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Emotions and experiences of parents of children with liver transplants: A qualitative study

Karaciğer nakli uygulanan çocukların ebeveynlerinin duygu ve deneyimleri: Kalitatif çalışma

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ABSTRACT

Purpose: This study was conducted to determine the feelings and experiences of parents of children who underwent liver transplantation.

Method: The study was carried out between July 2019 and October 2021 at the liver transplant institute of a university in eastern Turkey. The population of the research consisted of the parents of 14 children (N=28) hospitalized in the clinic. Purposive sampling was used as the sampling method and 22 parents were included in the study. The data were collected face to face by the researchers with a survey and a semi-structured form and analyzed using the thematic (descriptive) analysis method.

Results: From parents' experiences; emotions (Sadness, Fear/Anxiety, Helplessness, Regret, Joy/Happiness, Hope/Despair, Guilt, Distress), family relationships (Conflict between family members, Inability to spare time for other children, Role change), social relationships (social isolation) and financial Four main themes were created: challenges. As a result of the study, it was determined that mothers experienced feelings of sadness, disappointment, guilt and helplessness when they first learned about their child's diagnosis, while fathers were very upset. It was determined that when the mothers were told that they needed an organ transplant, they saw this as a ray of hope and salvation from the disease and applied to become donors. It was determined that all fathers quit their jobs due to their children's illness and experienced financial difficulties.

Conclusion: It was determined that parents whose children received liver transplantation mostly felt sad and experienced difficulties. In order for nurses caring for children undergoing liver transplantation to provide holistic and family-centered care, it is important to determine the needs of parents during the transplantation process and implement the necessary nursing interventions.

Keywords: Children; emotion; experience; liver transplantation; parent

ÖZET

Amaç: Bu çalışma, karaciğer nakli uygulanan çocukların ebeveynlerinin duygu ve deneyimlerini belirlemek amacıyla yapıldı.

Yöntem: Çalışma Temmuz 2019-Ekim 2021 tarihleri arasında Türkiye'nin doğusundaki bir üniversitenin karaciğer nakli enstitüsünde gerçekleştirildi. Araştırmanın evrenini klinikte yatan 14 çocuğun (N=28) ebeveyni oluşturdu. Örnekleme yöntemi olarak amaçlı örnekleme kullanıldı ve 22 ebeveyn çalışmaya dahil edildi. Veriler anket ve yarı yapılandırılmış bir form ile araştırmacılar tarafından yüz yüze toplandı ve tematik (betimsel) analiz yöntemi kullanılarak analiz edildi.

Bulgular: Ebeveynlerin deneyimlerinden; duygular (Üzüntü, Korku/Endişe, Çaresizlik, Pişmanlık, Sevinç/Mutluluk, Umut/Umutsuzluk, Suçluluk, Sıkıntı), aile ilişkileri (Aile üyeleri arasında çatışma, Başka çocuklara vakit ayıramama, Rol değişikliği), sosyal ilişkiler (sosyal izolasyon) ve mali zorluklar olmak üzere dört ana tema Oluşturuldu. Çalışma sonucunda annelerin çocuklarının tanısını ilk öğrendiklerinde üzüntü, hayal kırıklığı, suçluluk ve çaresizlik duyguları yaşadıkları, babaların ise çok üzüldükleri belirlendi. Annelere organ nakline ihtiyaçları olduğu söylendiğinde bunu bir umut ışığı ve hastalıktan kurtuluş olarak gördükleri ve donör olmak için başvurdukları belirlendi. Babaların tamamının çocuklarının hastalığı nedeniyle işten ayrıldıkları ve maddi sıkıntı yaşadıkları saptandı.

Sonuç: Çocuğuna karaciğer nakli yapılan ebeveynlerin çoğunlukla üzüntü duydukları ve zorluk yaşadıkları belirlendi. Karaciğer nakli yapılan çocuklara bakım veren hemşirelerin bütüncül ve aile merkezli bakımı sunabilmeleri için ebeveynlerin nakil sürecindeki gereksinimlerinin belirlenmesi ve gerekli hemşirelik girişimlerin uygulanması önem taşımaktadır.

Anahtar Kelimeler: Çocuk; duygu; deneyim; karaciğer nakli; ebeveyn

Giriş

Today, liver transplantation is the only treatment option for children who have liver functions deteriorating to a life-threatening extent due to various causes, acute or chronic liver failure (Açar et al., 2021; Cuenca et al., 2017; Petersen et al., 2019). For this reason, liver transplantation has become routine practice at several transplant centers worldwide (Nikeghbalian et al., 2021). Advancements in the field of liver transplantation

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have led to an increase in the survival rates of children (Açar et al., 2021; Cuenca et al., 2017; Getsuwan et al.,2020; Parmar et al., 2017). After pediatric liver transplantation, the one-year survival rates of patients have been reported as 83.5% in Europe, 87% in Turkey, 83% in Iran, and 85% in the United States (Basturk et al., 2016; European Liver Transplant Regisrty, 2019; Kwong et al., 2020; Nikeghbalian et al., 2021).

Although liver transplantation saves the lives of children and increases their life expectancy, it is a stressful and difficult process for the families of children (Butsriphum et al., 2020; Cousino et al., 2017; Sarigol et al., 2017). In addition to not being able to find donors for the transplant, the substantial nature of the surgery, and mood swings about losing their children (Cousino et al., 2017), parents also experience emotional problems such as concerns about the complications that could develop after transplantation and unknowns about the process, fear, and regret (Cousino et al., 2017; Denny et al., 2012; Lerret et al., 2020). Moreover, having to leave their homes and even the city of their living, failing to perform their roles for other family members, increases the financial burden to be brought by the process and future-related concerns also lead families to experience psychological problems (Cuenca et al., 2017; Lerret et al., 2020). It has been reported that more than half of parents whose children have received liver transplants experience posttraumatic stress disorder (Kaller et al., 2014) and mood disorders (Butsriphum et al., 2020). Şahin et al. (2016) determined that a psychiatric diagnosis was made in 65.7% of parents whose children were liver transplant candidates (Şahin et al., 2016). In a systematic review carried out with parents of children who received organ transplants, it was found that the parents usually experienced posttraumatic stress, and their mental health problems increased (Cousino et al., 2017).

