



Determining the Difficulties of Parents with Children in Home Care Who Were Discharged from Intensive Care

Çocuğu Yoğun Bakımdan Taburcu Edilen Ebeveynlerin Evde Bakımda Yaşadıkları Güçlüklerin Belirlenmesi

© Gülçin Bozkurt¹, © Duygu Sönmez Düzkaça², © Gülzade Uysal³, © Tülay Yakut⁴, © Atiye Karakul²

¹Istanbul University-Cerrahpaşa, Cerrahpaşa Faculty of Health Sciences, Department of Midwifery, İstanbul, Turkey

²Tarsus University Faculty of Health Sciences, Department of Nursing, Mersin, Turkey

³Sakarya University of Applied Sciences Faculty of Health Sciences, Department of Nursing, Sakarya, Turkey

⁴Istanbul University, İstanbul Faculty of Medicine, Department of Pediatric Intensive Care Unit, İstanbul, Turkey

Abstract

Introduction: This study was performed to determine the difficulties experienced by parents with children in home care who were discharged from intensive care.

Methods: A phenomenological qualitative method was used to determine the difficulties experienced by the parents. The sample of the study consisted of parents (n=22) whose children met the inclusion criteria and needed home care. The data were analyzed in the MAXQDA qualitative data analysis program in accordance with Colaizzi's seven-stage method.

Results: The average age of the children in the study group was 85.63±58.40 months. 56.7% of them were male. 40% of the children were followed up with a diagnosis of neurological disease. All children discharged from the intensive care unit had tracheostomy. 95.4% of them used home-type mechanical ventilators, and 95.3% were fed enterally. In line with the data obtained from the interviews of the parents, it was determined that there were difficulties in terms of feelings about discharge, physical conditions for home care, family relationship, social relationship, difficulty in physical care, inadequacy in support systems and financial status.

Conclusion: The home care of children, who are dependent on medical technology and discharged from intensive care, is mostly performed by their families. Children dependent on medical technology should be supported by home care personnel to avoid potential risks.

Keywords: Home care, child, intensive care

Öz

Giriş: Bu çalışma, çocuğu yoğun bakımdan taburcu edilen ebeveynlerin evde bakımda yaşadıkları güçlükleri belirlemek amacıyla yapılmıştır.

Yöntemler: Ebeveynlerin yaşadığı güçlüklerin belirlenmesinde fenomenolojik kalitatif yöntem kullanılmıştır. Çalışmanın örneklemini dahil edilme ölçütlerine uyan, çocuğu evde bakım gereksinimi olan ebeveynler (n=22) oluşturmuştur. Veriler, Colaizzi'nin yedi aşamalı yöntemi doğrultusunda MAXQDA nitel veri analiz programında analiz edilmiştir.

Bulgular: Çalışma grubundaki çocukların; ortalama yaşının 85,63±58,40 ay olduğu, %56,7'sinin erkek ve %40'ının nörolojik hastalık tanısı ile takip edildiği saptanmıştır. Yoğun bakımdan taburcu edilen çocukların tamamının trakeostomisi olduğu, %95,4'ünün ev tipi mekanik ventilatör kullandığı ve %95,3'ünün enteral yolla beslendiği belirlenmiştir. Ebeveynlerin görüşmelerinden elde edilen veriler doğrultusunda; taburculuğa ilişkin duygular, fiziki koşullar, aile ilişkisi, sosyal ilişki, fiziksel bakımda zorluk, destek sistemlerinde yetersizlik ve ekonomik güçlük olmak üzere yedi tema elde edilmiştir.

Sonuç: Yoğun bakımdan taburcu edilen tıbbi teknolojiye bağımlı çocuklar evde bakım hizmetleri ekiplerinden yeterince destek almamaktadır. Bu hastaların evde bakımları ailelere tarafından yapılmaktadır.

Anahtar Kelimeler: Evde bakım, çocuk, yoğun bakım

Address for Correspondence/Yazışma Adresi: Gülzade Uysal, Sakarya University of Applied Sciences Faculty of Health Sciences, Department of Nursing, Sakarya, Turkey

E-mail: gulzadeuysal@gmail.com **ORCID ID:** orcid.org/0000-0002-1019-852X

Received/Geliş Tarihi: 17.01.2024 **Accepted/Kabul Tarihi:** 20.03.2024



Introduction

Owing to the development of intensive care technologies, the number of patients who are taken care of at home (connected to a home mechanical ventilator) is increasing.¹ It has been determined that 6.6 out of every 100,000 people in Europe² 9.9 in Australia, and 12 in New Zealand³ survive using a mechanical ventilator at home. The number of children in Turkey who are taken care of at home using a ventilator remained unknown.⁴

Patients who need intensive care survive more in parallel with technological developments. Some health problems of the intensive care patients, who are treated and followed up during the critical period, may become chronic in the future. Long-term stay of chronic intensive care patients in the intensive care leads to bed occupation, an increase in the cost, mortality, morbidity and workload. In order to use the limited number of intensive care beds more efficiently, to reduce the complications of staying in the intensive care unit, to provide moral support and to improve the quality of life, it is recommended that the stable intensive care patient whose emergency condition improves, should be taken care of at home.^{1,5-8}

