

The Effect Of End-Stage Renal Disease On Psychosocial Life, Coping Methods And Patients' Organ Transplant Perception: A Qualitative Research*

Son Dönem Böbrek Yetmezliğinin Psikososyal Yaşama Etkisi, Başetme Yöntemleri ve Hastaların Organ Nakli Algısı: Nitel Bir Araştırma

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ABSTRACT

Objective: End-stage renal disease is an important and common disease that negatively affects the biopsychosocial life of patients. In kidney transplantation, which is one of the most distinguished treatment methods of end-stage renal disease, life experiences, transplant expectations and views of patients prepared for transplantation are important in the success of the surgical intervention. This study was carried out to investigate the effects of end-stage renal disease on the lives of patients who are planned for transplantation, their methods of coping with the disease and thoughts on organ transplantation.

Material and Method: The research was carried out by using descriptive phenomenological pattern which is one of the qualitative research types. The population of the study consisted of all patients who were hospitalized in the organ transplant service of a university hospital and planned to undergo a kidney transplant, and the sample was 15 patients who met the research criteria and were willing to participate. The data collected with the patient presentation form and semi-structured in-depth interview questions were evaluated by the thematic analysis method.

Results: When the opinions of the patients about the effect of renal failure on psychosocial life and the methods of coping with the disease were examined, two main themes and 12 sub-themes were obtained. In the research, it was observed that end-stage renal disease causes various losses in the lives of the participants, they are desperate about the future and feel depressed, they experience obscurity, they see themselves different from the society and think they are stigmatized, their body image and self-esteem is disturbed by the disease and they distrust the healthcare professionals, they use emotion-oriented coping methods more often, although they experienced various fears related to organ transplantation, they described organ transplantation as quality living, freedom and hope.

Conclusion: In this study, detailed data on psychosocial life experiences, coping methods and organ perception of patients preparing for transplantation were obtained. It is thought that these data will be an important guide in providing comprehensive and individualized nursing care to facilitate adaptation to life during long and indefinite waiting period for patients who are waiting for organ transplantation.

Key words: Kidney failure, Nursing care, Dialysis, Transplantation, Qualitative Research

ÖZET

Amaç: Son dönem böbrek yetmezliği, hastaların biyopsikososyal yaşamını olumsuz etkileyen önemli ve yaygın bir hastalıktır. Son dönem böbrek yetmezliğinin en seçkin tedavi yöntemlerinden biri olan böbrek naklinde, nakile hazırlanan hastaların yaşam deneyimleri, nakile ilişkin beklentileri ve görüşleri cerrahi girişimin başarısında önemlidir. Bu çalışma, son dönem böbrek yetmezliğinin, nakil planlanan hastaların yaşamlarına etkisi, hastalıkla başetme yöntemleri ve organ nakline ilişkin düşüncelerini incelemek amacıyla yapıldı.

Yöntem: Araştırma, nitel araştırma türlerinden tanımlayıcı fenomenolojik desen kullanılarak gerçekleştirildi. Araştırmanın evrenini, bir üniversite hastanesinin organ nakli servisinde yatan ve böbrek nakli yapılması planlanan tüm hastalar, örneklemini

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ise araştırma kriterlerine uyan ve katılmaya istekli olan 15 hasta oluşturdu. Hasta tanıtım formu ve yarı yapılandırılmış derinlemesine görüşme soruları ile toplanan veriler, tematik analiz yöntemi ile değerlendirildi.

Bulgular: Hastaların böbrek yetmezliğinin psikososyal yaşama etkisine ilişkin görüşleri ve hastalıkla baş etme yöntemleri incelendiğinde iki ana tema ve 12 alt tema elde edildi. Araştırmada, son dönem böbrek yetmezliğinin katılımcıların yaşamlarında çeşitli kayıplara neden olduğu, gelecekle ilgili umutsuz oldukları ve kendilerini depresif hissettikleri, bilinmezlik yaşadıkları, kendilerini toplumdan farklı gördükleri ve damgalandıklarını düşündükleri, benlik saygısı ve beden imajlarının hastalıktan olumsuz etkilendiği ve sağlık çalışanlarına güvensiz oldukları, duygu odaklı başetme yöntemlerini daha çok kullandıkları, organ nakli ile ilgili çeşitli korkular yaşamakla birlikte organ naklini nitelikli yaşamak, özgürlük ve umut olarak tanımladıkları görüldü.