For parents, children are valuable individuals who are seen as their future, brought up with care, educated, and supplied with their needs by using one's all resources (Açar et al., 2021). Therefore, in organ transplantation, parents become donors to restore their children's health (Kikuchi et al., 2015). This transforms the parent from a healthy individual to a surgical patient (Agerskov et al., 2019; Kikuchi et al., 2015). The organ donors of children were their parents in 95% of the participants of the study conducted by Zhang et al. (2014), while this rate was 87.6% in the study by Gökçe et al. (2011) (Gökçe et al., 2011; Zhang et al., 2014). It was reported that half of the donors of liver transplants in the United States in 2017 were the relatives of children, whereas the Japanese Liver Transplantation Society stated that 95% of donors were the parents of the children requiring liver transplants (Kwong et al., 2020; Umeshita et al., 2016). Yuen et al. (2019) found that 51.9% of the donors of such transplants were mothers, 48.1% were fathers, and according to the Japanese Liver Transplantation Society, 55% of donors were mothers (Umeshita et al., 2016; Yuen et al., 2019).

The donor status of a family member (Li et al., 2021), the mother's prolonged duration of stay at the hospital due to the care of the child, and the father's attendance to work affect the family system significantly (Cousino et al., 2017; Evgin et al., 2013; Karabudak & Conk, 2018; Kikuchi et al., 2015; LoBiondo-Wood et al., 2004). This situation assigns family members and parents additional tasks other than their basic care roles (Agerskov et al., 2019; Evgin et al., 2013). After transplantation, children are completely dependent on their parents in the provision of their healthcare needs. In general, the mother takes on the care of children, and the father takes on financial responsibilities (Karabudak & Conk, 2018). This prevents parents from spending enough time for themselves and with other family members and looking.

Their other healthy children, and it leads them to experience distress because they cannot be with these other family members (Açar et al., 2021; Evgin et al., 2013). Furthermore, it has been determined that due to their insufficient social support and inability to participate in social activities, parents feel loneliness (Açar et al., 2021; Evgin et al., 2013), and as a result of this, they experience tensions in their marriage relationships (Açar et al., 2021; Kikuchi et al., 2015). As a consequence of these problems they experience in the caregiving process, parents may experience some health problems including fatigue, burnout, hopelessness, and anxiety (Evgin et al., 2013). The health statuses of the parents play a critical role in protecting and increasing the level of the child's health (Butsriphum et al., 2020; Denny et al., 2012; Zhang et al., 2014). Therefore, alleviating the problems experienced by parents of children receiving liver transplants as much as possible is among the basic duties of nurses.

In the literature review that was conducted in this study, no study that was conducted in Turkey to determine the emotions and experiences of parents of children with liver transplants could be encountered. In the scope of holistic care for protecting and improving the lives of children receiving liver transplants, it is important to determine the emotional hardships and needs experienced by parents in the transplantation process. Therefore, this study was conducted for the purpose of revealing, explaining and defining the subjective emotions and experiences of the parents impartially and comprehensively.

Material and Method

Study Design

This qualitative study was conducted phenomenological design.

Study Time and Location

This study was carried out between July 2019 and October 2021 at the liver transplant institute of a university in eastern Turkey.

Study Population and Sample

The population of the study consisted of the parents of 14 children (N = 28) hospitalized in the mentioned clinic. This study used the purposive sampling method. Of parents, 2 mothers and 2 fathers were not included in the study due to language problems. In addition, the participants included 22 parents, including 12 mothers and 10 fathers because the father of one of the children did not agree to participate in the study, and the parents of another child were not together. The sample included parents who were literate, did not have any visual-hearing impairment, were able to verbally communicate, and agreed to participate in the study.

Data Collection Instruments

To collect the data, a form was prepared by the researchers based on the relevant literature (Karakavak and Çırak, 2006 Yayan and Düken, 2019) which consisted of two parts was used. While the 1st part included questions on the demographic characteristics of the participants, the 2nd part included questions on their emotions and experiences (Table 1).

Data Collection Procedure

Data were collected by the researchers using the face-to-face, in-depth and semi-structured interview method (Maxwell, 2012). Before the in-depth interviews, the permission of the participants was received to use an audio recording device. All participants gave permission for audio recording. For prevent data loss during the in-depth interviews, while one of the researchers asked the questions to the participants and took notes in written form, the other researcher recorded the audio. Each interview lasted approximately 30 to 60 minutes. The interviews were held in an allocated room where the participants could be left alone with the researchers in a way that would ensure their privacy to the maximum degree. During the interviews, the researchers avoided using judgmental, instilling, directing and negative statements and attitudes towards the participants. The interviews were completed when the responses of the participants started to repeat, and the researcher reached a point of data saturation.

Table 1. Interview questions

Could you tell me what you felt when you learned about the diagnosis of your child for the first time?
What did you feel when you were told that your child had to get a liver transplant?
How did the liver transplantation process affect your relationships with other family members?
How did the liver transplantation process affect your social life? Could you elaborate?

Ethical Approval

Before starting the study, institutional permission was obtained from the Medical Center, ethical approval was obtained from the University Health Sciences Non-Interventional Clinical Studies and Publications Ethics Committee (Decision No: 2019/378), and informed consent was obtained from the participants by providing them with information about the study. In the text where the use of a voice recording device is specified, it has been ensured that the privacy of identities and voice recordings is guaranteed. The research was conducted in compliance with the Helsinki Declaration.

