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“WE HAVE LEARNED TO SPEAK WITH OUR EYES”: REFLECTIONS OF THE PEDIATRIC PALLIATIVE CARE PROCESS ON FAMILY LIFE

“GÖZLERİMİZLE KONUŞMAYI ÖĞRENDİK” PEDİATRİK PALYATİF BAKIM SÜRECİNİN AİLE YAŞAMINA YANSIMALARI

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ABSTRACT

Objective: This study was conducted to examine in detail the experiences regarding the care process of family members providing pediatric palliative care.

Method: A qualitative research method was adopted for the study. The reason for choosing this method was to understand the phenomenon of the reflections of the experiences of family members who care for children (0-18 years old) in the palliative care process in family life. Data were collected using a semi-structured interview form from the primary caregivers of 10 pediatric patients hospitalized in the pediatric palliative care unit of a children's hospital in Ankara. The data obtained was subjected to descriptive analysis through the "Maxqda 2020 Analytics Pro" analysis software.

Results: Themes created regarding the reflections of the palliative care process on family life are examined and grouped under four headings. These are: "Perception of Palliative Care", "Difficulties in the Palliative Care Process", "Coping Mechanisms of Families" and "Effects of the Palliative Care Process on Family Life". Regarding their socio-demographic characteristics, the caregivers' education levels were low and their income levels were moderate. In terms of the characteristics of the caregiving process, the families were primarily aware of what palliative care is, spent much time during the day for care, and experienced various difficulties (psychological, social, economic) with the care process, causing changes in family ties.

Conclusion: Multidisciplinary teamwork is needed to manage the many difficulties that the palliative care process brings to the lives of caregivers and to increase the coping capacity of caregivers and their quality of life by taking into account all psychosocial and economic contexts of their lives.

Key Words: Pediatrics, Palliative Care, Life Experience

ÖZ

Amaç: Bu araştırma pediatrik palyatif bakım veren aile üyelerinin bakım sürecine dair deneyimlerini derinlemesine incelemek amacıyla yapıldı.

Yöntem: Araştırmada, nitel araştırma yöntemi benimsendi. Bu yöntemin seçilme nedeni palyatif bakım sürecinde olan çocuk grubu (0-18 yaş) hastalara bakım veren aile üyelerinin, bakım sürecine dair deneyimlerinin aile yaşantılarına yansımalarına ilişkin fenomenin anlaşılmasıydı. Araştırma kapsamında, Ankara ilinde hizmet veren bir çocuk hastanesinin pediatrik palyatif bakım servisinde yatmakta olan 10 çocuk hastanın primer bakım verenleri ile yarı yapılandırılmış görüşme formu kullanılarak veriler toplandı. Elde edilen veriler, “Maxqda 2020 Analytics Pro” analiz programı aracılığıyla betimsel analize tabi tutuldu.

Bulgular: Palyatif bakım sürecinin aile yaşamına yansımalarına dair oluşturulan temalar araştırmada dört başlık altında toplandı. Bu başlıklar; “Palyatif Bakım Algısı”, “Palyatif Bakım Sürecindeki Zorluklar”, “Ailelerin Baş Etme Mekanizmaları” ve “Palyatif Bakım Sürecinin Aile Yaşamına Etkileri” olarak belirlendi. Sosyo-demografik özelliklerine göre bakım verenlerin eğitim düzeylerinin düşük, gelirlerinin orta seviyede olduğu görüldü. Bakım verme sürecine ilişkin özelliklerine göre ailelerin çoğunlukla palyatif bakımın ne olduğuna dair farkındalıkları olduğu, gün içerisinde bakıma fazla zaman ayırdıkları, bakım süreci ile birlikte çeşitli zorlukların (psikolojik, sosyal, ekonomik) yaşandığı, aile içi ilişkilerde değişimlere neden olduğu görüldü. Bunun yanı sıra ailelerin psiko-sosyal destek ihtiyacının olduğu ve aldıkları hizmetlerden kısmen memnun kaldıkları ortaya çıktı.

