



The experiences of parents of children in pediatric palliative care: A qualitative study

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ABSTRACT

Purpose: This study aims to better understand the experiences of mothers of children receiving pediatric palliative care.

Design and methods: The qualitative phenomenological method was used to determine the mothers' experiences. The study sample included 15 mothers. Individual interviews, an introductory information form and a semi-structured interview form were used for data collection. The data were analyzed with Colaizzi's seven-step method. MAXQDA was used for coding and creating themes.

Results: Three main themes of the interviews emerged; family experiences, social life and care in the palliative care unit. The mothers said that family relationships were affected, that they experience fear of loss, that they experience depression, that all responsibility for treatment and care lies with the mothers, and that there is no social support. Mothers said that they are in the same place as mothers of children in similar situations and that they are happy and comfortable because they have single rooms. In addition, the mothers stated that they are very afraid of the COVID-19 virus infecting their children and therefore losing their children.

Conclusions: The mothers experienced some problems such as fear of loss, depression, care burden, social support, exclusion, daily life, social relationships, feeling safe, and emotional effect.

Practice implications: Pediatric nurses need to understand mothers' anxiety, grief, relationships with their children, and coping strategies to provide support.

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Introduction

Pediatric palliative care (PPC) is an active care approach that includes physical, emotional, social and psychological elements (Eshaghian-dorcheh et al., 2019). It concentrates on increasing patients' quality of life and providing support for families. It includes symptom management, decision making, death and grief (World Health Organization, 2018). Prolonging the life expectancy of children due to advances in science and technology requires (technology/life-extending/ supportive...) care (Donnelly et al., 2018). This care is provided for children with various life-limiting and threatening diseases such as congenital anomalies, cancer, and neurological conditions. Depending on the progress of the diseases, the children's development may be restricted. Families are an essential part of the pediatric palliative care approach (Nazzal & Al-rawajfah, 2018). Children are mostly dependent on

family members for daily activities and their health needs (Oliveira Barros et al., 2019). Even though mothers and fathers have different roles, they generally carry out health, work, education, daily activities, and leisure activities together (Feudtner et al., 2019). However, these kinds of routines may be shaped around the needs of the children receiving care (Fonseca et al., 2021; Weaver et al., 2019). Mothers often give up their time, social lives and own health needs to meet their children's needs (Bourke-Taylor & Jane, 2018). Due to the unstable condition of children with life-limiting diseases, the parents have to spend most of their lives in the hospital (Lindemann et al., 2020). This increases the mothers' burden and negatively affects family dynamics (Nazzal & Al-rawajfah, 2018).

Pediatric palliative care is not only intended for children but the whole family (Lindemann et al., 2020). Therefore, most care and treatment decisions are made jointly by parents and healthcare professionals, as opposed to a single autonomous decision-maker (Donnelly et al., 2018). Mothers experience an incredible workload due to the children's illness which included managing the physical, cognitive and emotional work generated by the situation (Winger et al., 2020).

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Mothers need health care professionals to communicate relevant information, listen to the mothers and give information straightforwardly (Verberne et al., 2017; Winger et al., 2020). Since mothers spend more time in the hospital, they may need a close confidant among the healthcare professionals (Ribbers et al., 2020). To reduce negative effects, family meetings and information sharing should be planned and done continuously by multidisciplinary teams. Parents should be included in decision-making processes (Donovan et al., 2019). The number of qualitative studies on psychosocial problems experienced by mothers whose children are being treated in the pediatric palliative care unit during this difficult period is limited (Donovan et al., 2019; Ribbers et al., 2020; Woodgate et al., 2015). Studies carried out in intensive care and palliative care units have determined that emotional symptoms such as anxiety, sadness, sorrow, feeling empty, and apathy increase. The most common causes of stress in mothers caused by their children being treated in the intensive and palliative care units are being away from home, feeling helpless, and loss of control (Collins et al., 2016; Donovan et al., 2019; Ribbers et al., 2020; Verberne et al., 2019; Woodgate et al., 2015; Zimmermann et al., 2016). However, parents whose children are in palliative care have many needs in addition to their psychosocial needs. One of these needs is to inform parents. Parents should be given information in a way they can understand, starting from the moment of diagnosis. This information should include the children's illness and treatment, complications, current situation, practices and services to be performed (Snaman et al., 2020). Another requirement is to improve the quality of life of children and parents. In addition, the children's illness may socially isolate the parents from society and cause the deterioration of friendships and neighbours relations. For this reason, the social relations of the families before the illness and their social activity needs should be supported. In addition, as the care burden of the mother, who is primarily responsible for the care, increases, they should be supported to move away from home at certain and regular intervals (Akard et al., 2019).