Data Analysis

After all interviews were completed, the quantitative data were analyzed in terms of frequency, mean, standard deviation, and percentage values. The qualitative data were analyzed using the content analysis method to derive replicable and valid results on the content of the data (Graneheim & Lundman, 2004). To ensure the validity and reliability of the study, the first researcher read the collected data and listened to the audio recordings, the recordings were manually transcribed, and a collective text file was created. The created text file was read several times, and the statements of the participants were coded comparatively, firstly based on the most frequently stated points, similar points and identical points, and then, based on different points. The coded data were combined in a meaningful way to create themes. An independent researcher who is an expert in qualitative research methods reviewed the text and created the themes and sub-themes of the statements (Graneheim & Lundman, 2004; Maxwell, 2012). The themes created by the independent expert and those created by the researcher were compared, and they were determined to be similar.

Study Limitations

The study was limited to parents of children who had liver transplants at a university hospital; hence, their experiences cannot be extrapolated to other regions

Results

The interviews were conducted with a total of 22 parents, including 12 mothers and 10 fathers. The mean age of the mothers was 32.00±10.41, and the mean age of the fathers was 36.90±7.68. While 50% of the mothers and 80% of the fathers had primary-secondary school degrees, all families but two were living in another city. 91.7% of the mothers were not working, 60% of the fathers left their jobs due to treatment of their children, and the income levels of 75% of the families were low. 75% of the families had 1-2 children, and the child who was given the liver transplant in 58.3% of the families was their first child. All participants applied for becoming donors. All transplants belonged to live donors, and 5 of the donors were the fathers of the children.

As a result of the content analyses of the interviews, four themes were created, in addition to sub-themes under these four themes (Table 2).

Table 2. Themes

Main Themes	Sub-Themes
1. Emotions	Sub-Theme 1. Sadness Sub-Theme 2. Fear/Concern Sub-Theme 3. Helplessness Sub-Theme 4. Regret Sub-Theme 5. Hope/Hopelessness Sub-Theme 6. Joy/Happiness Sub-Theme 7. Guilt Sub-Theme 8. Distress
2.Family Relationships	Sub-Theme 1. Conflict between family members, Sub-Theme 2. Not being able to spare time for other children, Sub-Theme 3. Role change
3.Social Relationships	Sub-Theme 1. Social isolation
4.Financial Difficulties	

Main Theme 1. Emotions

In this study, it was determined that the participants (n=20) experienced mood swings when they first learned about the diagnoses of their children and that their children had to get liver transplants. Participants stated that they felt positive and negative emotions. These emotions are grouped under the sub-themes of Sadness, Concern/Fear, Helplessness/Sacrifice, Regret, Hope/Hopelessness, Joy/Happiness, Guilt, Distress.

Sub-Theme 1. Sadness: In this study, all participants stated that they experienced emotional breakdowns including shock and sadness when they first learned about their children's diseases and the treatment method. Some participants said they felt very sad due to the continuation of the health problems of their children after transplantation, the fact that one of their family members was the donor, and problems experienced in the transplantation process. Some statements of the participants were as follows:

Mother 2: *It was terrible, it all went dark. The entire world came crashing about my ears at that moment (eyes filled with tears while mentioning the situation).*

Father 2: *I felt horrible when I first learned, I thought everything was over at that time.*

Mother 12*: Should I be sorry because my husband gave his liver, or sorry for my child… Both tore my heart out. The day of the surgery left me breathless, I never want to remember that day (started crying but continued after she wiped her tears).*

Sub-Theme 2. Fear / Concern: The participants stated that they experienced concerns and were very afraid about uncertainties regarding the health of their children and potential negative outcomes after transplantation such as infection and tissue rejection.

Father 7: *My daughter is not well now, she constantly has problems. We are even afraid of going home. I am afraid every moment at home that she will get worse. We cannot put our heads on the pillow, we rush out of the bed when my daughter coughs, we have forgotten what sleep is.*

Mother 8: *I still have concerns about my child's recovery. I am afraid of my child's body rejecting the organ. They say some children reject the new liver after 6, 9 or 12 months.*

Mother 12: *We took time off and went to Maraş last holiday, and it was a terrible experience. My relatives kept coming and going, the kid caught an infection and had a very high fever, we immediately came back. Stayed in intensive care for days. I am deathly afraid of someone even touching my child. My mental health is ruined, believe me. I am terrified that something bad will happen. I used to be so in peace and very happy. Now, even when I am laughing, I laugh with hesitation, as if we are on the brink of something [bad] happening.*

Sub-Theme 3. Helplessness*:* The case of one's children who are considered the most valuable things they have in life experiencing health problems and the uncertainty of the process may lead parents to feel helpless. They demonstrate this helplessness by becoming donors for their children and sacrificing their health.

Additionally, they think donating their organs is the unconditional duty and responsibility of every parent. All parents who participated in this study had applied to become donors.