Sonuç: Palyatif bakım sürecinin bakım verenlerin yaşamına getirdiği birçok zorluğu yönetmelerinde, bakım verenlerin baş etme kapasitelerinin artırılmasında, yaşamlarının psiko-sosyal, ekonomik tüm bağlamlarının dikkate alınarak yaşam kalitelerinin artırılmasında multidisipliner ekip çalışmasının gerekliliği ortaya çıkmaktadır.

Anahtar Kelimeler: Pediatri, Palyatif Bakım, Yaşam Deneyimi

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INTRODUCTION

Palliative care is the active, holistic care of individuals with progressive and incurable diseases, especially those nearing the end of life. It aims to improve the quality of life of patients, their families, and caregivers [1]. The World Health Organization (WHO) made great progress in this field by defining palliative care for the first time in 1986. WHO defined palliative care in 1986 as "active total care of patients who do not respond to curative treatment." It is important to control pain, other symptoms, and social, psychological and spiritual problems [2]. With many major and minor changes made in 2002, palliative care was defined as an "approach" rather than "active total care" [3]. In short, this new definition of WHO emphasizes the importance of improving the quality of life of the patient and the caregiver by starting palliative care in the early stages of the disease.

Both children and adults can benefit from palliative care. Approximately 35% of the world's population and 40% of underdeveloped countries are adolescents and children under 20. It is estimated that the number of children (newborns, infants, children and adolescents up to 19 years of age) needing pediatric palliative care each year is up to 21 million. In addition, approximately 2.5 million children die every year due to serious health problems and various diseases, and more than 98% of these children die in low- and middle-income countries. According to 2011 data, pediatric palliative care services were unavailable in 65.6% of countries [4]. Connor et al. (2016) emphasize that of the more than 21 million children with health problems who will benefit from palliative care services yearly, more than 8 million need specialized children's palliative care worldwide [5].

Palliative care uses a multidisciplinary and interdisciplinary team approach to protect the bio-psycho-social health of patients and their relatives [3,6,7]. The palliative care team comprises physicians, nurses, social workers, psychologists, physiotherapists, dietitians, therapists (occupational, occupational physical, etc.) and clergy [8]. Caregivers have a significant role in palliative care. The primary caregiver is important in the pediatric palliative care process and is usually a family member. Considering the complex process of palliative care, the caregiver takes on an extra burden with the responsibility of the patient.

For this reason, health professionals contact palliative care patients' relatives as companions and as a part of the treatment. In addition, the focus of the services related to coping with the problems of the disease is physical symptoms, psychiatric/spiritual /socio-economic problems, end-of-life needs and mourning period [9]. The palliative care team focuses on both the child and their caregivers. It contributes to improving their psychosocial well-being and quality of life. It must have sufficient expertise to address the child's and family's physical, psychological, emotional, spiritual and social needs. Based on this, this study examined the parents providing pediatric palliative care and their experiences regarding the care process, considering the psychosocial and economic contexts of their lives.

METHOD

Study Design and Participants

This study used the phenomenological approach, one of the qualitative research designs. The phenomenological approach focuses on phenomena we are aware of daily but do not have a deep and detailed understanding of [10]. In phenomenological studies, data sources are individuals or groups who experience the phenomenon that the research deals with and can express or reflect this phenomenon. This study examined the exploratory aspects of an existing situation to understand the families' perception of palliative care and their coping mechanisms with the difficulties experienced in this process.

In the study, answers were sought to the following questions:

1-What are families' perceptions of pediatric palliative care?

2-What are the difficulties experienced by families during the pediatric palliative care process?

3-What are the mechanisms families use to cope with the difficulties experienced in the pediatric palliative care process?

4-What are the main situations that affect families during the pediatric care process?

The study data was collected from family members who provided primary care to pediatric patients receiving treatment in the pediatric palliative care unit of a children's hospital in Ankara and participated in the study voluntarily. The interviews were held in the interview rooms of the services, considering the sensitivity of the children's care. During the interviews, no deficiencies regarding the care of the children were mentioned, and the nurses on duty in the ward were asked for help regarding the care of the child receiving treatment during the interview. The researchers had no prior contact with any of the study participants. The study's participants are parents whose child was receiving inpatient treatment in the pediatric palliative care service and who volunteered to participate in the study. A total of 10 people were interviewed, including nine mothers and one father. The research included all the participants who cared for children receiving treatment in the department. Data were collected from the participants by in-depth interviews. The interviews were audio recorded and the participants were informed about the subject in the "Informed Consent Form".