Sonuç: Bu çalışmada, nakile hazırlanan hastaların psikososyal yaşam deneyimleri, baş etme yöntemleri ve organ algısı konusunda ayrıntılı veriler elde edildi. Bu verilerin, organ nakli bekleyen hastalara, uzun ve belirsiz bekleme süresince yaşama uyumu kolaylaştırıcı, kapsamlı ve bireyselleştirilmiş hemşirelik bakımı sunulmasında, önemli bir rehber olacağı düşünülmektedir.

Anahtar Kelimeler: Böbrek yetmezliği, Hemşirelik bakımı, Diyaliz, Organ nakli, Nitel araştırma

Introduction

End-stage renal disease (ESRD) is a common health problem in the world and in our country. According to TurkStat 2018 data, 14,263 people are reported to have died due to kidney failure. Treatment methods such as hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation (RTx) are applied to patients with ESRD; although the most exclusive treatment method is RTx, dialysis methods are used more commonly because of the limited number of organs that can be transplanted (Doğan, et al. 2020:1). According to 2019 data, it is reported that dialysis is applied to 64,656 people, kidney transplantation to 3,140 people and that 22,981 people expect kidney transplantation in Turkey.

Dialysis is a life-saving treatment and a new life experience for patients with ESRD. In a study by Hagren et al. (2005: 294-300), patients who underwent hemodialysis treatment described the dialysis machine as 'a reminder that they still live while they should have died'. Dialysis treatment, which also changes the life it saves, negatively affects patients' survival rate and quality of life (Suwabe, et al. 2018). In addition to having a chronic disease, patients experience many limitations and intense physical-psychosocial difficulties (Yılmaz Karabulutlu – Okanlı, 2011: 25-31). Disability due to dialysis limits daily life activities and negatively affects self-care and self-efficacy (Mollaoğlu, 2011: 181-186). It is emphasized in the literature that low quality of life and functional capacity increase mortality (Jablonski, 2007: 29-37; Thong, et al. 2009: 225-230; Amro, et al. 2014: 23-33; Amro, et al. 2015: 27-35; Ng, et al. 2020).

Patients with ESRD are registered on the "National Organ Transplant Waiting List" and transplantation takes place after a long examination and waiting period. While "waiting" for patients is a stressor alone, it can also cause anxiety, fear, agitation, despair, anger and hopelessness. Patients who are expecting a kidney from a cadaver donor may experience this uncertainty more intensely and may think that their only chance is transplant. Since this idea means to wait for someone to die at the same time, the feeling of helplessness can turn into guilt (Akgül Ceyhun, 2009).

Many RTx receiver have unrealistic expectations about what will happen in post-transplant life (Crawford, et al. 2017: 1204-1207). Therefore, pre-operative preparation of patients who decide for RTx should be enriched with individual training. Knowing the biopsychosocial life experiences of patients in the RTx waiting period will contribute to increasing the success of transplantation through individualization of care. In line with these views, the opinions of individuals, who are hospitalized for RTx, about the effects of ESRD on their lives, coping with the disease and organ transplantation were examined in detail.

Research Questions

1. How does kidney failure affect individuals' psychosocial life?
2. What are the individuals' coping methods?
3. What do individuals expect from transplantation?
4. What is the meaning of transplantation for individuals?

Method

Study Design

Phenomenology, which is a qualitative research type, investigates the meaning of individuals' life experiences related to an event or aims to understand a concept/event. The purpose of this approach is to depict experiences rather than to describe, group or interpret experiences (Neubauer, et al. 2019: 90-97). This research, which aims to gather comprehensive information about the psychosocial experiences of patients with ESRD and its treatments and who are planned for RTx, was conducted using a descriptive phenomenological pattern, one of the qualitative research types.

Sample

The sample of the study was determined by purposeful sampling method. Patients who were planned to have RTx



at the organ transplant center of a university hospital, are 18 years and older, are hospitalized for RTx, with no communication problems, and with no diagnosed psychiatric diseases were included in the study. The number

of participants was determined according to data saturation and the study was terminated with 15 patients. (Table 1) (Creswell - Plano Clark, 2017).