***Mother 5:** I gave up on the world for my child. If they wanted my heart at the time, I would give even my heart for my daughter.*

***Father 5:** One becomes helpless. We were hopeful of healing with medication, but the doctors said a transplant was required.*

***Mother 10:** When they said she needed to get a transplant, I became the donor. I was not conscious at all about where I was or what I was doing. It was as if I started another life. I recited the Shahada while going into surgery, I was ready for death. I was willing to accept even death so that my daughter could get better.*

***Sub-Theme 4. Regret**:* The mothers (n=6) reported that they did not take their children to the doctor when they got ill first and they felt regret as they witnessed the pain their children experienced. As opposed to the mothers, none of the fathers expressed regret. Some statements of the mothers indicating regret were as follows:

***Mother 5:** My daughter got jaundice. We took her to shrines, but we brought her to the hospital 2 months later after her jaundice did not go away. They said she required a transplant due to bile duct obstruction. They said they would be able to remove this obstruction if I had brought her immediately. I am very regretful for not taking my daughter to a hospital.*

***Mother 6:** I thought he would recover…they are thinking about a second transplant now. I was so regretful that… My other son gave his liver. I would not let him [give his liver] if I knew this would be so. I have already given up on this one [the child receiving the transplant]. Will he recover, will he die… May God also say 'enough'. I did not know I would be this miserable, suffer this much (messes with her hair and sighs).*

***Mother 10:** Whenever I feel no longer able to endure, I think if only I had not given my liver. If only whatever could happen (means death) had happened, I say I would have already forgotten by now (her eyes filled with tears, she went silent for a while and then sighed). I see, my child suffers, I suffer. I sometimes feel like that and sometimes repent.*

Sub-Theme 5. Hope/Hopelessness: In this study, the participants stated that they got their hopes up for the future of their children especially when they learned that the transplant was successful and observed the improvements in their children. On the other hand, being aware of the possibility of organ rejection and issues such as the absence of the desired improvements in the health of the child led them to experience hopelessness.

***Mother 1:** I started to have hope when I learned that the disease has a treatment. I always had hope, that my child will have a transplant and get up. …but I was still very sad even by thinking about this.*

***Father 1:** The option of transplantation made us afraid at first, but we were hopeful that she would bet better. Her older brother donated the second transplant, but her body rejected it. I no longer believe she will get better. The fact that this is her third transplant made up lose hope, but we have to do this.*

***Mother 6:** The world does not revolve around this child. I can no longer bear it. Mine [the case of her child] is very difficult, those who were here with me recovered and left, and I am here. I want what I have experienced to be a dream (she was speaking with tears in her eyes and sighing). I have no hope left after the second transplant.*

Sub-Theme 6. Joy/Happiness: Improvements in their children's health cheer parents up and make them happy. Most of the participants (n=10) of this study stated their observation of the improvements in the health of their children and happiness brought by being donors as follows:

***Mother 2:** I am happy now, my child is well, I am glad I became a donor. People around me strongly tried to prevent me from doing it, they did not want me to give [my liver], saying that the child was already dead. Even the doctors said her survival was unlikely, they gave her a 10% chance. I was not expecting this much, I am very happy.*

Father 5: *I am very happy that I became a donor for my daughter, and she is improving. I feel better as my daughter gets better (a smile on his face).*

Sub-Theme 7. Guilt: The participants (n=5) reported that they experienced guilt as they were far from their homes, they could not spend time with their other children, and they were not able to fulfill their responsibilities.

Mother 4: *I am very sad that I am away from my other child, I feel guilt because I cannot spare enough time, I feel I have left my other child incomplete.*

Mother 6: *My daughter took some exams. The results of two came out as zero [points]. She is burdened with the household chores. My entire life has been ruined because of the transplant.*

Sub-Theme 8. Distress: The difficulties of the transplantation process and prolonged stays in the hospital led the mothers to experience burnout. Additionally, the responsibility of their husbands to work, the care of the child by the mother and economic problems led to distress by affecting their family relationships negatively.

Mother 6: *My husband and I are on very bad terms due to financial and sentimental issues. Fighting every day… Constantly arguing.*

Father 1: *We do nothing for ourselves. My family is unrestful… We are all centered around our daughter. We have no thought or expectation other than her.*

Main Theme 2. Family relationships

A child having a transplant affects not only the child but also all family members. Conflicts were experienced among family members at the stage of applying to become donors. Under this heading 3 sub-themes were created to be Conflict Between Family Members, Not Being Able to Spare Time for Other Children, and Role Change

Sub-Theme 1. Conflict between family members**:** Most participants (n=16) expressed that they had conflicts with their relatives before transplantation regarding the issue of becoming a donor, and their communication was disrupted.

Mother 2: *My husband's uncle called my father and said to him that I should not be giving my liver, and I should let the child die. I was very angry for this, I shouted at him. I said, 'how could you speak like that! She is my life.' My husband also did not want me to have surgery if the chances of my daughter surviving were low.*

Mother 5: *My family did not want me to become a donor. They said, you are young, you can have another child later. My mother did not hold my daughter in her arms, she never kissed her, she thought her disease was contagious. I have never talked to my mother [since], I am angry with her. She treated my daughter very badly, she pressured me. My husband's family also did not want it [being a donor]. They did not want my husband to donate his liver, they said 'he is the father, he should not put himself in a difficult situation" I am no longer talking to them.*

Sub-Theme 2. Not being able to spare time for other children**:** Almost all mothers (n=12) who were interviewed stressed that they could not spend time with their other children because they were far from their homes, and they were very sad about this as this negative affected their other children.

Mother 3: *I feel terrible, I cannot be a mother to my other child, always says, that "hospital became your home, I miss you, mom, why do you not come? Everyone's mother is with them". Has not spoken to me (crying).*

Mother 8: *When my son got the transplant, I was away from my daughter for three months, and my daughter did not come to me when she first saw me the next time. She was brought up by her grandmother. She calls her 'mother'. She runs away when she sees me. I get devastated when is see this.*

Father 3: *My wife and child are in the hospital. I cannot always be with them as I am working. I am staying with my mother with our other child. We are all shattered around like this.*

Sub-Theme 3. Role change: Due to the patriarchal structure of Turkish society, mothers usually take on the care of the child. This prevents the mother from performing her roles at home and leads her to experience sadness.