The study was conducted on 09/08/2023 with the approval of pediatric palliative care unit of a children's hospital in Ankara, Clinical Research Ethics Committee. Before the interview, written consent was received from each participant, including the ethical rules and other study elements. The researchers observed a high desire to participate, with the idea that this study would benefit the relatives of the patients treated in the pediatric palliative department. The research data was collected between 15/09/2023 and 15/11/2023 after completing all preliminary preparations. After the data was collected, the organized data sets were edited and transcribed. Moreover, the data analysis procedure started.

Before the interview, a meeting was held with the chief of the pediatric palliative clinic and other healthcare professionals working there, and the development of the questionnaire to be used in the study was worked on. After the questionnaire took its final form, it was implemented. Additionally, a pilot interview was conducted to check the understandability of the questions. In the research, in-depth interviews were conducted using semi-structured interview forms. If questions were needed in other interviews, care was taken to take notes and add them to the next interview form. However, since no questions could change the study's course, no additions or deletions were made to the questionnaire. A voice recorder was used to access the evidence accurately and reliably during data collection. Information about using the voice recorder was given to the participants and included in the consent form.

In determining the participants, criteria were sought: providing primary care to a patient in pediatric palliative care, being Turkish Citizen, and being a first-degree relative. For this reason, criterion sampling and homogeneous sampling were used. In this sampling method, a small and homogeneous sample is taken and studied in detail [11]. In the analogous sampling method, the sample may include a homogeneous subgroup in the population, or a highly specialized situation related to the problem of the research [12].

Thematic analysis was used in the data analysis. Thematic analysis is a method used to identify, analyze, and report patterns (themes) in data. It allows to organize data set at the smallest size and describe it in depth (richly) [13]. MAXQDA 2020 program was used to process the data. The audio recordings were deciphered by the researchers and digitalized. The digital data were then added to the analysis program. The researchers reviewed the data before coding. To ensure the reliability of the data, they were printed out and read to the participants before the analysis, and the accuracy of the data obtained was confirmed. The inductive method was followed to code the data, and the obtained data was freely coded. Categories were created by taking into account the standard features of the coded data.

The study's data were obtained by face-to-face interviews with the parents of 10 patients hospitalized in the pediatric palliative care service. The names of the patient's parents were coded as flower names, and their confidentiality was protected. In the study, participants' important statements regarding the findings were taken, and the participants' code names, ages, and genders were added to the end of the statements (e.g., Bougainvillea, 28, K.). All the researchers were involved in every phase of the study. Miles-Huberman formulation was used to ensure the validity and reliability of the research. Coding was done by a person other than the researchers who were not involved in the study, and the code similarity rate between the researchers and the researchers was calculated as 87.5%. In this regard, it was understood that the coding system was valid and reliable. Since the research was conducted with a qualitative design, it was checked within the scope of the Standards for Reporting Qualitative Research (SRQR) checklist. As a result of coding, four themes and 15 categories were created (Table 1).

Table 1. The distribution of the created themes and categories

Subject	Themes	Categories
Pediatric Palliative	Challenges in the Palliative Care Process	Psychological Challenges
		Physical Challenges
		Difficulties in Social Life
		Economic Challenges
	Perception of Palliative Care	Palliative Care Definition
		Expectations for Palliative Care
		Shortcomings of Palliative Care
		Benefits of Palliative Care
	Coping Mechanisms of Families	Emotional Coping Methods
		Strengthening with Social Support
		Spirit
	Effects on Family Life	Adverse Effects
		Positive Effects
		Neutral Effect

Ethical Approval

The study protocol was approved by the Etlik City Hospital Clinical Research Ethics Committee for the implementation of the study (Decision Number: AEŞH-EK1-2023-232). The study was carried out in Declaration of Helsinki. Before the data collection, all participants provided written informed consent.