Table 1. Demographical and clinical characteristics of participants

Variables	n=15	%	min-max mean \pm SD
Age			
18-30	4	26,7	19-56 years of age Mean: 38 \pm 11,8
31-43	5	33,3	
44-56	6	40,0	
Sex	8	53,3	
Male	7	46,7	
Female			
Educational Background			
Primary School	5	33,3	
Middle School	4	26,7	
High School	2	13,3	
University	4	26,7	
Marital Status			
Married	11	73,3	
Single	4	26,7	
People They Live With			
Alone	2	13,3	
With Spouse and Child(ren)	8	53,3	
With Their Family	2	13,3	
With Their Spouse	3	20,0	
Employment Situation			
Unemployed	7	46,7	
Employed	6	40,0	
Retired	2	13,3	
Social Security			
Yes	15	100	
Existence of any other Chronic Disease			
Yes	11	73,3	
No	4	26,7	
Applied Treatments			
Hemodialysis	9	60,0	
Peritoneal Dialysis	2	13,3	
Hemodialysis and Peritoneal Dialysis	1	6,7	
Medicine Treatment	3	20,0	
Duration of Hemodialysis			
Never Applied	5	33,3	1-16 years
1-5 Years	6	40,0	6.4 years
6-10 Years	1	6,7	
More than 11 Years	3	20,0	
Peritoneal Dialysis			
Never Applied	12	80,0	1.5-5 years
1-3 Years	1	6,7	3.5 years
More than 4 Years	2	13,3	
Transplantation Waiting Period			
Not Enlisted	5	33,3	0-10 years
Less than 1 Years	4	26,7	5.4 years
More than 4 Years	6	40,0	
Donor			
Cadaver	5	33,3	
Mother	3	20,0	
Father	1	6,7	
Spouse	3	20,0	
Aunt	1	6,7	
Cross-Transplantation	1	6,7	
Sister	1	6,7	

Data Collection

Preparation

The study was carried out between December 2011 and July 2012. "Informed Volunteer Consent Form" and "Patient Information Form" were filled in after the participants were informed about the research before the beginning. Qualitative data were collected through in-depth individual interviews using a semi-structured questionnaire.

In-Depth Interview Process

A pilot interview was held with three participants under conditions similar to the study. Patients who were pilot interviewed were not included in the study. In-depth interviews were conducted with the participant at a scheduled time. In-depth interviews were conducted with the participant at a scheduled time. In-depth interviews continued until data saturation was achieved, and while the shortest interview lasted 25 minutes, the longest one lasted 57 minutes. During the interviews, a voice recorder was used with the permission of the patients. During all the interviews, attention was paid to the participants' reactions and behaviors, breaks given in the interview, and notes about the environment to be recorded in the interview guide.

Statistical Analysis

The interviews were audiotaped and then transcribed verbatim. Data were analyzed using qualitative content analysis (Braun & Clarke, 2006). For the data analysis, the following steps were followed respectively:

1. Familiarizing with the data: Transcribing the data, reading and rereading the data, noting down initial ideas.
2. Generating initial codes: Coding interesting features of the data systematically across the entire data set, collating data relevant to each code.
3. Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes: Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map.
5. Defining and naming themes: On-going analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme.
6. Producing the report: As the final step for the analysis, vivid and compelling extract examples were selected. Those selected extracts were analyzed again relating back of the analysis to the research question and literature in order to producing a report of the analysis.

The collected data were presented using direct quotations from the participant narrations and in order not

to reveal the participants' real identity; a nickname was given to each participant.

Validity and Reliability of The Research

In this research, the researcher acted meticulously in order not to affect the feelings and thoughts of the participants, asked the questions clearly and objectively, conducted the interviews in a chat mood. Besides using a voice recorder, the researcher noted her individual observations (body language, etc.) and all the data she obtained was transcribed complete and unbiased.

The findings were examined separately by the researchers and themes were created. The themes from the individual analysis were compared and discussed until a consensus was reached at by examining the data repeatedly. Apart from the researchers, the determined themes were examined and coded by three experts who are experienced in qualitative research. In order to check the reliability of the data, these encodings were coded by two experts who did not have information about this research. The consistency of the themes coded by experts was checked by calculating the value of "kappa" in the SPSS program. Kappa value was found to be 0.89 ($p = 0.00$). This result was interpreted as a perfect meaningful agreement between codings, in other words, high internal reliability was reached at (Günbayı, 2014).

Ethical Considerations

Every stage of the research was conducted according to ethical principles. Before the implementation of the study, the necessary institutional permissions and ethics committee approval from the "Ethics Committee of Mediterranean University" (dated 15.11.2011 numbered 63) were obtained. Participation was voluntary, and participants who agreed to be interviewed signed a written consent form.