The Pediatric Palliative Care Unit where the study was carried out in the hospital was opened in November 2018 as the first and only unit in the Aegean region. This study is the first study conducted in our unit where we shared the experiences of mothers. In addition, in our country, the PPC unit's work is integrated with the Home Health Services (HHS). It has a telephone line and free service can be obtained. Home visits and interventions are made by the HHS. HHS contributes to the support of parents by communicating with parents. Palliative care seeks to improve the quality of life of patients and parents dealing with life-threatening illnesses by preventing and reducing physical, psychosocial, and spiritual suffering through early identification. It is based on managing the children's care as well as possible. The quality of care provided to the patient plays an important role in increasing the quality of life in pediatric palliative care. Therefore, it is necessary to determine parental needs and satisfaction to increase the quality of pediatric palliative care. So, it is important to know the perceptions of the mothers about the services they receive and their views and experiences about the service process. In addition, effective interventions are needed to better support mothers. This study, it was aimed to better understand the experiences of mothers of children receiving pediatric palliative care.

Materials and methods

Study design

This was a qualitative study based on interviews with mothers. The qualitative phenomenological method was used to determine the experiences of mothers of children in the pediatric palliative care unit. Qualitative research reveals the perspectives and perceptions realistically and holistically, using different qualitative data creation methods such as observation, interview and document analysis. The main purpose of qualitative research is to focus on the experiences and perspectives of

the participants and ensure that their "perceptions and experiences are revealed" (Yüksel & Yıldırım, 2015). In phenomenological studies, data are usually made using in-depth interviews (Wilson, 2015). The phenomenological approach provides an in-depth insight into the experiences of the participants (Speziale et al., 2011). The data obtained using this method were evaluated using Colaizzi's seven-step method for data analysis. This scientific approach ensures the authenticity and rigorous evaluation of the data by scientific standards (Colaizzi, 1978).

Settings

This study was carried out from February to September 2020 in the pediatric palliative care unit of a hospital in the province of Izmir in Turkey. The care and treatment process for inpatients in the PPC unit is carried out with a multidisciplinary team approach. In the PPC unit; nurses (11), doctors (2), a psychologist (1), a moral support specialist (religious officials) (1), a physiotherapist (1) and a social service expert (1), are working, and interpreters are called for foreign patients when necessary. Indications for admission to the Pediatric Palliative Care Unit consist of pediatric patients (0–18 years old) who need long-term supportive treatment. Also in the PPC unit, caregivers (mother, father, sibling, caregiver, etc.) who will care for their children are provided with all necessary training for the care of the patient. In addition, training participation forms are filled out and recorded. The patient is prepared for discharge after the caregiver is sure that the child is fully cared for (tracheostomy care, percutaneous endoscopic gastrostomy care, aspiration, pressure sore care, etc.), nutrition and treatment (drug dose calculation, preparation of drugs, etc.). Since the families of the patients cannot work during this period, the cost to society and the family is very high. The nurse inform the family about the economic support they can get and how to reach them. The nurse help to get support from voluntary organizations.

Participants

The study population included 35 mothers of children in the pediatric palliative care unit from February to September 2020. In qualitative research, the sample size is determined based on reaching data saturation. Data analysis began with the preparation of the data. Researchers read the transcript several times until they felt that they understood what the mothers had said. The meaning was subsequently formulated for significant statements, which were then organized into themes. The themes were further integrated into descriptions. Two researchers analyzed the data independently. In case of any disagreement, they reviewed the transcripts and discussed them together until they agreed. The sampling was completed with the enrollment of 15 mothers. It has been recommended that the sample size should be not too small to limit reaching saturation (Onwuegbuzie & Leech, 2007). Saturation and ratification of data were the guiding principles affecting sample size, as was indicated by Morse (Morse, 2015). The inclusion criteria were; (1) volunteering to participate in the study, (2) being over 18 years old, (3) having no communication complication (visual, auditory or mental), (4) having a child who has been receiving care in the pediatric palliative care unit for at least 10 days, and (5) speaking Turkish.