The length of hospital stay of patients is prolonged due to insufficient discharge planning and home care services. The home care team should coordinate the health care of children who are dependent on complex medical technology and need home care. In recent years, the number of children who are dependent on complex medical technology and followed up at home was reported to increase significantly.⁹ It was emphasized that taking care of patients at home instead of the hospital has been cost-effective to if those patients needed long-term care. In the USA, the cost of daily care of intensive care patients connected to mechanical ventilators was reported to be between 600-1500 dollars,^{10,11} whereas the monthly health care costs were 21,570 dollars in the intensive care and 7.050 dollars in home care and therefore the home care should be promoted.¹² It has been demonstrated that with the development of home care services, discharging children became easier and hospitalization reduced, in addition to many other advantages including social factors and low cost.¹³ The needs of technology-dependent children and families should be clarified.⁹ Determining the difficulties experienced in home care of children discharged from intensive care will provide more insight in terms of the management of home care services. This study was carried out to determine the difficulties experienced by parents with children in home care who were discharged from the intensive care unit.

Study Question

What are the difficulties experienced by parents with children in home care who were discharged from the intensive care?

Materials and Methods

Type of Research

The research was carried out using the phenomenological research method from qualitative research. The data were obtained between January and June 2018 by using quantitative and qualitative methods. Qualitative research method was used to determine the difficulties experienced by parents in home care.¹⁴ The obtained data were evaluated using Colaizzi's seven-stage data analysis method.¹⁵

Study Population and Sample

The population of this study consisted of 42 children who were cared for at home after being discharged from the pediatric intensive care unit of a university hospital. In qualitative research, sample size varied according to sample diversity and data saturation.¹⁶ Data saturation was achieved when no new information emerged in the interviews.¹⁷ Therefore, the sample of the study consisted of 22 parents who agreed to participate in the study. Inclusion criteria for the study were: (1) The parent had a child who needed home care after intensive care, (2) the child was under 18 years old, (3) the parent had no communication problems (sight, hearing, mental), (4) the parent could speak Turkish.

Data Collection Tools

"Descriptive information form" was used to describe the socio-demographic characteristics of the parents and the "Semi-structured interview form" was used to determine the difficulties experienced.

Descriptive information form: It was obtained by the "data collection form" prepared by the researchers in accordance with the current literature.^{1,2,18} The data collection form consisted of 28 questions and two sections.

Semi-structured interview form: For the purpose determined in the research, the semi-structured interview form was prepared by the researchers in accordance with the literature in order to examine the feelings and difficulties of the parents in depth and to guide the interview.¹⁹⁻²¹ There were 13 questions in the semi-structured interview form. Opinions of seven experts were taken for the content validity of the semi-structured interview form.

Voice recorder: Kingboss HS-27 voice recorder was used to record the interviews. The voice recorder had a capacity of 8 GB and can record for 24 hours.

Data Collection

A pilot study was carried out with the data collection tools, which were finalized with expert suggestions. In the pilot

study, three parents were interviewed and these parents were not included in the sample.

The parents were informed about the purpose of the study by considering voluntariness in study participation, and their written and verbal consents were obtained.

In-depth interviews were conducted at home in accordance with the scheduled appointment. These interviews were performed by a researcher. During the interviews, audio recordings were made with the permission of the parents. After the data collection process was completed, the audio recordings were converted into written texts by the researchers.

Statistical Analysis

Descriptive data were analyzed using number, percentage and mean statistical tests in the Statistical Package for Social Sciences (SPSS) 21.0 package program.

Colaizzi's seven-stage method was used for the analysis of qualitative data. At first, the voice conversations were recorded. Then, the interviews were deciphered using MAXQDA program. Each written transcript has been read multiple times by all authors. Secondly, important statements about the difficulties experienced by the parents were determined from the transcripts. Next, the important statements that emerged were formulated. At the fourth step, the formulated meanings reflecting the difficulties experienced by the parents were grouped into clusters of seven themes. In the fifth step, the basic structure of the difficulties experienced by the parents were defined. At the last stage, the findings were confirmed by contacting the parents again (Colaizzi, 1978). The relationship of codes with subcodes was analyzed with MAXQDA in coding and creating themes.

For the internal validity of the study, a semi-structured interview form was created in line with the literature. As a result of the content analysis, integrity was ensured by checking the hierarchical relationship between themes, codes and subcodes. In addition, an expert opinion was consulted at this stage. The texts belonging to two parents were randomly selected from the interview data and given to an expert in this field and expert confirmation was provided to ensure that the data collected during the interview reflected the real situation. At the same time, all of the findings obtained from the parents were given directly without comment.

For the external validity of the study, the researcher submitted all data collection tools, raw data, coding made during the analysis phase, and the perceptions, notes, writings and inferences that form the basis of the report to the expert review and confirmation review was carried out. In addition, the findings were verified by contacting the parents again.

Results

The average age of the children enrolled in the study was 85.63 ± 58.40 (min-max: 15-216) months. 54.5% (n=12) of them were boys and 45.5% (n=10) of them were girls. The mean ages of the mothers and fathers were 35.13 ± 6.48 (min-max: 28-53) and 39.23 ± 6.38 (min-max: 28-53) years respectively.