RESULTS

The thematic analysis of the data obtained from this study was made and the findings are shown in Tables 2 and 3. When the opinions of patients about the effect of kidney failure on psychosocial life and the methods of coping with the disease were examined, two main themes and 12 sub-themes were obtained. The sub-themes of the main theme '*The Disease's Effect on Life*' are determined as *loss, despair, depression, uncertainty, internalized stigmatization, negative body image, distrust towards healthcare professionals, family relations, relations with the social circle*; and the sub-themes of the main theme "*Individual Coping*" as *emotion-oriented coping – avoidance, problem-oriented coping* (Table 2).



The Disease's Effect on Life - Main Theme

Loss Sub-Theme

"When this happens, one feels like half a person. While the folks are play around, we cannot go out, everyone finishes a liter of water under the heat in a seam, we cannot drink. I used to work after I started dialysis but it was not like before...you go into dialysis four hours a day, you can do better things during that four hours. You can spend time with your family. You can go somewhere and come back, but you're bedridden..." (P3, from Mother)

"I was an athlete, I used to do sports every morning and run. But I had to quit this after the disease. I am so sad... Everything is gone..." (P14, from Sister)

Despair Sub-Theme

"... I was hopeless, you know... I had very critical times and illnesses. I mean I was waiting for death. I was having my last time in dialysis, because I could not get the full result anymore, I gradually lost hope ..." (P8, from Cadaver).

Depression Sub Theme

"I received psychological treatment. I did not go to hospital, but I received medication treatment. I received it for 3-4 months and continued until recently. I was very afraid of dialysis; I did not want dialysis treatment. I was very upset because of my condition, why me, why was I like this, what did I do? I was always thinking about these" (P5, from Aunt-in-law)

Uncertainty Sub-Theme

"...waiting on that list... It was not clear when it would happen. I also had no other vein for dialysis, I would continue a little more with catheter but it was not clear how long the catheter would last..." (P4, from Cadaver)

Internalized Stigmatization Sub-Theme

"...You feel a deficiency inside. I used to feel in society like there was something wrong with us (referring to individuals who receive dialysis)... of course they are healthy (meaning healthy individuals), better. Healthy people speak, work, do whatever they want, we cannot. No matter what, we are weak... we are below them ..." (P6, Cross Transplantation)

Negative Body Image Sub-Theme

"...adolescence was very difficult for me. It was awful. I was not feeling beautiful at all, feeling like I wasn't growing like the others (healthy ones). Some things are already delayed, like menstruation... I was feeling strange!" (P9, from Cadaver)

"I would be very uncomfortable with how I look. My arm vessels developed very quickly because of the fistula (showing the arm, the vessel wall is very apparent and thick) they were very swollen, most of my friends were very surprised when they saw it, asking whether my arm would stay like this and why..." (P1, from Cadaver)

Distrust Towards Healthcare Professionals Sub-Theme

"Dialysis is a commercial sector, there may be doctors who mislead you. They may not want you to be transplanted. I heard around me... There are dialysis centers looking like a hairdressers. They go up to the feet of people, they grab customers from each other as if they are getting customers, I heard that too. When one hears these, one cannot trust..." (P11, from Mother)

Family Relations Sub-Theme

"While talking to my friends, there were obstacles due to the families. They would say you're sick, your friend smokes or does this, they'll make you to it too, don't see them. They play around with other people, they are comfortable, you were not equal with them... They were always trying to protect me, they didn't send me anywhere because they thought they would hurt me" (P9, Cadaver).



Table 2. Patients' views of renal failure on psychosocial life and their coping methods

Main Theme	Sub-Theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	f	%
The Disease's Effect on Life	Loss	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	15	100
	Despair	√		√	√	√	√	√	√	√		√	√				10	66,6
	Depression	√	√	√		√	√		√	√	√	√				√	10	66,6
	Uncertainty	√	√		√		√		√	√	√					√	8	53,3
	Internalized Stigmatization	√		√			√	√		√		√					6	40,0
	Negative Body Image	√		√					√	√		√					5	33,3
	Distrust Towards Healthcare Professionals		√	√					√				√				4	26,6
	Relations with the Social Circle	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	15	100
	Family Relations	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	14	93,3
Individual Coping	Emotion-oriented Coping– Avoidance	√	√		√		√		√		√	√	√		√	√	10	66,6
	Problem-oriented Coping			√				√						√			3	20,0