Mother 6: *I am not able to take care of my other children, the others have not seen us for two years, my daughters are always crying, they want me to come [back home]. My children at home have had many burdens. They are doing what I should be doing. Their peers are out and about, and mine carry the burden of cooking and household chores.*

Main Theme 3. Social relationships

All parents make many sacrifices to protect the health of their children. All interviewed parents stated that they gave up on or postponed their own wishes because they dealt with the care of their children, they did not do anything for themselves, and they did not want to see anyone to prevent their children from getting an infection. This led the parents to become exhausted. The expressions in this heading were coded and the sub-theme of Social Isolation was created.

Mother 7: *I have not done anything for myself. I cannot even attend my doctor's appointment. I cannot leave my daughter by herself. My perspective on life has changed. I sometimes do not want to live, sometimes want to break everything. Other times, I thank God for coping.*

Sub-Theme 1. Social isolation: Some participants (n=18) reported that they reduced the number of their social interactions to protect their children from infections:

Mother 10: *You cannot enter a new environment, you cannot get into crowds, you cannot stay in warm places, because infection might happen.*

Father 5: *We do not accept visitors as my daughter is ill, we do not go out. This disease confined us to our homes.*

Mother 12: *I have given up on myself. For Allah's sake, is there life anymore? I have forgotten everything. I get through my entire day in this room.*

Main Theme 4. Financial difficulties

The treatment costs brought about by transplantation, prolonged hospital stays due to the distance of the transplant center and leaving work because one of the parents is a donor damage the financial statuses of families.

Father 1: *I used to be a driver. We came here from another city for the treatment. I had to quit my job because we were in the hospital for a long time. My older son at home helps us financially. People in my close circle did not support us at all. I used up all my money for this surgery. My relatives said, 'it is not worth it, let the girl die'. ...but I said, 'I have one home and I would sacrifice it for my daughter if needed'.*

Mother 4: *We are financially in a very bad place. Because of my poor financial status, I was not able to bring my child on time. My husband is now trying to find the money.*

Mother 7: *We have been strained a lot financially. We constantly changed homes. In her first transplant, my daughter would cry saying she was hungry, I would feed her bread with tomato paste spread on it. Now, a friend of my husband's buys our groceries.*

Discussion

Pediatric liver transplantation is a process with many complications (Cousino et al., 2017). This situation affects parents and other family members from several aspects (Eaton et al., 2016). In this study, parents of children who had received liver transplants, experienced many emotional, social and economic problems, and their family relationships had deteriorated

The parents mostly experienced negative emotions such as sadness, fear, concern, helplessness, hopelessness, and regret. It was seen that parents whose children were diagnosed with chronic liver failure and waiting for transplants experienced sadness, helplessness, hopelessness, concern, fear, and devastation (Ghent et al., 2019). Similar studies in the literature have been found that parents experience psychological problems during the transportation period (Kaller et al., 2014; Kikuchi et al.,2015; McLoughlin et al., 2021; Thys et al., 2015; Walker et al., 2019). These emotional problems may be explained by the possibility of parents to lose their children, who are considered the most valuable persons in their lives, risk of tissue incompatibility, lack of information about the process, financial problems, and insufficient social support.

Parents donate without hesitation with the hope that they can increase their children's chances of survival (Agerskov et al., 2019). In our study, all included parents applied to donate their livers for their children. There are also similar study results in the literature (Agerskov et al., 2019; Ordin et al., 2017). Parents being donors have led to conflicts between them and family elders. This have led to distress and sadness in the families of the participants.

In addition to the sadness they experienced before transplantation, the parents who participated in this study also experienced sadness, regret and concern after transplants. These emotions that were experienced intensely, especially by the mothers may be associated with their witnessing of the suffering of their children and the absence of any improvement in the health of their children despite the transplant. Previous studies have determined that parents experience concern, anxiety, sadness (Lerret et al., 2017; Yadav et al.,2017; Wright et al., 2017; Zhang et al., 2014) and regret (Mjøen et al., 2011; Wirken et al., 2019; Thys et al., 2015) because of the uncertainty and unpredictability about the future health of their children, the risk of graft rejection, and potential complications.

The parents had positive emotional reactions to the treatment. They stated that they gained hope by seeing transplantation as a way for their children to recover from their disease, they became happy and felt joy. Yadav et al. (2017) observed that the effects of the long-term psychological stress emerging in relation to a chronic disease decreased after the transplant (Yadav et al., 2017). Doğan et al. (2020) determined that 92.5% of parents had positive emotions when they learned that their children would get transplants (Doğan et al., 2020). It may be argued that parents naturally react positively when they learn that their children have a chance to survive.

Every family has its normal dynamics (Karakavak and Çırak, 2006). In particular, a significant event such as the child in the family requiring a liver transplant affects the family dynamics negatively (Lefkowitz et al., 2014). The mother's stay in the hospital with the hospitalized child, the working status of the father, or the donor status of one of the parents may lead to problems such as difficulties in providing care for their other, healthy children, not being able to spend enough time with them, and not being able to perform household roles (Ong et al., 2021; Ay, 2019; Sheikhalipour et al., 2019). In our study, the majority of parents experienced conflict between family members, all parents except two reported that they were unable to spare time for their healthy children, and they failed to perform their roles in the family. In the study by Yayan et al. (2019), it was determined by 73.4% of parents experienced changes in their family relationships after transplantation (Yayan and Düken, 2019). In their meta-analysis, Kikuchi et al. (2015) reported that parents whose children received organ transplants experienced their family relationships were disrupted (Kikuchi et al., 2015). Studies that have been conducted similarly have revealed problems in the roles and in-family relationships of parents (Gökçe et al., 2011; Altuğ et al., 2019). To adapt to such changes in family dynamics, family elders (grandfather, grandmother, close relatives) or the older children of the family take on the duties of the parents. In our study, it was also determined that household chores were left to daughters, and older male children took on the roles of the fathers at home.