When the diagnoses of the children in the study group were examined, it was detected that 36.3% (n=8) of them were discharged with a neurological disease. The rest of the children were discharged with a metabolic disease (31.8%, n=7), drowning (13.6%, n=3) and post-op non-extubating and an infectious disease (9%, n=2). It was determined that the children who were taken care of at home after the intensive care unit spent an average of 64.43 ± 42.45 (min-max: 15-180) days in the intensive care unit, and 27.40 ± 21.16 (min-max: 4-94) months at home (Table 1).

The findings revealed that all of the children were discharged with tracheostomy. 95.4% of them used home-type mechanical ventilators, and 95.3% of them were fed with enteral nutritional support systems (gastrostomy, nasogastric or orogastric tube) (Table 2).

Table 1. Characteristics of children and families (n=22)

Characteristics	Min-max	Mean \pm SD
Length of stay in intensive care (days)	15-180 days	64.43 \pm 42.45
Length of stay in the service (days)	7-210 days	46.78 \pm 58.78
Home care period (months)	4-94 months	27.40 \pm 21.16
	n	%
Mother's education		
Primary school	12	54.5
Middle school	6	27.3
Higher education	4	18.2
Father's education		
Primary school	7	31.8
Middle school	10	45.4
Higher education	5	22.8
Occupation status of parents		
Mother not working	20	90.9
Father not working	2	0.9
Family type		
Nuclear family	19	86.3
Extended family	3	13.7
Family income		
Income less than expenses	11	50
Income equal to expenses	10	45.4
Income more than expenses	1	4.6
SD: Standard deviation		

When the trainings given while preparing for discharge were examined, it was observed that all families were informed about care practices (mouth, eye, general body care, etc.), tools used, what to do in an emergency, aspiration and nutrition. 90.9% (n=20) of the families were informed about treatment practices and tracheostomy care. Similarly, 90.9% (n=20) of them were trained for wound care and infection prevention, and 63.6% (n=14) of them were informed about basic life support training. It was detected that 90.9% (n=20) of the mothers and 9.1% (n=2) of the others took care of the child after discharge.

86.7% of the families applied to the home health services center, but only 36.7% of them benefited from these services. When the services provided by the home health services center were investigated, it was determined that 60% of the families did not receive any service, 23.3% of them received medical treatment/follow-up, 6.7% of them had physiotherapy, 6.7% of them had care and finally one person received an ambulance service.

When the services provided by the home care teams were examined, it was detected that the blood was withdrawn from six patients for the laboratory, wound care was provided to two patients and psychological support was provided to one patient. Tracheostomy replacement, tracheostomy care, aspiration, nasogastric/orogastric tube and urinary catheter

insertion, body care etc. were not performed by home care teams.

Content Analysis of Qualitative Findings

In accordance with the data obtained from the interviews of the parents within the scope of the study, seven themes were obtained including feelings about discharge, physical conditions for home care, family relationship, social relationship, difficulty in physical care, inadequacy in support systems and financial difficulties.

Theme 1. Feelings About Discharge

In this section, the feelings that parents had when they first learned that they would be discharged are discussed. In this theme, care-related inadequacy anxiety, worry, fear, uneasiness, helplessness, burnout, lack of self-confidence, hope and joy/happiness codes exist (Figure 1). The subcode hierarchical map of parents' feelings about discharge has been given in Figure 1.

Some of the parents stated that they experienced anxiety about being inadequate especially regarding the care of the child. *"It was very terrible. At first, I couldn't even aspirate, my spouse did."*(K4). More than half of the parents declared that they felt fear, anxiety and uneasiness when they learned that their child would be discharged. *"Since I saw it for the first time, I felt bad at first. I was thinking about what to expect and how to do it. I was worried"* (K17). Some other parent added *"We had questions about whether we would have problems with the electricity. What would we do if it's gone? I was very afraid about intervening D. if something would happen."* (K12). One other parent said, *"The ventilator made us quite nervous"* (K8).

Some of the parents reported that they experienced helplessness and burnout. *"... when the doctor says, let's*

Table 2. Preparations for home care at discharge		
Characteristics	n	%
Getting home from the hospital		
By themselves	5	22.7
Support of the home health services center	1	4.6
112 ambulance	15	68.1
Municipal ambulance	1	4.6
Being ready to be discharged		
Yes	18	81.8
No	4	18.2
Home support systems*		
Tracheostomy	22	100
Household mechanical ventilator	21	95.4
Gastrostomy	8	36.3
Nasogastric/orogastric	13	59.0
Re-hospitalization after discharge		
Yes	13	59.0
No	9	41.0
Number of re-hospitalizations after discharge (n=13)		
1 time	6	46.2
2 times	3	23.0
3 or more times	4	30.8

