 (43.8) (83.0)	50 (56.2) (76.9)	0.298; 0.585
	No	23 (20.5)	8 (34.8) (17.0)	15 (65.2) (23.1)	
Riding a horse	Yes	20 (17.9)	5 (25.0) (10.6)	15 (75.0) (23.1)	2.092; 0.148
	No	92 (82.1)	42 (45.7) (89.4)	50 (54.3) (76.9)	
Swimming	Yes	37 (33.0)	10 (27.0) (21.3)	27 (73.0) (41.5)	4.188; 0.041
	No	75 (67.0)	37 (49.3) (78.7)	38 (50.7) (58.5)	
Doing sports	Yes	59 (52.7)	21 (35.6) (44.7)	38 (64.4) (58.5)	1.562; 0.211
	No	53 (47.3)	26 (49.1) (55.3)	27 (50.9) (41.5)	
Embracing everyone	Yes	52 (46.4)	17 (32.7) (36.2)	35 (67.3) (53.8)	2.753; 0.097
	No	60 (53.6)	30 (50.0) (63.8)	30 (50.0) (46.2)	
Moving to a new home	Yes	27 (24.1)	6 (22.2) (12.8)	21 (77.8) (32.3)	4.675; 0.031
	No	85 (75.9)	41 (48.2) (87.2)	44 (51.8) (67.7)	
Going to the hairdresser/barbershop	Yes	28 (25.0)	10 (35.7) (21.3)	18 (64.3) (27.7)	0.306; 0.580
	No	84 (75.0)	37 (44.0) (78.7)	47 (56.0) (72.3)	
Wearing heels¶	Yes	13 (16.5)	3 (23.1) (9.4)	10 (76.9) (21.3)	1.191; 0.275
	No	66 (83.5)	29 (43.9) (90.6)	37 (56.1) (78.7)	

¶: Calculated over the number of women.

DISCUSSION

The results of this study revealed that parents who made significant changes in their lives had first-degree relatives and/or friends who were diagnosed with COVID-19 infection. It was determined that these families were bored with the changes and had difficulty staying at home, but this situation was not compelling for the caring parent and child.

According to the joint WHO and China report, COVID-19 in adults is 3-10%, mostly through domestic transmission, especially in large families (11). In Turkey, according to the T.C. Ministry of Health data, the rate of those who had COVID-19 infection was reported to be 9.8% (12). COVID-19 has been found with a rate of 2.1-2.7% in children (13,14). For COVID-19 infection, where epidemiological studies still continue, it is observed that the presence of older age, male gender, immunodeficiency, heart disease, and respiratory diseases constitute a high risk and cluster in some families (11,12). Mortality rates vary according to age and region, but it has been reported as 21.9% globally and 2.57% in our country (11,12). In our study group, the rate of those who had COVID-19 infection was lower, and no mortality was observed. This situation may have caused these families, who already experienced social difficulties and isolation due to their children's illness, to come out of the COVID-19 pandemic process with less harm than expected.

Having a child with a life-limiting/threatening disease negatively affects the lives, feelings, thoughts, and behaviors of family members. Parents need to change their duties and responsibilities, financial resources, vital activities, and behaviors (15). In addition to the child's disease, many family problems such as psychological, social, financial, and education accompany the process. Studies show that these families are more physically and emotionally vulnerable and lead a lower quality of life (16). Evidence-based data show that some families choose to be at home and together in this challenging process, while some families choose a more isolated life and spend time in the hospital (17). Our study reveals that children with life-limiting/threatening diseases and their caregivers are already accustomed to the challenges. Besides, those with a first-degree relative/friend who had COVID-19 during the pandemic are more careful, have grasped the seriousness of the situation, and have made significant changes in their lives as a whole family. This may be due to being a caring parent, having an ill child, close contact with COVID-19, and exposure concerns.