Relations with the Social Circle Sub-Theme

“I used to get out of dialysis, sad, pale, they would say that I was so weak and wouldn't live, that I would die in the night or in the morning. I could not enjoy anything then (social settings). I was going home, giving myself to alcohol, drinking alcohol. The society was influencing me... I never showed my illness to the other person. They used to ask how I was, I would say that I am very well, I am not sick...” (P12, from Spouse)

Individual Coping Main Theme

Emotion-Oriented Coping – Avoidance Sub-Theme

“It could have been worse because these are things happening to everyone, not only me. I say thank god for this... My friends are always praying. I pray myself. These comfort me. Yasins are read and prayers are made after me...” (P2, from Father)

Problem-Oriented Coping Sub-Theme

“I said to myself this is your life now. So you have to enter the machine. This does not mean that it is the end of everything. At that time, I received little psychological help for about a month. After that, did I rally...” (P1, from Cadaver)

When the participants' views on RTx were examined, two main themes and 8 sub-themes were obtained. The sub-themes of the theme are identified as ‘Fear’ are fear of death, failure in the transplanted kidney/returning to dialysis, fear of limited life experience after transplantation, fear of cancelation of transplantation, fear of damage in the

donor; and the sub-themes of the main theme ‘The Meaning of Organ Transplantation for the Individual’ as quality living, freedom/elimination of obstacles, and hope (Table 3).

Fear Main Theme

Fear of Death Sub-Theme

“... I had no other vein for dialysis, I could continue a little more with catheter but it was not clear how long the catheter would last.” (P4, from Cadaver)

Failure in the Transplanted Kidney/Returning to Dialysis Sub-Theme

“...Some people tell, that there are those who experienced bad things, and those whose kidneys did not work. Different things happen to different people. When I heard something positive or negative, I was unavoidably affected from the outside” (P2, from Father)

“I could not have been transplanted, a disease could have occurred, I could have gone back to dialysis” (P15, from Spouse)

Fear of Limited Life Experience After Transplantation Sub-Theme

“...the transplant will perhaps limit my life. Because I will have to be more careful, I will have to use medicines, I mustn't go out for some period...” (P13, from Mother)



“I will not be able to do heavy work, so I need to protect my kidney just like how I protect the fistula. I will have to not tire myself, pay attention... Also, my friends will enlist, I will not be able to go...” (P3, from Mother)

Fear of Cancellation of the Transplantation Sub-Theme

“... I was afraid whether I would have a flu when they called me for transplantation. Because in such cases, the transfer was canceled. I was worried about that. It would already be taken from my brother once before, but it was canceled; I didn't want to experience the same emotions again.” (P10, from Cadaver)

Fear of Damage in the Donor Sub-Theme

“...I couldn't rejoice. Because the other person will be disabled as well. Their health will also deteriorate. If they also get kidney disease, I lose myself. Because I'm already sick but if it happens to them too...” (P7, from Spouse)

The Meaning of Organ Transplantation for the Individual Main Theme

Quality Living Sub-Theme

“First of all, it will increase the quality of my life... I will pay more attention to myself, my child, my house, my spouse and more. I will make my social life more active. Everything that will be more beautiful.” (P8, from Cadaver)

“Health means, living comfortably” (P7, from Spouse)

Table 3. Patients' Views on Kidney Transplantation

Main Theme	Sub-Theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	f	%
Fear	Fear of Death		√	√	√	√	√										5	33,3
	Failure in the Transplanted Kidney/Returning to Dialysis		√	√		√				√							4	26,6
	Fear of Limited Life Experience After Transplantation		√	√										√		√	4	26,6
	Fear of Cancellation of Transplantation	√							√		√					√	4	26,6
	Fear of Damage in the Donor					√	√	√								√	4	26,6
The Meaning of Organ Transplantation for the Individual	Quality Living	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	15	100
	Freedom	√		√	√			√	√		√	√		√			8	53,3
	Hope				√	√	√			√				√		√	6	40,0

Freedom/Elimination of Obstacles Sub-Theme

“I want to be freer and wide open. Because going to dialysis constantly prevented some things” (P9, from Cadaver)

“Water, all I want is to be able to drink water... I mean I can't think of anything else. I long for water so much, and also eating a melon (laughs out loud). My potassium was always high. I could eat fruit limitedly... I want to travel and have fun like normal people. I was doing these, but now I think I will be more independent, happier and more comfortable.” (P1, from Cadaver)