*: The patient has more than one support system

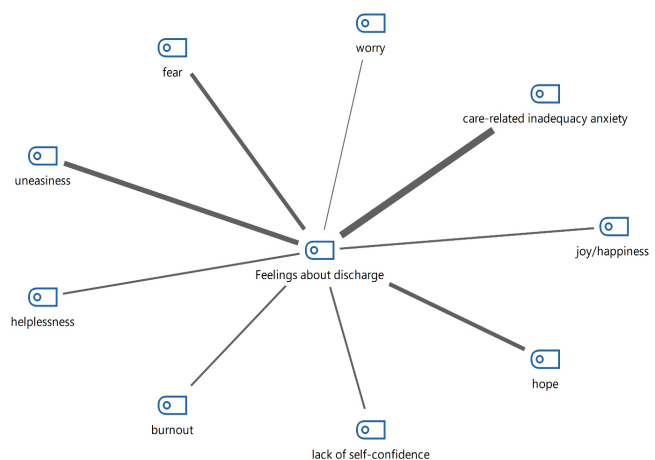


Figure 1. Feelings about discharge code-subcode sections model

discharge you, you can get out now; my direct thought was, okay, there was nothing left to do, you could go. He thought there was nothing left to do" (K3). One of the parents reported having lack of self-confidence regarding the care. "There are things we see for the first time. There were a lot of devices, a lot of things I had to do. I thought I couldn't be able to..." (K22).

Two of the parents stated that they felt hope and joy/happiness when they found out that their child would be discharged. "He had a tracheostomy and we were going to go out with a ventilator. After all this was also a step forward and we could go home. It was about the recovery process" (K6). Another parent said, "I was so glad. I felt on top of the world. Going home made me have great joy. We would be more comfortable at home ..." (K15).

One parent added, "I could rest at home and have a better time with my children. I could provide better opportunities for my children." (K18).

Theme 2. Physical Conditions for Home Care

This theme includes the physical conditions of the parents whose children were taken care of at home. This theme consists of special room reservation, staying in the same room and cleaning/hygiene increasing codes. (Figure 2). The subcode hierarchical map of the parents' physical conditions for home care is demonstrated in Figure 2.

Some of the parents stated that they reserved a private room for their children. "We tried to provide a room. We were using it as a cellar, we prepared the room for him first" (K11). The vast majority of parents declared that they were more careful about the hygiene of their houses after their children were discharged. "We don't even let anyone else into my child's room except the two of us. We have quarantined. We keep everything clean." (K5).

Several parents reported that they had to stay in the same room with their children. "He still sleeps with us because I

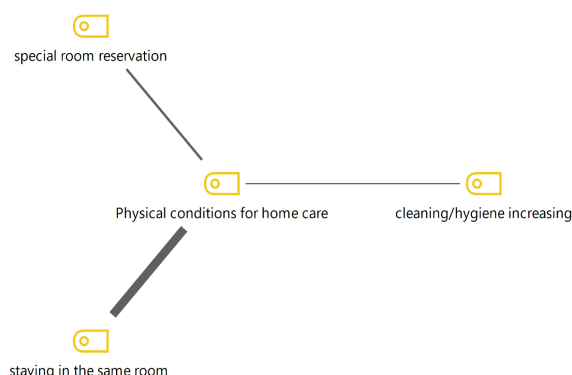


Figure 2. Physical condition for home care code-subcode sections model

feel the need to take care of him 24/7, we are always in the same room." (K14).

Theme 3. Family Relationships

This theme includes the experience of the parents in the family relationship during the home care process. This theme consists of the codes to protect family integrity, difficulty in communication with family members, mother-centered care, taking time for oneself, touching and communicating with the child (Figure 3). The subcode hierarchical map of the family relationship of parents is given in Figure 3.

Almost all of the parents stated that they had difficulties in communicating and spending time with their family members. "We can't go anywhere together. When I go to my hometown, my wife stays at home. When she leaves, I stay. We can't spend time together" (K10). A parent mentioned that they had difficulty in maintaining family integrity due to the child's need for care. "I had to leave my other child to my mother or my older sister. This made me careless. I could not spend time with my spouse." (K19).

The majority of parents reported that they or their spouses had the responsibility of taking care of their children. "No one could take care of the way I did. I could leave her for an hour or two out of necessity and come quickly only when we went to the hospital. I took care of everything" (K7).

One of the parents mentioned that she was able to take time for herself because she took care of her child at home. "When I was at home, at least I could leave her to my husband and distract myself on Sunday. I could eat, buy clothes or something" (K20). Another parent stated that she could spend more time with her child because she took care of her child at home. "I used to leave the house in the morning and come back in the evening just to see my child for half an hour a day. All my time was spent in the traffic jam of Istanbul.

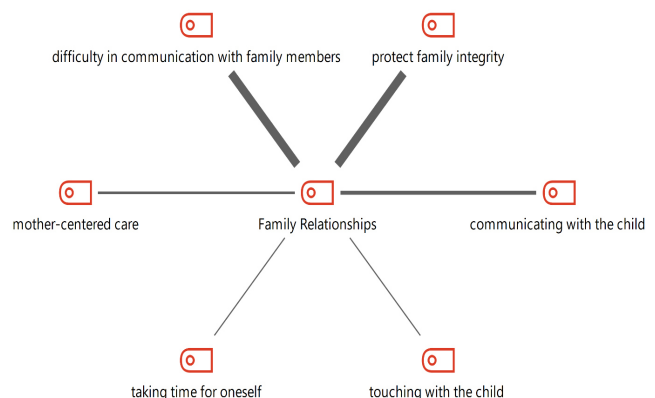


Figure 3. Family relationships code-subcode sections model

At home, I could touch my child more and spend more time" (P16).