Care for children with life-limiting/ threatening diseases and their families has become more difficult with infection control measures and restrictions (18). In our country, the area where families' quality of life is affected the most in pediatric palliative care is the social field, and the importance of providing social support on quality of life has been demonstrated (19). Social distance and visitor restrictions applied to ensure infection control during the pandemic process are for the protection of families and healthcare workers. However, stricter rules and restrictions for these children who already have social difficulties and their families increased the time they stayed at home, prevented them from receiving care support, and caused an increase in social difficulties (20,21). Our study revealed that the family as a whole had difficulty staying at home due to new rules, restrictions and quarantine practices. When only the life of the child-caregiving parent couple was questioned, it was observed that staying at home and living with restrictions did not bring additional difficulties. This situation made us think that the restrictions cause distress and difficulties in other familiy members, and the caregiver and the caregiving parent are already used to this lifestyle. The low COVID-19 infection rates for these children and families with chronic respiratory disease may be due to this lifestyle they are used to.

Health threats against oneself and their loved ones cause psychosocial stress in individuals (19). During the pandemic process, psychosocial changes occurred due to interruptions in routines, separation from family members and friends, lack of daily needs, salary cut, social isolation, and school closure, and the reactions to these new normals are variable (15,19). In infectious diseases, the feeling of malaise, overestimation of the possibility of infection, excessive and inappropriate adoption of precautionary measures may be seen, as well as rejecting the risks of infection, not performing recommended health behaviors such as hand hygiene and social distance (15,16,19). The lifetime prevalence of depression was reported as 10.8% and anxiety as 4.66% (22-25). During the COVID-19 pandemic, depression was reported in 19% of adults and anxiety in 14% (26). It has been shown that social isolation and loneliness are associated with bad moods (19). During the COVID-19 process, individuals had to be more at home and live in isolation. In the literature, people who have not had an epidemic before, those who are worried about not being able to find enough surgical masks, those who are not able to work from home, and those who are worried about not being able to find enough materials are stated as people who are prone to anxiety and depression and who are recommended more psychological support (26). It has been reported that those who have experienced epidemic diseases before are more resistant, experienced in obeying the precautions, and less stressed (25). Contrary to what was expected in our study, the most important concern of families has been identified as the health of family and friends and the long-term future. The reason why there is little concern about the health of the child-caregiving parent may be that they are already living mostly at home and partly in isolation.

This situation may be related to the fact that there is no significant change in the routine life of the caregiver and the child receiving care.

Individuals increase their adaptation capacity by functionally re-meaning a traumatic event and change their perspective on events. Although some aspects of post-traumatic strengthening emerge immediately, most effects extend over a long period of time and develop over time. The speed of this development varies according to demographic factors, the effect of the traumatic event and the stress it creates, the resources available, the strength of social solidarity, the use of functional coping skills, and personality traits (27). Despite having a child with pediatric palliative care patients and the added COVID-19 pandemic, parents and families have hopes, dreams, and expectations. The most apparent expectation in our study was visiting grandmother, seeing the rest of the family, getting together with relatives and friends were found to be in the social area. Going on vacation, swimming, and moving to a new home is an indication of the need for change. In our study, psychological support was found to be the most expectation from palliative care, and the difficulties experienced less were the medication and supplies. In pediatric palliative care, it can be said that the COVID-19 pandemic most prominently causes psychosocial distress.

Study Limitations

Since the study was an inquiry for the past year, the variability of the situations that families feel anxious and hoped for due to difficulty in remembering and rapid changes in the process are the limitations of the study. Again, since the phone records did not belong to a single parent (mother or father), the differences in viewpoints in the inquiries made are a limitation of the study in terms of standardization.

CONCLUSION

The COVID-19 pandemic process in pediatric palliative care is a milder and better prognosis than expected. Families whose first-degree relatives suffer from the disease make significant changes in their lives. Psychosocial difficulties are the most obvious areas of distress. Due to the nature of the pandemic, there may be different challenges in each country.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Izmir Dr Behçet Uz Children's Hospital Clinical Researches Ethics Committee (Date: 25.03.2021, Meeting Number: 540, Decision Number: 2021/06-05).

Informed Consent: All patients signed the free and informed consent form.

Referee Evaluation Process: Externally peer-reviewed.

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

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

Author Contributions: All of the authors declare that they have all participated in the design, execution, and analysis of the paper, and that they have approved the final version.

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