Hope Sub-Theme

“...at least one day I will not have the fear that my kidney will run out.” (P13, from Mother)

“...I feel very happy that I will be saved, I will get rid of this dialysis... There is hope, there is hope for life.” (P6, Cross Transplantation)

Discussion

In addition to the difficulties caused by, and the specifications of the disease, how individuals perceive the disease is an important factor in the survival of individuals



with chronic diseases in a balanced and harmonious manner (Yılmaz Karabulutlu – Okanlı, 2011: 25-31). In this study, when the opinions of the participants about the methods of coping with the disease and the effect of ESRD on psychosocial life were examined, it is seen that ESRD caused various losses in patients' lives such as despair and depression about the future, experienced uncertainty, thought they are stigmatized because of the disease, and considered themselves different from the society, their self-esteem and body images were negatively affected by the disease and some participants were distrustful towards healthcare professionals (Table 2).

Undoubtedly, although ESRD treatments are a savior for patients, they also cause losses in all aspects of life. In this study, all of the participants stated that ESRD and related treatments caused serious physical and psychosocial losses in their lives. It was determined that the disease had psychological losses such as loss of physical strength, energy and stability of patients; peritoneal dialysis patients' dependence on a room of the house - hemodialysis patients' to a dialysis center, loss of time due to frequent and long hours of dialysis; dietary obligations (especially water restriction), interruption of education and poor school performance; restriction of participation in social activities, not being able to maintain hobbies; economic losses due to the inability to find a job or work as before; the fact that the disease prevents socially finding someone and getting married, the change of body appearance and loss of body integrity due to fistulas and changing skin color, and mental energy loss. In the literature, there are many studies related to physical, social and mental losses. In a qualitative study, it was found that various symptoms such as fatigue, weakness, and insomnia in patients with ESRD increase physical restraint, affecting daily life activities, negatively affecting job-work performance and causing job loss (Ng, et al. 2020). Another study reported that more than half of ESRD patients experience symptoms such as fatigue, pain, itching, decreased appetite, and muscle cramps (Almutary, et al. 2013: 140–150). In the study of Krespi et al. (2008), hemodialysis was found to bring restrictions on the life of all patients. Similarly, Öztürk et al. (2013) stated that 35.1% of patients could not work due to illness or treatment, while 87.1% needed support while meeting self-care needs. In another study, 72% of patients undergoing hemodialysis stated that they experienced problems in professional life and 70% experienced economic problems (Kral - Yurtsever 2013: 61-76). In a qualitative study conducted by Moran et al. (2010), in interviews with patients waiting for kidney transplantation, it was observed that the patients had expressions of dependence and loss on the theme of being in the state of waiting. For example, following statements are used; *"My life is on hold. I work in construction and there may be some physical tasks. I do not know what the employer will do when I get leave (for dialysis) every other day. I have to come here three times a week for 4.5 hours... It will continue like this until I receive transplantation"*. In another qualitative study, hemodialysis treatment was defined by patients as *"interfering with daily life, limiting"* (Fisher, et al. 1998: 553-563). The result obtained in this study that the losses and limitations are intensely felt by the

patients and have a significant effect on the biopsychosocial life supports the previous research results.

Despair was also approved by the North America Nursing Diagnosis Association (NANDA) in 1986 as a nursing diagnosis and defined as 'a situation where the individual sees limited or no alternatives or cannot find personal options and cannot use energy for their own benefit' (Asti, et al. 2006: 490-497). In the study conducted by Dadalı (2009), it was found that in 77.6% of the patients of dialysis treatment had the thoughts of despair. In another study, it was stated that 60% of patients undergoing dialysis treatment were on the waiting list and 35% had no hope for transplantation (Yılmaz Karabulutlu – Okanlı, 2011: 25-31). In another study, 68.4% of patients stated that they could not recover (Mutlu, 2007). In a qualitative study conducted by Moran et al. (2010), the statements of patients waiting for RTx about despair on the themes of uncertainty and waiting were included. In a study conducted by Oktay (2011), it was found that as hemodialysis treatment patients increased their 'perception of disease', they lost their personal control and fell into despair.

In this study, It was found that the participants thought that dialysis was an end for them and they had no hope to recover; some even preferred death over dialysis for a period of time; and that they experienced uncertainty due to reasons such as long waiting period difficulty and indefinite duration of transplantation. The results of our research, which are in line with the literature information and other studies, can be evaluated as an expected result of patients who have been trying to deal with a serious problem for many years and experience negative events related to their illnesses repeatedly and remain helpless.