Theme 4. Social Relationship

This theme includes the experience of the parents about their social relationship during the home care process. This theme consists of codes of loneliness, exclusion, child-centered life and visitor restriction (Figure 4). The subcode hierarchical map of the social relationship of parents is given in Figure 4.

The majority of parents stated that their children felt lonely and excluded during the home care process. *"My social life was restricted. People were coming over, bu I could not go to them. In other words, my mother has been two streets away, but sometimes I couldn't visit them for two or three months" (P1).* Another parent said, *"When I started going out with my child recently, many families did not let their children be with my kid" (K4).*

Some parents confessed that their social life was restricted. *"You know, if A. had not been like this, maybe I would have been in Thailand with A. today" (K13).* Another parent added *"... at first, I did not let people into her room so that my child would not get infected" (K12).*

Theme 5. Difficulty in Physical Care

This theme includes statements about the parents' experiences in the physical care of their children. This theme consists of the codes of difficulty in feeding the child, difficulty in daily life activities, insomnia and difficulty in accessing health care services (Figure 5). The subcode hierarchical map of the parents' difficulty in physical care is shown in Figure 5.

Some parents stated that they had difficulties in feeding their children and performing activities of daily living. *"I did not know how to feed my child with those hoses, it was very difficult at first" (K2).* Another parent added, *"It was hard to carry him due to his weight. ...especially when it is shower time..." (K18).*

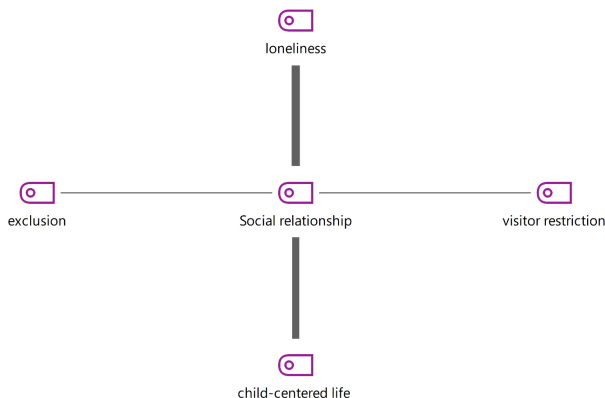


Figure 4. Social relationship code-subcode sections model

Almost half of the parents stated that they had insomnia due to the high care burden of their children. *"I was getting nervous every night, I waited by her side all the time in case something happens. Of course, I took medicine for 3 years ... now I only take it to sleep" (K9).* One of the parents reported that their child had difficulty in accessing health services. *"The concentrator (oxygen concentrator) broke down at night. My spouse called Ministry of Health. What they told us was there was nothing they could do. They said there was no machine in the institution if ours was broken down and we could take it back when it opens" (K20).*

Theme 6. Inadequacy in Support Systems

This theme includes inadequacy in support systems that the parents experience. This theme consists of insufficient social support, healthcare worker support, and spiritual support codes (Figure 6). The subcode hierarchical map of inadequacy in parents' support systems is demonstrated in Figure 6.

Some parents stated that the social support they received from their spouses, family, neighbors, relatives and health workers was insufficient. *"I have no spouse, no one but us" (K3).* Another parent added, *"We have been the only ones to take care and support. There has been no one to provide such support. If we had a very urgent job, we had to hire a paid nurse." (K8).*

One parent stated that spiritual support was useful for them. *"...I don't know, I pray a lot. You know, a lot. I'm reading the Quran. My support has always been spiritual." (K21).*

Theme 7. Financial Difficulties

This theme includes financial difficulties that the parents experience. This theme consists of support codes for difficulty in obtaining medical supplies, power outage/lack of generator, one of the parents quitting job and care costs (Figure 7). The economic status subcode hierarchical map of the parents is shown in Figure 7.

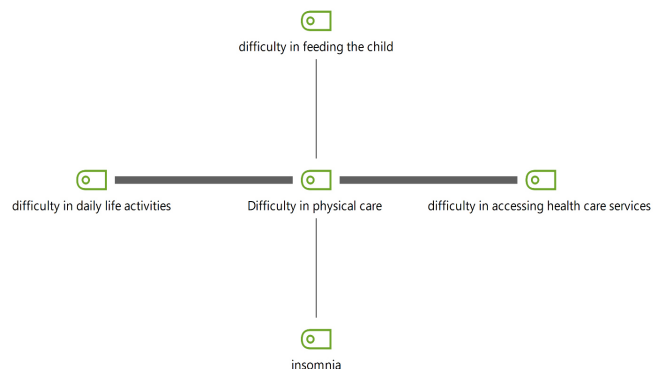


Figure 5. Difficulty in physical relationship code-subcode sections model

Two of the parents stated that their children had difficulty in obtaining medical supplies. *"First of all, we had a lot of financial problems. We had to pay for them since most of our materials were not covered by the report."* (K10). Another parent stated that she had difficulty due to a power cut/lack of generator. *"When there is an emergency, for instance when our electricity is cut-off, the machines did not have batteries ... I had to grab everything, look for people to help me. I called my nephew; he was somewhere else. Other people had things to do. This time the child turns purple, I call the ambulance, I have no money"* (K13).