Data collection

An introductory information form was used to determine the sociodemographic characteristics of the mothers and children, and a semi-structured interview form was used to determine the mothers' experiences.

The introductory information form: This form was created by the researcher after a review of the literature. It has questions about the participant's age, gender, education levels and specific characteristics.

The semi-structured interview form: This form was prepared after a review of the literature (Collins et al., 2016; Ribbers et al., 2020;

Verberne et al., 2019; Woodgate et al., 2015; Zimmermann et al., 2016), and expert opinions about its suitability were obtained from ten experts. Because in qualitative research, the questions must be fully understandable by the mothers. Therefore, it is recommended to carry out preliminary studies to evaluate the suitability of the questions. In this way, the answers of the mothers in our study showed that the questions were perceived correctly by the mothers. A pilot study was undertaken to maximise the utility of the interviews. Three mothers were chosen from the study population for the pilot study, and they were excluded from the study sample. The interviews were carried out and the suitability and comprehensibility of the questions were evaluated by experts in the field. Interview questions are as follows;

- What do you think about your child's health status?
- What do you think about your child's treatment and care in the Pediatric Palliative Care Unit?
- How do your child's treatment and care in the Palliative Care Unit affect you?
- What did you experience during the treatment and care process? How does your child's being treated and cared for here affect your life?
- Who will support you when you are in the hospital?
- What do you need here to manage your child's health problem?

Voice recorder: A Sony ICWDPX240.Ce7 voice recorder was used to record the interviews. It can record up to 32 h (MP3 8 kbps).

Semi-structured interview

The individual interviews with the mothers who agreed to participate in the study took place in the patient meeting room of the unit to ensure a quiet and comfortable environment. The patient's care nurse was present at the patient's side when the mother was interviewed by other researchers. The mothers filled out the introductory information form before the interviews. Then, the interviews were carried out using the semi-structured interview form. The interviews were concluded when data saturation was achieved (when the participants' statements started to resemble each other). Each interview lasted 45–60 min. In addition, the interviewer has various studies on qualitative research methods.

Ethical statement

The research was approved by a clinical research ethics committee (02.01.2020, decision number 05) of the hospital where the study was conducted.

Written informed consent was obtained from the mothers before the interviews, explaining the purpose of the study, usefulness, the time for the interview and that an audio recording device would be used. The names of the participants were kept confidential, and the nurses were identified with codes (P1, P2, P3...).

Data analysis

The sociodemographic data were analyzed using SPSS 22.0 software. They are shown as numbers and percentages. Thematic analysis was used for qualitative data. Colaizzi's seven-step method was used for analyzing the data. In the first step, audio recordings were saved. Each written transcript was read multiple times by both researchers. In the second step, important statements about the experiences of the mothers were determined from among transcripts. In the third step, significant expressions were formulated. In the fourth step, the formulated meanings reflecting the experiences of the mothers were grouped into clusters of three common themes. In the fifth step, we compiled an exhaustive description of everything generated in steps 1–4. In the sixth step, the basic structure was defined for the experiences of mothers. In the final step, the findings were confirmed by contacting the participants again (Colaizzi, 1978). MAXQDA was used for coding and creating themes.

Truthfulness

In qualitative research, the criteria used for ensuring the reliability of the research results are reliability, verifiability and transferability (Speziale et al., 2011). To ensure reliability, researchers read and classified the transcripts multiple times and independently. To increase the reliability of the data, the authenticity of the data was maintained. In addition, after the transcripts were created, the participants were interviewed again, and they were asked whether there were any statements they wanted to add or remove. To ensure accuracy and reliability, all transcripts were reviewed. The researcher who confirmed reliability was experienced in qualitative research and familiar with the subject of the study. The responses of the mothers were conveyed in their original forms to ensure accuracy. The researchers who confirmed reliability were experienced in qualitative research and familiar with the subject of the study. In addition, one of the researchers who confirmed the reliability worked in a pediatric palliative care clinic for two years.