As is known, hemodialysis (HD) treatment causes many mental problems, especially anxiety and depression, in patients (Topbaş - Bingöl, 2017: 36-42). The presence of depression also affects the immune system, personal hygiene and combat power, negatively affects the course of the disease and shortens the average life span (Küçük, 2006). In the study conducted by Partridge and Robertson (2011), the prevalence of anxiety and depression in patients undergoing dialysis treatment was found to be significantly higher than social norms (Partridge - Robertson, 2011: 504-510). In the study conducted by Aştı et al. (2006), it was stated that the feeling of being dependent on treatment, treatment team and family members, needing help and losing control causes anxiety, despair, and depression in individuals. In another study, it was reported that 'fatigue' and 'depression' occur in a cycle and are frequently affected by hemodialysis treatment and patients' coping styles (Flythe, Dorough et al., 2018: 1842–1852). In this study, it was concluded that the state of despair of the participants affected their emotional state and caused them to feel depressed. This result, which is in line with the literature, is multifactorial and can be considered as an expected situation when despair is associated with the uncertainty experienced by patients.

Individual or society; when faced with a situation that bothers and frightens them, they often choose to exclude it (Arslan - Konuk Şener, 2009: 1-8). Internalized



stigmatization can be defined as worthlessness, shame, secrecy and withdrawal, which arise as a result of the acceptance of negative stereotypes by one's own self (Çam – Çuhadar, 2011: 136-140). In a qualitative research conducted with adolescents who underwent hemodialysis treatment, patients stated that they were constantly embarrassed to undergo dialysis, they tried to hide the disease, and they were jealous of other people because they were healthy, and defined dialysis as "agonizing". In the same study, adolescents stated that they felt different because of the diet restrictions, because they could not get the foods everyone can eat and drink (Akgül, 2005). In the study, it was found that the participants often describe healthy individuals with words such as "normal", "they...-we...", and compare themselves repeatedly with people who are not sick, and distinguish each other as sick-healthy; and that some patients expressed the obstacles posed by the emotional oppression they experienced from the society in their lives. In this study, the results obtained that some patients with ESRD approved stigmatization for themselves and consequently self-stigma supports the literature and Akgül's study result. Considering that stigmatization, which also has the effect of social teachings, is considered in terms of its impact on health, it is thought that individuals who internalize stigmatization are more isolated, alienated and socially withdrawn, and this may cause incompatibilities in treatment and care processes.

ESRD, which is a chronic disease, alters the patient's body and adversely affects the body image (Finnegan-John-Thomas, 2012). In this study, the patients stated that they felt ugly, they did not see themselves as before when they looked in the mirror, their colors became faded and they tried to hide their scars. The results of a cross-sectional study by Leonard (2013) showed that patients with HD had higher body-image impairment than the general population. Another study found that patients who underwent HD experienced body image defects more commonly than patients with RTx (Sadeghian, et al. 2016). In a qualitative research conducted by Akgül (2005) in adolescents, it was stated that the body image was negatively affected due to reasons such as short height, fistula being obvious from outside, being mocked around by people, and being called a dwarf. In another study, it was found that 51.7% of patients who underwent dialysis thought that their appearance changed after the disease, and 47.5% were uncomfortable with their appearance (Kıvrak, 2008). In this study, the result obtained from the dialysis treatment that naturally creates negative body image perception due to the opened fistulas that change the appearance and integrity of the body, and the skin color changes over time shows a parallel with previous studies (Finnegan- John & Thomas, 2012; Akgül, 2005; Kıvrak, 2008).

Although trust is necessary to create an environment where the meanings, ideas, information and problems required for professional care are shared effectively, weak trust may impair the ability or willingness of 'patients' to comply with treatment and care recommendations (Alpers, 2018: 313-323). In this study, it was determined that the majority of the participants trusted the healthcare professionals, but some patients thought that the healthcare

professionals might have commercial concerns over health. This result was interpreted as individuals' sense of trust may sometimes weaken towards the healthcare professionals due to loss, despair, uncertainty and some negative experiences experienced at various stages of treatment.