One of the parents stated that he had to quit his job and had financial difficulties in caring for his child. *"I had my own company, you know what happens, it obviously bankrupted. When you don't care about your company, it fails. We had to shut it down. I'm not working now"* (K1). Another parent stated that they had financial difficulties due to high care costs. *"Unfortunately, children like S., how to say it, it is very sad to say but if you have money these children will live. There are a lot of maintenance costs. They can't live if you don't have money, that's all"* (K15).

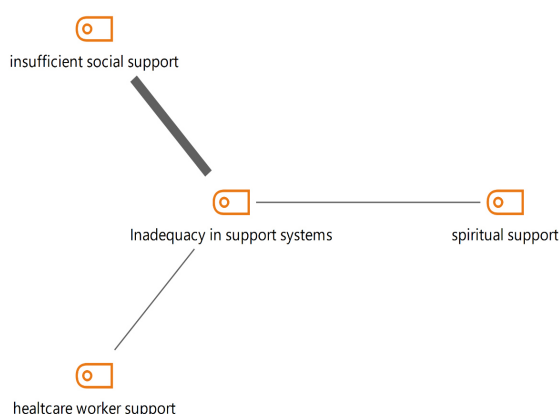


Figure 6. Inadequacy in support systems code-subcode sections model

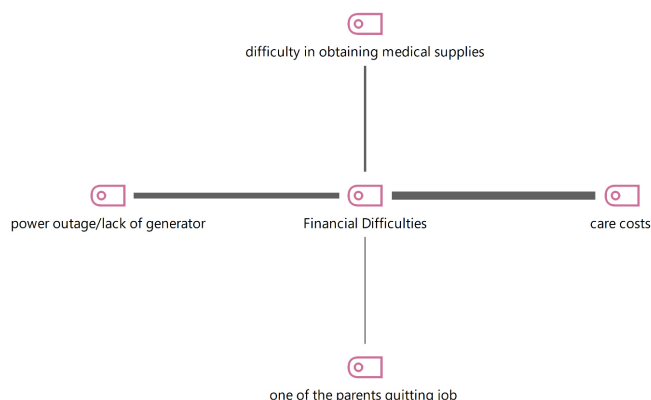


Figure 7. Financial difficulties code-subcode sections model

Discussion

In order to use the limited intensive care capacity more efficiently, provide moral support when the patient goes back to the family environment, reduce the complications that increase the length of stay, and maintain and increase the quality of life; it is highly recommended to take care of the stable intensive care patients, whose vital functions have improved, at home.⁶ Taking care of the children who need home care is more difficult than the others. The parents usually have difficulties in the care of these children in many aspects.²² The findings obtained in this study, which was conducted to determine the difficulties experienced by the parents in the home care of the children discharged from the intensive care unit, were compared and discussed in accordance with the literature.

In this study, parents stated that they experienced many complex emotions when they found out that their child would be discharged. They reported that most of their feelings included being inadequate in the care of the child, anxiety, worry, fear, uneasiness, helplessness, burnout and lack of self-confidence. Children who are discharged from the intensive care unit and need home care should be fed with tracheostomy, ventilator support, gastrostomy and nasogastric tube. Parents who do not have the necessary skills to care for their child are known to be anxious. Teaching parents how to practice medical practices might reduce anxiety and stress levels.^{20,23} In addition, two parents in the study group stated that they were hopeful and happy when they found out that their child would be discharged. In the literature, it was reported that parents usually prefer taking care of their children at home rather than the hospital.⁹ Taking care of children with long-term care needs at home may be preferred to provide comfort to the child and family. However, technology-dependent children should be supported by home care teams considering possible risks at home.

In order to maintain a safe environment at home to the children discharged from intensive care, the home must be physically prepared. In addition, intensive care conditions should be made at home and security measures should be taken against all possible risks that may be encountered at home to increase the comfort of the child and family.²⁴ Some parents reported that they prepared a room in the house for their child before their children were discharged, whereas the others mentioned sleeping in the same room with their children. The vast majority of parents declared that they pay more attention to the hygiene of the house after the discharge. For at home care of children on mechanical ventilators, having a clean environment, optimal temperature and clean ventilation can reduce the risk of infection. Home care may need to be individualized in order to best meet

the complex requirements of children with special health care needs and their families. The physical conditions of the child at home should be arranged within the scope of family-centered care.^{9,24}

In this study, all of the mothers stated that they or their spouses were primarily responsible for the care of their children, and they had difficulties in family relations, maintaining family integrity and communicating with family members. Similarly, previous studies demonstrated that the care burden of mothers was quite high.²⁵⁻²⁸ It has been stated that it is not easy for parents to transfer their responsibilities to someone else.²⁷ Home care teams and social support systems should be well coordinated in order to support the family and the home care needs of children who are dependent on medical technology. When home care services and social support systems are insufficient, families continue their lives with individual solutions. However, the best results for all parties can be achieved with a family-centered, systematic and comprehensive care approach.⁹

Parents of children with home care needs often spend most of the day caring for their children. Therefore, social relations of parents are negatively affected.^{19,29} In this study, parents stated that they lead a child-centered life because their children need home care. They also stated that they do not let people in when they want to come to their homes due to infection concerns, and they feel lonely and excluded. In the literature, it was declared that the parents think that people in their social circle do not understand the health status of their children and themselves. Parents are emotionally affected and feel socially excluded.^{27,30}

In the study, parents reported that they had difficulties in feeding the child and performing daily life activities. These parents mentioned that they encountered problems in accessing health services. In a similar study, parents of children with tracheostomy connected to mechanical ventilator at home reported that the child had problems in feeding, positioning, and bathing.³¹

Similar to our findings, parents reported that they had problems in accessing health care. Studies showed that families who had difficulty in accessing health services feel safer in the hospital and prefer staying at the hospital.²⁷ In our country, technology-dependent patients, especially, have problems in accessing home care services.