Results

The demographic characteristics of the mothers

The mothers' mean age was 32.13 ± 6.5 (min. 22; max.45) years. Of them, 69% had resided for most of their lives in big cities (a Province with a total population of more than 750,000 people), and 46.7% lived in their own homes in Izmir. Of the participants, 53.3% had their first child hospitalized in the unit. None of the mothers was working. Their descriptive characteristics are shown in Table 1.

Table 1
Sociodemographic characteristics of the mothers (n = 15).

Descriptive characteristics	Number	Percentage (%)
Where have you resided for most of your life (2/3)?		
Village	5	33.3
District	6	40.0
Province	4	26.7
Where do you live in Izmir?		
With relatives	2	13.3
Hospital	6	40.0
Own home	7	46.7
Family type		
Elementary family	12	80.0
Extended family	2	13.3
Fragmented family	1	6.7
Number of children		
1	2	13.3
2	8	53.4
3	5	33.3
Which of your children is hospitalized?		
1st	8	53.3
2nd	6	40.0
3rd	1	6.7
Maternal education level		
Illiterate	1	6.7
Literate	1	6.7
Primary School	7	46.7
High School	1	6.7
University or more	1	6.7
Paternal education level		
Primary School	6	40.0
High School	1	6.7
University or more	6	40.0
Paternal employment status		
Working in a regular income job	11	73.3
Working in an irregular income job	4	26.7
Income Status		
Income is less than expenses	9	60.0
Income is equal to expenses	5	33.3
Income is greater than expenses	1	6.7

Table 2

Sociodemographic characteristics of the children (n = 15).

Descriptive characteristics	Number	Percentage (%)
Diagnosis		
Cerebral Palsy (CP) + Motor Mental Retardation (MMR)	3	20.0
CP + Epilepsy	2	13.3
SMA	6	40.0
Safosine A deficiency	1	6.7
CP + MMR + Epilepsy	2	13.7
Microcephaly	1	6.7
Gender		
Female	9	60.0
Male	6	40.0
	Mean ± SD	
Age	6.80 ± 4.6 (min. 1; max.16)	
The children's hospitalization time	25.93 ± 9.3 (min. 10; max.45)	

SD: Standart deviation.

The demographic characteristics of the children

The mean age of the hospitalized children was 6.80 ± 4.6 (min. 1; max.16). Of them,40% were diagnosed with Spinal Muscular Atrophy (SMA), nine were females, and six were males. The mean duration of their stay in the pediatric palliative care unit was 25.93 ± 9.3 (min. 10; max.45) days (Table 2). The majority of diagnoses in our study consisted of SMA, epilepsy, cerebral palsy, mental retardation, rare diseases, and metabolic diseases. The number of repeat admissions of children who were included in the study to the PPC unit is five. Reasons for hospitalization are pneumonia, tracheostomy change, opening gastros-tomy, providing nutrition, and education requirements related to health care to the family.

Content analysis

Three themes emerged – family experiences, social life, and care. These themes and their sub-themes are shown in Table 3.

Theme 1: family experiences

In the theme of family experience, the mothers described family relationships, fear of loss, depression, care burden, and social support (Fig. 1). The mothers said that family relationships were affected during the treatment and care of their children. One of the mothers said that her husband does not take care of her child and that she is forced to look after the child herself.

"To be honest, my husband is careless. He does love our child, but he is not interested. To be honest, I have fought alone. I have tried to look after our child alone. I have tried to understand. Sometimes, I think... I burnout" (P8)

Many of the mothers said that they are sad, unhappy, and tired because they cannot see their other children while their child is in the pediatric palliative care unit.

"I am kept away from my other children when I come to the hospital. I also feel sorry for them. Sometimes I cry. I have two other children. One goes to school, and one is two years old, but I cannot pay attention to them. It is hard for all of us." (P5)

One of the mothers said that her relationship with her husband and other children is better since visiting hours are unlimited in the pediatric palliative care unit.

"Other units have visiting hours. They only allow visitors from 1-2 pm. for example. My husband works, so he could not go there during visiting

Table 3

Themes and subthemes from the mothers' interviews.