Parents who have a child who has a chronic disease may be prone to social isolation in their efforts of staying with their child, caring for them, protecting them from dangers, and covering costs (McLoughlin et al., 2021; Ong et al., 2021; Yayan et al., 2020; Engin et al., 2021). In this study, it was determined that parents experienced social isolation. It was determined in the studies by Doğan et al. (2020) about kidney transplants and Ordin et al. (2017) about liver transplants in children that parents of these children had limited social lives. The finding in this study that the parents postponed their social lives may be associated with their characteristics as parents in Turkish culture who have protective behaviors. Kikuchi et al. (2015) found in their study that parents of children who underwent solid organ transplantation sacrificed social activities to protect their children's health (Kikuchi et al 2015). Nevertheless, this isolation experienced by parents at a time where social support is needed most may lead them to experience loneliness, hopelessness, anxiety and, fear, as well as cause them to perceive life to be meaningless (Yadav et al., 2017; Yayan and Düken, 2020; Engin et al., 2021). In our study, some parents expressed that they experienced hopelessness, loneliness, burnout and fear, and life was meaningless for them. These negative emotions of parents will negatively influence the recovery process of the child (Karabudak and Conk, 2018; Yayan and Düken, 2020). It is stated that the emotional and social support given to parents is important to help them cope with these negativities they experience (Karabudak and Conk, 2018; Yayan and Düken, 2020; Günay and Özkan, 2019).

In addition to emotional problems, parents may also experience financial problems (Cuenca et al., 2017; Zhang et al., 2014). It was determined that almost all of the participants experienced serious economic problems due to reasons such as their low socioeconomic status, having to leave work, and having to change cities for the transfer process. Yayan and Düken (2019) reported that there were changes in the work lives of 64.6% of parents, and 71.5% of parents had economic problems (Yayan and Düken, 2019). Other studies have also identified economic hardships among parents whose children receive liver transplants (Akbulut et al.,2020; Cousino et al 2017; Killian, 2017; Lerret et al.,2017; Sarigol, Ordin et al., 2017; Walker et al., 2019). All these results show that the transplantation process is difficult in many aspects, and especially the presence of a health problem in the child affects the whole family.

Conclusion and Recommendations

Understanding the experiences of parents of children with liver transplants is crucial to improving holistic care and comprehensive long-term care. In this study, it was determined that parents of children with liver transplantation experienced many emotional, familial, social and financial difficulties. Nurses who care for pediatric patients undergoing transplantation should provide the necessary psychosocial support so that parents can better cope with the process and preserve the integrity of their family dynamics. In addition, it should direct them to relevant resources to receive social support services.

References

Açar, A., Karataş, H. & Özgönül, A. (2021). Quality of life and care burden of parents of transplanted. *Journal of General Health Sciences,* 3(1), 41-50. https://doi.org/10.51123/jgehes.2021.16

Agerskov, H., Thiesson, H,, Spechte, K. & Pedersen, B.D. (2019). Parents’ experiences of donation to their child before kidney transplantation: a qualitative study. *Journal of Clinical Nursing,* 28(9-10), 1482-1490. https://doi.org/10.1111/jocn.14734

Akbulut, S., Gunes, G., Saritas, H., Aslan, B., Karipkiz, Y., Demyati, K., ... & Yilmaz, S. (2020). Differences in parents of pediatric liver transplantation and chronic liver disease patients. *World Journal of Clinical Cases, 8*(11), 2162. https://doi.org/10.12998/wjcc.v8.i11.2162

Altuğ, N., Ecevit, Ç. O., Karakoyun, M., Taşçı, E. K., Bolışık, B. & Aydoğdu, S. (2019). Determination of variables influencing the quality of life in children with liver transplantation. *J Pediatr Res*, *6*, 208-12. https://do./10.4274/jpr.galenos.2018.34654

Ay Kaatsiz, M. A., & Oz, F. (2020). The effectiveness of psychoeducation given to mothers of children with cancer. *J Psychiatric Nurs*, 11(2), 129-140.

Baran, G. (2018). The burden of care and life satisfaction of the Turkish mothers of children with cancer. *JCCNC*, 4(4), 175-184. https://doi.org/10.32598/jccnc.4.4.175

Basturk, A., Yılmaz, A., Sayar, E., Dinçhan, A., Aliosmanoğlu, İ., Erbiş, H., ... & Artan, R. (2016). Pediatric liver transplantation: our experiences. *The Eurasian Journal of Medicine*, *48*(3), 209. **h**ttps://doi.org/10.5152/eurasianjmed.2016.0147

Butsriphum, N,, Getsuwan, S., Prabpram, W., Chuthapisith, J., Tanpowpong, P., Lertudomphonwanit, C. & Treepongkaruna, S. (2020). Family function in pediatric liver transplant recipients residing in a developing country. *Transplantation Proceedings*,52 (3), 920-925. https://doi.org/10.1016/j.transproceed.2020.01.035

Cousino, M. K., Rea, K. E., Schumacher, K. R., Magee, J. C. & Fredericks, E. M. (2017). A systematic review of parent and family functioning in pediatric solid organ transplant populations. *Pediatric Transplantation*, 21(3), 12900. https://doi.org/10.1111/petr.12900

Cuenca, A. G., Kim, H. B. & Vakili, K. (2017). Pediatric liver transplantation. *In Seminars in Pediatric Surgery*, 26(4), 217-223.WB Saunders. https://doi.org/10.1053/j.sempedsurg.2017.07.014

Denny, B., Beyerle, K., Kienhuis, M., Cora, A., Gavidia-Payne, S. & Hardikar, W. (2012). New insights into family functioning and quality of life after pediatric livertransplantation. *Pediatric Transplantation*, *16*(7), 711-715. https://doi.org/10.1111/j.1399-3046.2012.01738.x

Doğan, S., Çelik, E., Öztürk, K. & Aydemir, S.(2020). Psychological resilience of families with children with kidney transplantation. *Journal of Nephrology Nursing*, 15(3), 240-250. https://doi.org/10.47565/ndthdt.2020.21