Social support has been identified as one of the most common and effective strategies for coping with stress and maintaining psychological/physical well-being.³² Although parents receive support from their spouses or families, social support seems to be insufficient for many parents. Family and friends have difficulties in understanding the situation of the child and the

parents.^{29,30,33} Park³⁴ demonstrated that the care burden of parents with social support has been low. In a study of Boyden et al.²⁸, social support was shown to reduce the burden of care. Similarly, Park and Lee³⁵ concluded that there was a positive relationship between social support and parental care burden. In this study, it was determined that parents need the support of health professionals for the care of their children. The support of the healthcare team is important to provide safety and comfort to the child and parents.²³

Economic difficulties due to conditions that require long-term care, treatment and frequent hospitalization are a universal problem, especially for families with low socio-economic status.^{13,21} Parents in the study group stated that their children had economic difficulties due to the cost of care. In similar studies, it has been observed that families of children who need home care have financial difficulties.^{28,33,36,37} In addition, the work life of the parents of the child who needed home care has been negatively affected, which caused economic problems.³³ The impact of economic difficulties should be considered when coordinating home care services.

Study Limitations

It was challenging to support the cases if the in-depth interviews were unstable in the home setting because the targeted patients resided in various İstanbul neighborhoods. Analysis of the independent variables' similarity was not possible.

Conclusion

Children who are discharged from the intensive care unit and are dependent on mechanical ventilator are most likely taken care of by their families. The results of this study revealed that there were difficulties in terms of feelings about discharge, physical conditions for home care, family relationship, social relationship, difficulty in physical care, inadequacy in support systems and financial status. Children dependent on ventilators should be supported by home care personnel to avoid potential risks. Supporting families emotionally, socially and economically are highly recommended.

Acknowledgment: We wish to thank the parents of children with autism for their assistance in this study by helping with data collection, and Mr. David F. Chapman for editing the manuscript.

Ethics

Ethics Committee Approval: Ethical permissions were obtained from the public İstanbul University, İstanbul Faculty of Medicine Ethics Committee in order to conduct the study (23.12.2017, no: 48).

Informed Consent: Approval was obtained from the family of the participants.

Authorship Contributions

Concept: G.B., D.S.D., G.U., Design: G.B., D.S.D., G.U., T.Y., Data Collection or Processing: G.B., D.S.D., T.Y., Analysis or Interpretation: G.U., A.K., Literature Search: G.B., D.S.D., G.U., A.K., Writing: G.B., D.S.D., G.U., A.K.