Themes	Subthemes	
Family experiences	Family relationships	"There are almost no family relationships anymore. You forget everything. It is like you only have this one child. You feel like there is nobody else." (12)
	Fear of loss	"I am afraid that something will happen to my child when I turn my back." (5)
	Depression	"I try to be strong. I have to get used to the interventions here. I feel burned out sometimes." (7)
	Care burden	"Since he has been like this since he was a baby, it is still like he is my baby. I hover over him. I do not trust anybody. If I weren't here, nobody could care for him." (2)
	Social support	"Nobody supports me. Only my oldest daughter supports me, and then only if I have something very important to do. Then I leave him with her. We arrange the hours for my daughter's convenience. That's how it is. I cannot do anything freely." (1)
	Social life	Exclusion
Daily life		"Sometimes I cannot even find the time to by bread." (5)
Social relationships		"I am comfortable here. You sit and even your food comes to you. You do not have to clean. I can find time to talk on the phone." (3)
Care	Feeling safe	"They help me here when I ask them if something has happened." (1)
	Emotional effect	"In other units there are generally also normal children, and their views bother you. If I carry out a postural drainage in front of somebody else (who does not know what it is), they think I am hitting my child. They get mad at me. Since all the patients are like us in this unit, we are much more comfortable." (13)
	Information	"They have informed me about the tools and machines used." (6)
	Physical conditions	"It is wonderful to be able to be with my child and not having to leave him alone. Other units have visiting hours. They only allow visitors from 1 to 2 for example. My husband works, so he could not go there during visiting hours. But my child's siblings and father can come here whenever they want." (10)
	Education/ discharge	"They tell you everything before being discharged, even how to administer the drugs." (11)

hours. But my child's siblings and the father can come here whenever they want." (P10)

The mothers said that they and their other children experience sadness, sorrow, fear, anxiety, and fear of death the children in the pediatric palliative care unit. In addition, the mothers stated that they are very afraid of the COVID-19 virus infecting their children and therefore losing their children.

"They are sad, but they have gotten used to it. Before they always asked me why their sibling is sick. Now they do not ask anything. When they come to the hospital, they ask whether or not something will happen to their sibling." (P14)

One of the mothers said that she experienced psychological difficulties while caring for her child.

"This disease has affected me very badly, especially me. My son did not sleep for two years. He cried constantly. He did not understand. We had no eye contact. He had no feelings. It was a very difficult time. I fell into depression. Later, I went to a psychologist for six years and used medications." (P9)

All the mothers said that they feel responsible for the care of their children. *"It was easier when my child was a baby, I could handle it. But now that he is bigger, it is more difficult, and the spasms have increased. Up until now, I fed my child by mouth. A hole (tracheostomy) was made*

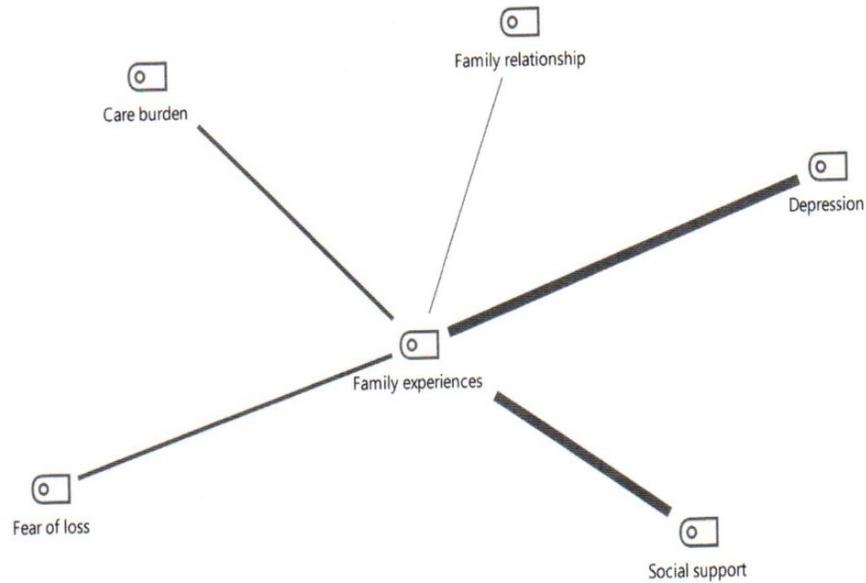


Fig. 1. Family experiences code-subcode sections model.

in his throat because he could not breathe. Now I am feeding him formula through his nose (nasogastric). It is very difficult for me. Especially in the bathroom. We bathe him together with his sister. I do not know how it is going to be when he gets bigger.” (P3) Many of them said that when their children were cared for in the pediatric palliative care unit, their care burden decreased due to the nurses and the healthcare team and their quality of life increased.