Eaton, C.K., Lee, J.L. & Loiselle, K.A. (2016). Pretransplant patient, parent, and family psychosocial functioning varies by organ type and patient age. *Pediatric Transplantation*, 20(8), 1137-1147. https://doi.org/10.1111/petr.12826

Engin E, Çam M.O, Demirkol H. (2021). A Life in Purgatory: Being the mother of a child with a bone marrow transplant. *Current Approaches in Psychiatry*, 13(2), 282-291. https://doi.org/10.18863/pgy.775939

Evgin, D., Erdem, E., Bayat, M., Poyrazoğlu, H. M. & Dursun, J. (2013). Experienced difficulties of children undergoing peritoneal dialysis and their mothers: A qualitative study. *Journal of Health Sciences, 22*(1), 7-17.

Getsuwan, S., Tanpowpong, P., Lertudomphonwanit, C., Chuthapisith, J., Butsriphum, N., Prabpram, W, ... , Treepongkaruna S. (2020). Health-related quality of life in pediatric liver transplant recipients. *In Transplantation Proceedings*, 53, 141-147. https://doi.org/10.1016/j.transproceed.2020.02.175

Ghent, E., Robertson, T., Young, K., DeAngelis, M., Fecteau, A., Grant, D., ... & Anthony, S. J. (2019). The experiences of parents and caregiver (s) whose child received an organ from a living anonymous liver donor. *Clinical Transplantation*, *33*(10), e13667. https://doi.org/10.1111/ctr.13667

Gökçe, S., Durmaz, O., Aydoğan, A., Celtık, C., Ozden, I. & Sökücü, S. (2011). Assessment of living donors with respect to pre- and posttransplant psychosocial properties and posttransplant family functioning in pediatric liver transplantation. *The Turkish Journal of Gastroenterology: The official journal of Turkish Society of Gastroenterology*, 22(1), 36-41.

Graneheim, U.H. & Lundman, B. (2004). Qualitative content analysis in nursing research:Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ*, 24(2), 105–112. http://dx.doi.org/10.1016/j.nedt.2003.10.001.

Günay, U. & Özkan, M. (2019). Emotions and coping methods of Turkish parents of children with cancer. *Journal of Psychosocial Oncology*, 37(3), 398-412. https://doi.org/10.1080/07347332.2018.1555197

Kaller, T., Petersen, I., Petermann, F., Fischer, L., Grabhorn, E. & Schulz, K. H. (2014). Family strain and its relation to psychosocial dysfunction in children and adolescents after liver transplantation. *Pediatric Transplantation*,18(8), 851-859. https://doi.org/10.1111/petr.12367

Karabudak, S.S. & Conk, Z. (2018). Phenomenological determination of the biopsychosocial effects of the dialysis treatment of the child on the parents. *Journal of Nursing Science*, 1(3),7-20. https://dergipark.org.tr/en/download/article-file/638910

Karakavak, G. & Çırak, Y.(2006). Emotions of mothers with chronic diseased children. *Journal of Istanbul University Education Faculty*, 7(12), 95- 112.

Kikuchi, R. & Kamibeppu, K. (2015). Parents' quality of life and family functioning in pediatric organ transplantation. *Journal of Pediatric Nursing*, 30, 463–477. https://doi.org/10.1016/j.pedn.2014.12.013

Killian, M.O. (2017). Psychosocial predictors of medication adherence in pediatric heart and lung organ transplantation. *Pediatric Transplantation*, 21(4), 12899. https://doi.org/10.1111/petr.12899

Kwong, A., Kim, W. R., Lake, J. R., Smith, J. M., Schladt, D. P., Skeans, M. A., ... & Kasiske, B. L. (2020). OPTN/SRTR 2018 annual data report: Liver. *American Journal of Transplantation*, *20*, 193-299. https://doi.org/10.1111/ajt.15674

Lefkowitz, D. S., Fitzgerald, C. J., Zelikovsky, N., Barlow, K. & Wray, J. (2014). Best practices in the pediatric pretransplant psychosocial evaluation. *Pediatric Transplantation*, *18*(4), 327-335. https://doi.org/10.1111/petr.12260

Lerret, S. M., White-Traut, R., Medoff-Cooper, B., Simpson, P., Adib, R., Ahamed, S. I. & Schiffman, R. (2020). Pilot study protocol of a mHealth self-management intervention for family members of pediatric transplant recipients. *Research in Nursing & Health*, *43*(2), 145-154. https://doi.org/10.1002/nur.22010

Lerret, S.M., Johnson, N.L. & Haglund, K.A. (2017). Parents' perspectives on caring for children after solid organ transplant. *Journal for Specialists in Pediatric Nursing*, 22(3), 12178. https://doi.org/10.1111/jspn.12178

Li, L., Yang, L., Dong, C., Yan, Q., Huang, W., Liao, T. & Sun, X. (2021). Psychosocial assessment of donors in pediatric living donor liver transplantation: A systematic review. In: *Transplantation Proceedings*. Elsevier, 53, 3-15. https://doi.org/10.1016/j.transproceed.2020.02.150

LoBiondo-Wood, G., Williams, L. & McGhee, C. (2004). Liver transplantation in children: Maternal and family stress, coping, and adaptation. *Journal for Specialists in Pediatric Nursing,*9(2), 59-66. https://doi.org/10.1111/j.1088-145X.2004.00059.x

Maxwell J.A. (2012). Qualitative Research Design: An Interactive Approach. New York: Sage Publications, 41.