Content Analysis

Maxqda 24 Program was used to content analysis. After the coding was done by the researchers, codes, categories and themes were reached with the inductive method. Four themes and 15 categories were obtained in the coding.

RESULTS

According to the findings obtained as a result of the data analysis, four themes were created: the perception of palliative care regarding the reflections of the palliative care process on family life, the difficulties encountered in the palliative care process, the method of coping with difficulties and the effects of the palliative care process on family life. Further, an analysis of demographic findings is included.

Socio-Demographic Characteristics of The Patient's Parents

A total of 10 people, nine women and one man, participated in the study, the youngest being 21 years old and the oldest being 41 years old. This shows that there was age and gender diversity in the study group. Most participants had an education level below the undergraduate level, and only one had a postgraduate level. Considering the participants' income status, only one had no income, while the other participants had sources of income (Table 2).

Findings Regarding the Perception of Pediatric Palliative Care

Within the scope of the Palliative Care Perception theme, four categories were created: the definition of palliative care, the shortcomings of palliative care, the benefits, and expectations about palliative care. Information about categories and coding is presented below.

Findings Regarding the Definition of Palliative Care: According to the data obtained, participants defined palliative care as quality of life, preparation for life at home, incurable conditions, tests, services and needs. In addition, some participants described palliative care from the perspective of a process and a unit where incurable diseases were treated. Some critical statements of the participants on the subject are given below.

"Palliative care is, of course, a process of preparing the child and the family a little bit for life at home. Frankly, palliative care gives me the impression that it is a preliminary preparation for me to be able to care for my child more safely at home as if someone is observing me and if I do something wrong, they will teach me the right thing." (Bougainvillea, 28, K.)

Palliative Care Gaps: “The palliative care gaps” category consisted of codes such as wrong medical guidance, failure to relieve the child's pain, lack of doctors, the harsh attitude of health professionals, and boredom of companions. Participants who observed doctors experiencing burnout stated that these caused deficiencies in palliative care. Participants who stated that the staff generally behaved well also stated that they might have difficulties in communication due to some professional disinformation. Families who were afraid to leave their children alone said that they had difficulties meeting their own needs, needed information in emergencies, and could not reach the service personnel in emergencies.

“Doctors are very “…….” and I don't want to say anything bad about them. But sometimes I come across such doctors that I go home and cry. For example, I have seen them scold me “…….”. Sometimes nurses say something that makes me sad, their words sound very different, sometimes they say a word, for example, that will make me sad for months. (...) We have so many patients. "Are we going to deal with them?" he said. This made me so sad, we were really on palliative. “I was the only patient” (Petunia, 30, F.)

Benefits of Palliative Care: As a result of the analysis, the codes of learning about medical care, receiving quality care, recovery, rooms being private for the family, knowing that you are not alone, and realizing your capacity and care money support was created. The discourse analysis showed that the participants generally preferred to stay in the ward in order to access health services easily, that they were happy to be with their children even though they were dependent on life support units, that the healthcare professionals empathized with them and tended to help them, and that they were relieved with the treatments their children received.

“We cannot go anywhere else, no other hospital will accept us. They push us with their hands. We don't know the child and his treatment. But at least this place knows the child, they know what to do immediately when I bring him. I have been here for a long time because they know that they can immediately intervene and tell the mother that we are starting this medicine on the baby, it feels better.” (Daffodil, 36, F)

Table 2. Sociodemographic analysis

Name	Age	Gender	Education status	Income status
Rose	21	Woman	High School Dropout	Minimum wage
Violet	27	Woman	Primary School Dropout	No Income
Daisy	28	Woman	High school	Above Minimum Wage
Magnolia	23	Woman	Middle school	Above Minimum Wage
Petunia	30	Woman	Middle school	Minimum wage
Bougainvillea	28	Woman	Postgraduate	Above Minimum Wage
Daffodil	36	Woman	Middle school	Minimum wage
Tulip	28	Woman	High school	Uncertain
Lotus	26	Woman	Associate degree	Above Minimum Wage
Evening primrose	41	Male	Primary school	Above Minimum Wage

Expectations for Palliative Care: This category has codes for support teams at home, raising awareness, psychological support for parents, and moderate attitudes of health professionals. On the other hand, five of the participants stated that they did not have any expectations. The "unexpected" coding created accordingly was included in this category.