Many of the mothers defined the people they received social support from as a mother, elder sibling (especially older sister), and spouse.

“Nobody supports me. Only my oldest daughter supports me, and then only if I have something very important to do. Then I leave him with her. We arrange the hours for my daughter’s convenience. That’s how it is. I cannot do anything freely.” (P1)

Theme 2: social life

This main theme has three subthemes; exclusion, daily life, and social relationships (Fig. 2). The mothers said that they are excluded from social relationships, that their daily life is affected, and that their social relationships are restricted or non-existent. Many of the mothers said that they do not have a normal social life and are only in contact

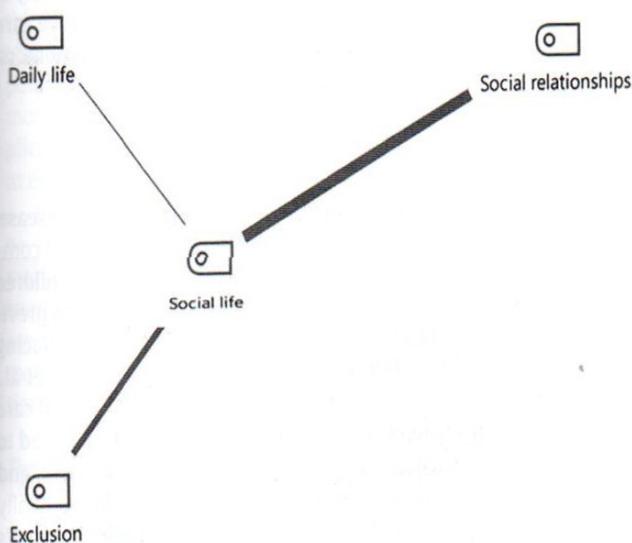


Fig. 2. Social life code-subcode sections model.

with their family members. While the mothers experience exclusion in normal life, they said that they feel like family with the other mothers in the pediatric palliative care unit. Some of the mothers said that they are excluded by friends.

“I do not have a social life at home. I cannot go out. I cannot meet any friends. They do not come to me. They say that they do not want to disturb me. I want them to come, but I cannot force anyone to do so. They do meet up with each other, but I stay at home.” (P15)

The mothers experienced no difficulties with daily activities when their children were small. However, when they got older, they were not even able to go to the supermarket. One of the mothers with an older child also emphasized that their social life was adversely affected because they had problems with the transportation of their children.

“I was able to take my child everywhere before, even to weddings. We went to the hippodrome once a week, and he would ride horses, and twice a week I would take him to special education. Now he is older, we do not have a car, and I cannot take him anywhere. Sometimes I am not able to go to the supermarket because I cannot leave him with his sibling.” (P7)

The mothers said that their social relationships decreased as their children got older and that they experienced difficulties with daily activities. The nurses in the pediatric palliative care unit encourage the mothers to socialize. They also plan activities from time to time for the mothers (tea time, mandala colouring, etc.). “You do not have the time to sit down at home. I must care for the child, make dinner and do the cleaning. I even drink my coffee standing up, but here we are very comfortable. During the day we sit here with the other mothers and chat. The nurses look after our children. Sometimes we even play games.” (P13). Another mother said: “We have created a WhatsApp group because we have been here for a long time and come regularly. From there, we chat, talk, have trouble, share everything... We became a family there...” (P4). However, some restrictions had to be applied to the unit due to COVID-19. For this reason, the mothers interviewed during the pandemic said that they had more fun and socialized more before the pandemic. “During our previous stay we would get together with the mothers and have fun here. Now we cannot leave the rooms due to the pandemic.” (P9).

Theme 3: care

The care themes contain mothers’ statements about care in the pediatric palliative care unit and how it has affected their lives (Fig. 3). The

and maintaining optimism help mothers maintain their daily lives (Verberne et al., 2019). So pediatric nurses working in the PPC can be educated to provide counselling to mothers.