McLoughlin, A., Wilson, C. & Swords, L. (2021). Parents' experiences of their child's solid-organ transplant: A meta-ethnography of qualitative studies. *Journal of Pediatric Psychology,* 1–13 doi: 10.1093/jpepsy/jsab108. https://doi.org/10.1093/jpepsy/jsab108

Mjøen, G., Stavem, K., Westlie, L., Midtvedt, K., Fauchald, P., Norby, G. & Holdaas, H. (2011). Quality of life in kidney donors. *American Journal of Transplantation*, *11*(6), 1315-1319. https://doi.org/10.1111/j.1600-6143.2011.03517.x

Nikeghbalian, S., Malekhosseini, S. A., Kazemi, K., Arasteh, P., Eghlimi, H., Shamsaeefar, A., ... & Salahi, H. (2021). The largest single center report on pediatric liver transplantation: experiences and lessons learned. *Annals of Surgery*, *273*(2), 70-72. https://doi.org/10.1097/sla.0000000000004047

Ong, Z. H., Ng, C. H., Tok, P. L., Kiew, M. J. X., Huso, Y., Shorey, S. & Ng, Y. P. M. (2021). Sources of distress experienced by parents of children with chronic kidney disease on Dialysis: A qualitative systematic review. *Journal of Pediatric Nursing*, *57,* 11-17. https://doi.org/10.1016/j.pedn.2020.10.018

Parmar, A., Vandriel, S. M. & Ng, V. L. (2017). Health-related quality of life after pediatric liver transplantation: a systematic review. *Liver Transplantation,* 23(3), 361-374. https://doi.org/10.1002/lt.24696

Petersen, I., Noelle, J., Buchholz. A., Kroencke, S., Daseking, M. & Grabhorn, E. (2019). Fatigue in pediatric liver transplant recipients and its impact on their quality of life. *Pediatric Transplantation,* 23(1), 13331. https://doi.org/10.1111/petr.13331

Sarigol Ordin, Y., Karayurt, Ö., Ünek, T. & Astarcıoğlu, İ. (2017). Pediatric liver transplant patients' transition to adulthood: Patient and parent experiences. *Nursing & Health Sciences*, *19*(3), 393-399. https://doi.org/10.1111/nhs.12358

Sheikhalipour, Z., Zamanzadeh, V., Borimnejad, L., Newton, S.E. & Valizadeh, L. (2019). Muslim transplant recipients' family experiences following organ transplantation. *Journal of Research in Nursing*, 24(5), 291-302. https://doi.org/10.1177/1744987118813671

Şahin, Y., Ziyaret, O. & Demir, B. (2016). Depression and anxiety in parents of children who are candidates for liver transplantation. *Arquivos de Gastroenterologia*, 53(1), 25-30. https://doi.org/10.1590/S0004-28032016000100006

Thys, K., Schwering, K. L., Siebelink, M., Dobbels, F., Borry, P., Schotsmans, P., ... & Elpat Pediatric Organ Donation and Transplantation Working Group. (2015). Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: A systematic review. *Transplant International*, *28*(3), 270-280. https://doi.org/10.1111/tri.12481

Umeshita, K., Inomata, Y., Furukawa, H., Kasahara, M., Kawasaki, S., Kobayashi, E., ... & Japanese Liver Transplantation Society. (2016). Liver transplantation in Japan: Registry by the japanese liver transplantation society. *Hepatology Research*, *46*(12), 1171-1186. https://doi.org/10.1111/hepr.12676

Walker, R. C., Naicker, D., Kara, T. & Palmer, S. C. (2019). Parents' perspectives and experiences of kidney transplantation in children: A qualitative interview study. *Journal of Renal Care*, *45*(3), 193-200. http://dx.doi.org/10.1111/jorc.12292

Wirken, L., van Middendorp, H., Hooghof, C. W., Sanders, J. S. F., Dam, R. E., van der Pant, K. A., ... & Evers, A. W. (2019). Psychosocial consequences of living kidney donation: A prospective multicentre study on health-related quality of life, donor–recipient relationships and regret. *Nephrology Dialysis Transplantation*, *34*(6), 1045-1055. https://doi.org/10.1093/ndt/gfy307

Wright, J., Elwell, L., McDonagh, J.E., Kelly, D.A. & Wray, J. (2017). Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services. *Pediatr Transplant*, 21, 12760. https://doi.org/10.1111/petr.12760

Yadav, P., Nunia, S., Bansal, A., Sureka, S. K., Jena, R., Ansari, M. S. & Srivastava, A. (2017). Multidimensional assessment of quality of life of children and problems of parents in Indian society after pediatric renal transplant: Beyond the conventional thoughts. *Pediatric Transplantation*, *21*(6), e13001. https://doi.org/10.1111/petr.13001

Yayan, E.H. & Düken, M.E. (2019). A Comparison of caregiving burden and social support levels of parents of children undergoing liver transplant. *Journal of Pediatric Nursing*, 47, 45-50. https://doi.org/10.1016/j.pedn.2019.04.022

Yayan, E.H. & Düken, M.E. (2020). Comparison of quality of life and caregiving burden of 2-to 4-year-old children post liver transplant and their parents. *Gastroenterology Nursing,* 43(4), 310-316. http://dx.doi.org/10.1097/SGA.0000000000000448

Yuen, W. Y., Tan, A., Karthik, S. V., Quak, S. H., Kow, A. W. C. & Aw, M. M. (2019). Health-related quality of life, clinical outcomes, and subjective experiences of parent donors of pediatric liver transplant recipients. *Pediatric Transplantation*, *23*(2), e13337. https://doi.org/10.1111/petr.13337

Zhang, W. X., Wei, H., Shen, Z. Y., Peng, X., Chen, X. G., Li, W., ... & Niu, Y. J. (2014). Concerns of and coping strategies by parents of pediatric liver transplant recipients: a qualitative study from China. *International Journal of Clinical and Experimental Medicine*, *7*(12), 5723. https://pubmed.ncbi.nlm.nih.gov/25664098