The analysis indicated that the participants expected to have palliative support teams outside the hospital. In addition, participants' expectations include the creation of various support mechanisms to continue their children's care when they want to take care of their daily work and take a break. In addition, the importance of creating an effective psychosocial support system was emphasized.

“It would have been great for me if there had been a psychologist when I was first diagnosed. "If I had someone with me in distress, I would like to express my troubles like this, but that is not possible right now." (Daffodil, 36, F)

Challenges in the Palliative Care Process

Within the theme of Challenges in the Palliative Care Process, there are categories of psychological difficulties, physical difficulties, economic difficulties and social difficulties. Information about categories and coding is presented below.

Psychological Challenges: Within the scope of the Psychological Difficulties category, fear of harm, psychological fatigue, traumatic effect of sibling death, inability to bear the child's suffering and intense emotional reactions were coded. In the analysis carried out, the statements of the participants who stated that they had a difficult time due to the uncertainties during the disease process and that they were quite worn out during the hospital period attracted attention. The families who make future plans for their children stated that they felt hopeless when they learned about this situation, that they became worried in case of any call or news about the health status of their children, and that this situation caused deep sadness and various psychological disorders in themselves and their ecological environment. Participants also stated that although they initially panicked about their children's seizures or health problems, they later accepted this situation and were able to act calmly in their interventions.

“I had a really hard time at first. He's bleeding slightly, and he's in pain because of the irritation. If you look at his hand, there are holes everywhere. I mean, they put a lot of pressure on us, I'm having a hard time with them. I mean, I don't want my child to suffer, frankly.” (Lotus, 26, F)

Physical Challenges: A result of the analysis created codes for dependence on the device, difficulty in medical care, neglecting one's health, inability to provide personal care, physical inadequacy of the home, weariness of the hospital environment and parental exhaustion. Focusing on the codes in question, the Physical Difficulties category was created. The participants stated that children who continued their treatment mainly depending on machines due to physical difficulties had problems in their self-care. They stated that the burden of care increased depending on the characteristics of their illness, that they also had difficulty in medical care, and that they experienced many physical problems while taking care of their children when they took them home. However, they said physical problems occurred in the children and themselves.

“If he wasn't always connected to oxygen, we would take him outside and take it for walks. Once he is connected to the second machine, we cannot disconnect him at all. Before, I put the oxygen tube in the stroller and walked around the neighborhood, as the children were walking around. But after that, when he couldn't sit down and do anything, he stayed like that.” (Daisy, 28, K.)

Economic Challenges: As a result of the analysis of participant statements, device/medication costs, hotel expenses, travel expenses, excess electricity bills and lack of medical supplies at home were coded. These codings were combined under a standard roof and the theme of Economic Challenges was created. The participants stated they fell into an economically difficult situation because some maintenance materials were imported products, and the machines' financial burden was high. In addition, people coming from outside the province had a problem with accommodation, and people living in the village had concerns about maintenance devices being turned off due to a possible power outage.

“We live in the village. There are constant power cuts. We were connecting him to an oxygen tube. My wife would take me to a place an hour and a half away, fill the oxygen tank and bring it back. It's all about money after all. “We had a little difficulty.” (Daisy, 28, F)

Challenges in the Social Field: Within the scope of the “Difficulties in the Social Field” category, codes for social isolation, adapting life to care, being away from the home environment, not receiving support, being dependent on others and third-person discourses are included. One of the striking findings is that the difficulties in the palliative care process were caused by limitations and emotional burdens rather than medical care. As a result of the analysis, it was understood that among the factors affecting the participants, not only the disease process but also negative environmental discourses were important negative factors.

“So, in fact, your social life is shaped according to the needs of the child. If he has a feeding time, you can adjust it according to his feeding time, and if he is sleeping, you can hear and rest, and when he is up, you are also up. If the general stabilization is good, that is, you always act according to the child's needs and care. " (Bougainvillea, 28, K.)

Coping Mechanisms of Families

Within the scope of the Families' Coping Mechanisms theme, emotional coping methods, empowerment with social support and spirituality categories were created.