Mothers experience great physical, emotional, and social difficulties (Collins et al., 2016; Zimmermann et al., 2016). Many studies have reported that the care burden of mothers was especially high (Weaver et al., 2019; Bourke-Taylor & Jane, 2018; Ling et al., 2016). In this study, all the mothers said that they feel primarily responsible for their children's care. They said that their care burden was reduced by help from the nurses and health team. It is not easy for mothers to transfer their care responsibilities to someone else. Pediatric palliative care services can effectively support mothers in terms of care and reduce the care burden (Ling et al., 2016).

Social support has been defined as one of the most common and effective strategies for coping with stress and maintaining physiological well-being (Ribbers et al., 2020; Verberne et al., 2019). Even though many of the mothers received support from their spouses and/or family members, the support given by the social system is insufficient or limited. Family members and friends may have difficulties understanding the children's and parents' situations. Therefore, mothers may be affected emotionally and excluded (Woodgate et al., 2015). Baumbusch et al. (2018) found parents who needed the help of their families and friends said that they felt lonely and were split between caring for their sick children in the hospital and caring for their other children at home.

The social life themes

In this study, some of the mothers said that they do not have any social relations and they cannot find a way to allow themselves to live their own lives, interact socially or engage in hobbies. Also, some mothers said that they experienced exclusion in normal life by friends. Therefore, mothers may be affected emotionally and excluded (Woodgate et al., 2015). In addition, all the mothers said that they feel primarily responsible for their children's care.

In this study, mothers stated that their social lives change (become more difficult) as their children get older. They stated that they did not have any problems going from one place to another when their children were small. Contrary to this situation, as children get older, they have difficulty taking their children out. For this reason, it has been revealed that the restrictions in the social life of mothers and fathers have increased. Mothers should be supported as much as possible so that they can do the activities they used to do in their spare time, go on holiday for weekends and for a long time.

This study showed that pediatric palliative care helped the mothers to socialize and cope with the illness. Sharing the same environment with mothers who have children like their own children strengthened the mothers' social relationships with each other. Mothers in the PPC unit have a WhatsApp group. However, there are no nurses or health personnel in this group. It was revealed in the interview with the mothers that the mothers were in interaction in these groups. These applications may increase parental interaction and offer the opportunity to establish a communication network among themselves.

In addition, the "Multi-Purpose Hall" in the clinic allows mothers to be supported socially. There are also some practices offered to the mothers of inpatients and at the initiative of the responsible nurse. For example, by bringing a hairdresser to the clinic, mothers' care needs are met and they feel better. Therefore, nurses need to encourage mothers to seek social support and help them to establish communication with peers.

The care themes

Providing parents with constant information about the health status treatment and care of their children and providing training increases the quality of life, self-confidence and satisfaction of both children and

parents (Eshaghian-dorcheh et al., 2019). This study determined that the mothers' self-confidence increased after they learned about the care their children needed. In our hospital, a palliative care consultation team was established. Consultation team; the palliative care unit consists of the responsible physician and the responsible nurse, dietitian, and psychologist. Inpatient consultation is requested and evaluated by the palliative care consultation team. Also in our country, the Home Health Services (HHS) has a telephone line and free service can be obtained. Home visits and interventions made by the home health unit are followed by the Provincial Health Directorate. In our hospital, the PPC unit works integrated with the HHS. It is questioned whether all patients hospitalized in the PPC unit are registered with the HHS. Those who are not registered are directed to the HHS and discharged after completing their registration. In addition, when there is a change in the health status of the children, families come to the hospital with support from the HHS. Parents should be in constant communication so that HHS can provide better service to them. Considering the long length of hospital stay and the cost of care for the dying individual, it was found that receiving health care in a palliative care centre was more cost-effective than receiving care in a public hospital thanks for the home care services. Through the provision of HHS, 24/7 access to medical advice, and enhanced, personally tailored care coordination. Gans et al. (2016) stated that palliative care program (home-based care) demonstrated an effective way to reduce costs. Similarly, Smith et al. (2014) demonstrated that palliative care provides cost savings.