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

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

References

1. Preuthippan A. Home mechanical ventilation in children. *Indian J Pediatr.* 2015;82:852-59.
2. Lloyd-Owen SJ, Donaldson GC, Ambrosino N, Escarabill J, Farre R, et al. Patterns of home mechanical use in Europe: Results from the Eurovent survey. *Eur Respir J.* 2005;25:1025-31.
3. Garner DJ, Berlowitz DJ, Douglas J, Harkness N, Howard M, et al. Home mechanical ventilation in Australia and New Zealand. *Eur Respir J.* 2013;41:39-45.
4. Oktem S, Ersu R, Uyan ZS, Cakir E, Karakoc F, et al. Home ventilation for children with chronic respiratory failure in Istanbul. *Respiration.* 2008;76:76-81.
5. Carter B, Coad J, Goodenough T, Moore A, Anderson C, et al. Home-based care for special healthcare needs. *Nurs Res.* 2012;61:260-8.
6. Sönmez Düzkaya D, Bozkurt G, Yakut T. Evaluation of Home Care Services Given to Medical Technology-Dependent Children That Were Discharged From Intensive Care Unit. *HSP.* 2017;4:204-11.
7. Ülgen Tekerek N, Dursun A, Akyıldız BN. Home Mechanical Ventilation in Children: Erciyes University Experience. *J Turk Soc Intensive Care.* 2017;15:28-33.
8. Norwitz G. The moral imperative of home health care for children: beyond the financial case. *Pediatrics.* 2019;143:e20182960.
9. Elias ER, Murphy NA; Council on Children with Disabilities. Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics.* 2012;129:996-1005.
10. Kahn JM, Rubenfeld GD, Rohrbach J, Fuchs BD. Cost savings attributable to reductions in intensive care unit length of stay for mechanically ventilated patients. *Med Care.* 2008;46:1226-33.
11. Dasta JF, McLaughlin TP, Mody SH, Piech CT. Daily cost of an intensive care unit day: The contribution of mechanical ventilation. *Crit Care Med.* 2005;33:1266-71.
12. National Association for Homecare and Hospice: Basic Statistics About Home Care; Updated 2008. Washington, DC: The National Association for Home Care and Hospice.
13. Ayar G, Şahin Ş, Uysal Yazıcı M, Gündüz RC, Yakut Hİ, et al. Evaluation of Home Care Services in Chronically ill Children. *Turkish J Pediatr Dis.* 2015;9:12-7.
14. Speziale HS, Streubert HJ, Carpenter DR. Qualitative research in nursing: Advancing the humanistic imperative. 2011; Lippincott Williams & Wilkins.
15. Colaizzi P. Psychological research as a phenomenologist views it. In: Valle RS, King M (eds.). *Existential phenomenological alternatives for psychology.* 1978; New York: Open University Press.
16. Onwuegbuzie AJ, Leech NL. A call for qualitative power analyses. *Quality & Quantity.* 2007;41:105-21.
17. Morse JM. Data were saturated. *Qualitative Health Research.* 2015;25:587-88.
18. Nasitowski J, Szkulmowski Z, Migdał M, Andrzejewski W, Drozd W, et al. Rozpowszechnienie wentylacji mechanicznej w warunkach domowych w Polsce [Prevalence of home mechanical ventilation in Poland]. *Pneumonol Alergol Pol.* 2010;78:392-8. Polish.
19. Baidawi S, Mendes P, Saunders BJ. The complexities of cultural support planning for Indigenous children in and leaving out-of-home care: The views of service providers in Victoria, Australia. *Child & Family Social Work.* 2017;22:731-40.
20. Bullen T, Taplin S, McArthur M, Humphreys C, Kertesz M. Interventions to improve supervised contact visits between children in out of home care and their parents: a systematic review. *Child & Family Social Work.* 2017;22:822-33.
21. Krakouer J, Wise S, Connolly M. "We live and breathe through culture": Conceptualising cultural connection for Indigenous Australian children in out-of-home care. *Australian Social Work.* 2018;71:265-76.
22. Toly VB, Musil CM. Factors related to depressive symptoms in mothers of technology-dependent children. *Issues Ment Health Nurs.* 2015;36:518-27.
23. Eshaghian-dorcheh A, Zandi M, Rassouli M, Tahmasebi M. The lack of systematic training for health care providers, a challenge for providing pediatric palliative home care: A comparative study. *International Journal of Pediatrics.* 2019;7:9481-96.
24. Sönmez Düzkaya D, Bozkurt G. Yoğun Bakım Hastasının Evde Bakımı. *Yoğun Bakım Hemşireliği Dergisi.* 2012;16:21-8.
25. Collins A, Hennessy-Anderson N, Hosking S, Hynson, J, Remedios C, et al. Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study. *Palliat Med.* 2016;30:950-9.
26. Zimmermann K, Bergstraesser E, Engberg S, Ramelet AS, Marfurt-Russenberger K, et al. Erratum to: When parents face the death of their child: A nationwide cross-sectional survey of parental perspectives on their child's end-of life care. *BMC Palliat Care.* 2016;15:1-14.
27. Karakul A, Kıratlı D, Akgül EA, Çelik T. The experiences of parents of children in pediatric palliative care: A qualitative study. *J Pediatr Nurs.* 2022;67:107-15.
28. Boyden JY, Hill DL, Nye RT, Bona K, Johnston EE, et al. Pediatric palliative care parents' distress, financial difficulty, and child symptoms. *J Pain Symptom Manage.* 2022;63:271-82.
29. Ribbers S, Wager J, Hartenstein-Pinter A, Zernikow B, Reuther M. Core outcome domains of pediatric palliative care for children with severe neurological impairment and their families: A qualitative interview study. *Palliat Med.* 2020;34:309-18.
30. Gans D, Hadler MW, Chen X, Wu SH, Dimand R, et al. Cost analysis and policy implications of a pediatric palliative care program. *J Pain Symptom Manage.* 2016;52:329-35.
31. Ateş B. Evde mekanik ventilatöre bağlı trakeostomi çocukların ebeveynlerinin bakım yükü ve depresyon düzeylerinin belirlenmesi. Yüksek Lisans Tezi. Yozgat Bozok Üniversitesi, 2019.

32. Toly VB, Blanchette JE, Musil CM, Zauszniewski JA. Journaling as reinforcement for the resourcefulness training intervention in mothers of technology-dependent children. *Appl Nurs Res.* 2016;32:269-74.
33. Foster CC, Shaunfield S, Black LE, Labellarte PZ, Davis MM. Improving support for care at home: Parental needs and preferences when caring for children with medical complexity. *J Pediatr Health Care.* 2022;36:154-64.
34. Park EY. Parental caregiving burden, depression, social support, and life satisfaction: A multigroup analysis of social support for parents of young children with brain lesions. *Rehabilitation Counseling Bulletin.* 2022;65:227-37.
35. Park GA, Lee ON. The moderating effect of social support on parental stress and depression in mothers of children with disabilities. *Occup Ther Int.* 2002;5162954.
36. Prieto V, Rozmus C, Cohen E, Lobiondo-Wood G. Caregiver burden, caregiving satisfaction, and health-related quality of life among caregivers of children with medical complexity. *Pediatric Nursing.* 2022;48:111-21.
37. Patel AD, Arya A, Agarwal V, Gupta PK, Agarwal M. Burden of care and quality of life in caregivers of children and adolescents with autism spectrum disorder. *Asian J Psychiatr.* 2022;70:103030.