Emotional Coping Mechanisms The participants stated that they felt relieved that their children had now entirely accepted the situation as part of their coping mechanism and that they were trying to show patience by getting used to it. The families who need emotional motivation said that they always tried to keep their hope for recovery fresh for their children, that they would not lose their upright stance no matter what, and that conscience was the most critical factor in this process. Although emotional relief methods generally appear to be crying and not overthinking about the issue, it can be said that emotional trauma is experienced in the development of emotional coping mechanisms. In addition, it was learned that the participants, who stated that they held on to life with their children, effectively volunteered to care for their children and that this situation was kept in an extraordinary place for their families.

“I don't want to get into too deep thoughts. So right now the process requires me to be in the hospital. I'm in the hospital. Of course, I don't feel very happy about this, but accepting the process is the most important factor that strengthens me.” (Bougainvillea, 28, F)

Social Support: In this study, social support is an important factor in the participants' coping mechanisms. Emphasizing that social support is an important empowerment mechanism, participants mainly stated that social support mechanisms are vital in cases where they are inadequate.

It was observed in the interviews that family support came to the fore. In this regard, the participants frequently emphasized the importance of spouses' involvement in the care process, and it was understood that family support was an important factor in resting and taking a break. At the same time, it was observed that economic assistance from stem families had an easing effect on the care burden. Some participants stated the importance of taking time for themselves, which is one factor that reduces the psychological pressure they are exposed to, and stated that their neighbors also helped with this situation. In addition, the research found statements that technological conveniences reduced psychological pressure.

“I think that people can heal themselves. In normal life, I tried to do things that made me happy whenever I had the chance. Drinking coffee is important to me. Reading a book, drinking coffee, taking short walks.” (Bougainvillea, 28, F)

“I installed a camera in the house, I monitor it from my mobile phone. When we go somewhere, I check the saturation device, heart rate, and oxygen level. I went out one day. Relatives write, "You are traveling." What if you go and enjoy it 100 percent, I get 10 percent of it." (Evening primrose, 41, M)

Spirit: It is understood from the participants' statements that spiritual elements have an important role in families' coping mechanisms. It was understood that the participants who saw this situation as a spiritual test were prepared for death by emphasizing their spiritual side and had a fatalistic perspective.

“My child has been entrusted to me by God. That's why I'm chosen and no matter what I do, this is a situation I can't prevent. I see it as a gift to myself. So, I was chosen to take care of him." (Bougainvillea, 28, F)

Effects on Family Life

Within the theme of “Effects on Family Life” are categories of positive and negative effects. Some participants stated that no factor in the family order had changed.

Negative Effects on Family Life: The main issue that negatively affected families whose children were receiving treatment in the palliative ward was the deterioration in the relationships between spouses. It is seen that there are conflicts arising from psychological tension between spouses, loss of communication between spouses, ruptures in relationships, and, finally, spouses blaming each other for this issue.

“For example, when my child's condition is bad, I may feel nervous and worried that something will happen at that moment. Because we are so afraid. If he doesn't understand my situation for a moment, either I will snap at him or he will snap at me. “It happens more in emergencies.” (Violet, 27, F)

Another situation that negatively affects family life is the negative behaviors of the root family or family circle. The participants who stated that there was a disintegration in the family structure stated that there were problems in the family of origin and their own families. They even faced situations such as being thrown into the sand.

“During that time, my daughter said: “Mom, do you have to go every day? Don't forget to go today. "How is my brother lying there?" he was asking questions. “He needs me. I have to go." When I said "we need you too." "You leave us every day." he said. “I think he has jealousy.” (Tulip, 28, F)

Positive Effects on Family Life: The families stated that developing a special communication with their children during this process contributed positively to the family and that this strengthened family ties. It is understood that families who communicate with their children make an effort to make them look good, and therefore they make an effort to make both their children and themselves look good.

“It would be safe to say that my daughter taught us how to talk with our eyes. I understand everything from your eyes. You know, when you're lying down, I understand your desire to "turn me around, I'm tired" or that you're hungry. After that, he said he wanted to be held, etc. I can understand it all. I sit down. I hold you in my arms. "I'll talk to him." (Daisy, 28, F)

In addition to its positive and negative effects, some participants state that it does not affect their family life. Some participants stated that there was no change in family interaction or social life.