The mothers felt safe in the unit because the healthcare team was always available and they would intervene immediately even at the smallest problem. Another study reported that mothers preferred caring for their children at home rather than in a hospital. Without the necessary skills, mothers may feel anxious about caring for their children at home (Elias & Murphy, 2012). Teaching caregivers how to do medical practices safely can reduce their anxiety, and stress levels and children's care at home gets easier and safe (Eshaghian-dorcheh et al., 2019). In our country, the mothers in the PPC unit are educated on tracheostomy care, percutaneous endoscopic gastrostomy care, aspiration, pressure sore care, etc., nutrition and treatment (drug dose calculation, preparation of drugs, etc.).

This study determined that the mothers experienced fear, concern and anxiety regarding their children's health status and treatment. Therefore, they exhibit a protective approach toward their children and think that nobody but them can care for them. In the literature, mothers display protective and defensive attitudes toward their children since they are convinced that their sick children are dependent on them and that only they know their child's situation. Taking control not only requires effort but also reduces mothers' concerns because the mothers know that their child's care will be arranged as they wish (Woodgate et al., 2015; Zimmermann et al., 2016).

Some of the interviews in this study were carried out during the COVID-19 pandemic. The mothers emphasized that with the spread of the virus in Turkey, the unit restricted visiting rights, which restricted communication with family members. The mothers were also restricted from leaving the patient room, which negatively affected their social relationships with other mothers. Weaver et al. (2020) reported that pediatric palliative care teams say that the number of children diagnosed with COVID-19 is low. It has also been reported that the coronavirus outbreak greatly affected the structure, care and services of pediatric palliative care teams.

Practice implications

Pediatric nurses in pediatric palliative care units should be able to assess the needs of the children and family comprehensively. They can improve the relationship with the patient and, at the same time, support the coping mechanisms of mothers. They should listen to mothers, respect their knowledge, skills, and decisions, and be able to cope with childhood illnesses with special needs. They must be able to

communicate with children. In future studies, a more specific aim can be determined for the needs of the mothers. In addition, Pediatric nurses working in the PPC unit can be educated in the management of mothers' problems.

Limitations

The findings of this study will contribute to the pediatric palliative care literature, but it has some limitations. First, the study was conducted mostly with mothers whose children have a neurological illness. Future studies should be conducted with larger samples that include different illnesses. Another limitation, in Turkey's pediatric palliative care unit, fathers are not allowed to stay with their children as attendants. Therefore, all the parents included in this study were mothers. Some restrictions were imposed in the pediatric palliative care unit due to the COVID-19 pandemic, which may have affected the mothers' experiences.

Conclusion

This study determined that mothers experience several difficulties. These difficulties were about family experiences, social life, and care. The mothers said that family relationships were affected, that they experience fear of loss, that they experience depression, that all responsibility for treatment and care lies with the mothers, and that there is no social support. In addition, they said that they are excluded from social relationships, that their daily life is affected, and that their social relationships are restricted or non-existent. Also, they feel safe because their children are being cared for in the pediatric palliative care unit, they feel better emotionally, they are satisfied with the physical conditions of the unit, they are being informed about the applications carried out, and they receive training about their children's treatment. Pediatric palliative care drastically reduces the burden of care on mothers. It also makes mothers feel more self-confident.

Author contributions

AK, DK, EAA: contributed to the conception and design of this study, collected the data, performed the statistical analysis and drafted the manuscript.

TÇ: contributed to the conception and design of this study, critically reviewed the manuscript and supervised the whole study process.

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Ethical approval statement

The ethics committee approval of the study was granted by the decision of the Board of Directors of the Clinical Researches Ethics Committee of University of Health Sciences Dr. Behçet Uz Child Disease and Surgery Training and Research Hospital (numbered, 05, dated January 02, 2020). The objective of the study was conveyed to the participating parents and written consents were obtained.

CRediT authorship contribution statement

Atiye Karakul: Conceptualization, Methodology, Data curation, Writing – original draft, Formal analysis, Supervision. **Didem Kiratli:** Writing – original draft, Formal analysis. **Esra Ardahan Akgül:** Writing – original draft. **Tanju Çelik:** Conceptualization, Methodology, Visualization, Investigation, Supervision.

Declaration of Competing Interest

The authors have no conflict of interest to declare.

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