“I can't lie, at first I made the decision saying "being a disabled mother would hinder my social life". I thought I couldn't spare time for myself. But the most important thing was family support.” (Daisy, 28, F)

DISCUSSION

Palliative care directly affects not only the child receiving palliative care services, but also all members of the family [14,15]. This effect can start when the child is diagnosed with the disease and continues indefinitely. This study aims to deeply examine the experiences of parents providing pediatric palliative care regarding the care process, considering their lives' psychosocial and economic contexts. According to the findings of this study, four themes were created regarding the reflections of the palliative care process on family life: palliative care perception, difficulties in the palliative care process, families' coping mechanisms and the effects of the palliative care process on family life.

The first significant finding of the study is that women generally take the caring role. In some similar studies conducted with relatives of people with diseases requiring care [16-18], it was found that a high percentage of women undertake caregiving tasks. As a result of the findings, gender-based division of labor puts women as primary caregivers.

During the interviews, when family caregivers were asked what palliative care meant to them, it was observed that families mostly tried to explain palliative care with sentences depicting the situation they experienced. Although families defined palliative care using different concepts in the interviews, most agreed that palliative care was an incurable condition, a test, preparation for life at home, service, and need. At this point, this typical sentence expressed by families shows that palliative care is defined as "a process and a unit where the treatment of incurable diseases is carried out".

The caregivers mentioned incorrect medical guidance regarding palliative care deficiencies, inability to relieve the child's pain, lack of doctors, and harsh attitudes of health professionals. Supporting this finding, Robinson, Gott, and Ingleton (2014) reported in their study that patients and families had difficulty understanding the language used by healthcare professionals when receiving information about the disease and that the communication between healthcare professionals and caregivers was weak during the care process [19]. Some studies have emphasised that open, honest and authentic communication is necessary to build trust in the professional relationship between health professionals and caregivers during the palliative care process [14,20]. In this study, communication skills between family caregivers are very important with health professionals during the palliative care process.

Another important finding is that caregiver families face many psychological, physical, economic and social difficulties during the palliative care process. Studies on the difficulties faced by families during the palliative care process show that both mothers and fathers have psychological problems during the palliative care process [18,21,22], economic [14,22,23], physical [24-26] and social challenges [14,23]. Our study is consistent with the results of these studies.

Qualitative interviews indicate that caregiver families can overcome the difficulties they experience during the caregiving process with various coping methods. In this study, the coping mechanisms used by families converged on different themes, including emotional coping mechanisms, social support and spirituality. It has been found that the methods of coping with the difficulties of families providing pediatric palliative care have similarities and differences. Similar studies support our findings. For example, in their study, Darlington et al. (2020) reported that families providing palliative care used various coping strategies such as humor, staying positive, defending others and staying strong, expressing emotions and preparation, and social support during the caregiving process [27]. In the study conducted by Verberne et al. (2019), palliative care families' caregiving process has been found to use coping strategies such as suppressing emotions by keeping the loss of their child at bay, seeking social support, taking control to arrange optimal child care, and adapting to and accepting ongoing change(s) [28]. Özdemir (2016), in his study, determined that 90.8% of the patient's relatives saw caregiving as a religious obligation, and 67.1% turned to religion more during caregiving [29]. This result provides a finding parallel to our research.

Another critical issue that families mention in their coping mechanisms is social support. In this study, the support system of families providing pediatric palliative care was provided by spouses, root family, environmental support (neighbor), economic support, spiritual beliefs, and technological developments to make life easier. Therefore, it has been seen that "social, economic, emotional, psychological and internal resources and strengths of the family" are the social support resources of families, and these social support resources are vital in determining the quality of life of families. In line with the findings in our study, parents providing pediatric palliative care appear to adopt more social support and a submissive approach as a method of coping with difficulties. Çetin (2018) found that the areas caregivers use most to cope with stress are seeking social support, a self-confident approach and an optimistic approach, respectively [30]. The submissive approach and the helpless approach were the areas that caregivers used least frequently to cope with distress. However, Gün (2017), investigating the coping situations with stress in caregivers of stroke patients, identified the most frequently used areas as self-confident approach, helpless approach and optimistic approach, respectively [31]. In a similar study conducted on nurses, Kopuz (2013) listed the most frequently used areas as self-confident, optimistic, and helpless [32]. In addition, some studies have reported that psychosocial intervention and social support during the caregiving process of palliative care families have a significant positive impact on the quality of life of caregivers [33,34]. Rutkowski et al. (2018) stated that the social support sources of families providing palliative care are "spouse, family, close friends, palliative care team members and spiritual beliefs." However, interdisciplinary care team members also reported providing "emotional" and "informational" support to patients and their families [35]. Therefore, it can be said that the studies conducted in the literature are similar to the results of the current study.

The palliative care process significantly affects the family's daily, social, cultural and economic life, especially marriage and family life [14,19,22,36-39]. In parallel with the literature, it is noteworthy that the findings, especially relationships between spouses, and the roles and functions of the family have been reshaped throughout the palliative care process.

Limitations

The research was limited to 10 families whose children were treated in pediatric palliative care unit of a children's hospital in Ankara. Regarding the study, by paying attention to the number of samples, an attempt was made to determine the time period during which the service provided the most service, and for this purpose, information about hospital planning was obtained. Accordingly, the time period in which the study was conducted constituted another limitation of the research. Due to the obligation to care for children in the study, interviews lasted a maximum of 60 minutes. Another limitation of the study was the lack of time for families who carry out the care burden of their children.

CONCLUSION

Four themes were created from our study: perception of palliative care, difficulties in the palliative care process, families' coping mechanisms and the effects of the palliative care process on family life. In the theme of palliative care perception, it was concluded that families were aware that services were generally provided to seriously ill and incurable patients and evaluated the process as learning medical care. Perception as a test is also frequently mentioned. According to the caregivers, the most critical deficiency is the negative attitude of health professionals, and the most crucial benefit is receiving quality care. In this case, considering the skills of the personnel in medical services, communication skills need to be improved as well. Additionally, caregivers' lack of expectations regarding the process and their need for support are noteworthy.

It is seen that psychological difficulties predominate in the theme of difficulties in the palliative care process. It is observed that intense emotional reactions such as sadness, stress, panic, shock and anxiety are prevalent. The other most frequently mentioned problem was not being able to bear the child's pain. At the same time, since pediatric palliative care is not widespread, coming to a limited number of palliative care services from surrounding provinces causes extra financial burdens such as hotel and travel expenses. Dependence on the device is shown to be the cause of social restrictions as well as physical strain.

Submissive approach methods are mostly used to cope with difficulties. However, the social support approach is more effective. Parents of the patient, who state that there are no problems in their family and social life, emphasize social support. Unfortunately, the negative effects of the palliative care process, which inevitably has repercussions on the family, have been frequently expressed. While only two of the patient's parents emphasize that it strengthens family ties, conflicts between spouses are among the most apparent negativities. Frequent hospitalizations, long discharge times, and stress due to care burden deeply affect family dynamics. The most important result of the research is that patients' relatives with solid social support mechanisms experience the process less distressingly.

Based on the research findings, it is necessary to develop home care support services regarding the palliative care process, share the burden of care, and raise awareness of the burden of care to increase the quality of life of patients and family caregivers. It is essential that psychosocial support systems continue to be provided both in the hospital and at home during the care process and that multidisciplinary practices are developed regarding case follow-up in sensitive processes such as the hospital process. In addition to raising awareness among families about social adaptation and life, it is recommended that communication-oriented training be provided to healthcare personnel and that studies be carried out to promote public awareness. Moreover, it is vital to determine job descriptions for the coordinated, effective and efficient work of multidisciplinary professions within the framework of care burden, medical care and social care.

Further studies should ask parents about their experiences at the moment they are first diagnosed, the mourning process and adaptation to social life, how to provide palliative-oriented support systems to parents of patients from different nationalities and cultures, researching effective support mechanisms that can be developed for families during the diagnosis and treatment stages, and adding literature to this field.

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