ESRD significantly affects patients' social circle and business life. When the researches on the subject are examined; in the study conducted by Mutlu (2007), it was found that 59% of the patients had decreased relations with their close friends and relatives and 12.8% had to change the environment they live in. In another study, 32.2% of patients on whom peritoneal dialysis was performed stated the following: "my work life was completely negatively affected", and 20.9% said "going to work has become very difficult now", and 44.4% said that "it is very difficult to continue social life" (Karaca, et al. 2012: 169-174). In the study of Çınar (2009), while the patients reported mostly problems related to work environment, sexual relations and social environment, it was determined that the social life of the majority of the patients was affected in the studies of Hiçdurmaz (2005) and Kral and Yurtsever (2013).

In this study, all of the participants stated that they had problems in their social relations; it was found that the society treated them differently, they were constantly interfered with their food, they were made recommendations, they were constantly treated as sick people, they felt excluded, they tried not to reflect their physical problems and emotional reactions due to their sarcastic attitudes and disdain, they avoided talking about the disease, and experienced restrictions in social relations. The participants defined their relationship with their friends more positively than their other social relationships. They reported that they had difficulty in participating in joint activities with their peers, but expressed that they were pleased with the constructive behavior of their close friends. It can be said that the physical impacts of the disease on the results of this study, which is similar to the previous study results, affect individuals of all aspects of life and lead individuals to make some changes about their social environment, as well as the perception of the society as a disdain by patients towards the disease and patients.

In addition to social relationships, family relationships are also affected by the disease. The disease means strengthening family relationships for some, and a series of problems for others. In a study, it was found that some patients had better social ties than before the disease, increased awareness of family members and friends with the emergence of symptoms, supplemented with additional care and support, as it is believed that patients are weak and require special attention (Ng, et al. 2020). In Karaca et al. (2012)'s study, it was found that 46.4% of patients on whom peritoneal dialysis was performed, used the phrase "nothing is as it were before, everything is more complex and difficult" and more than half of the patients had difficulties in their private lives. In a study conducted by Kral and Yurtsever (2013), it was reported that 49% of HD patients had problems in their relationships with spouses.

In this study, it was found that almost all of the participants were pessimistic, their families showed more



interest than before the disease, they could not fulfill their roles in the family, the family processes were negatively affected and that the patients reflected their mood changes negatively on their families. It was seen that all of the participants were happy not to talk about the disease in the family and to behave as if they were not sick. Single participants reported that being sick affects emotional relationships and appropriate partner selection, while married participants reported that fatigue negatively affects sexual life. It was found that patients with children were affected by their relationship with their children after ESRD, the responsibilities that children assumed from time to time increased and they were worried about them. These results are largely similar to other research results, but more qualitative research is thought to be needed.

Coping methods express special efforts, both behavioral and psychological, and play an important role in adapting to challenging situations (Aggarwal, et al. 2017: 49-52). Çetinkaya et al. (2008) investigated the attitudes of patients undergoing hemodialysis and peritoneal dialysis to deal with stress and found that patients used most commonly religious coping methods and the second, positive reinterpretation and development method. In a study conducted with patients who underwent peritoneal dialysis, 14.4% of the patients were reported to exhibit an emotion-oriented coping/avoidance strategy with the statement that "the disease is fateful" (Karaca, et al. 2012: 169-174). Coping methods express special efforts, both behavioral and psychological, and play an important role in adapting to challenging situations (Aggarwal, et al. 2017: 49-52). When coping methods are examined in this study; it was determined that most of the participants used emotion-oriented coping/avoidance, stating that the disease was destiny, that God created them like this and that this situation could not be resisted, that they could not change the result when they encountered problems and that they tried to comfort themselves by praying.

As can be seen, these research findings are similar to previous research results on the subject. The reaction against the disease and the strategies used by individuals are important factors to be taken into consideration in order to increase the patient's health and quality of life. Understanding coping methods will ensure that the healthcare professionals provide adequate support to prevent patients' pessimism and discouraging attitudes in living with the disease (Silva, et al. 2016: 147-154). When this result regarding coping methods is associated with the findings of depression and despair we have obtained, it confirms that there is a need for nurses to direct patients to develop a positive coping strategy.

When the opinions of patients about RTx are examined; two main themes and 8 sub-themes were obtained. Sub-themes of the main theme of "Fear" are fear of death, failure in the transplanted kidney/returning to dialysis, limited life experience after transplantation, cancellation of transplantation, fear of damage in the donor; sub-themes of the main theme of "The Meaning of Organ Transplantation for the Individual" were identified as quality living, freedom/elimination of obstacles, and hope (Table 3).

Although transplantation is seen as salvation, it is ultimately a surgical procedure and involves various risks. In the preoperative period, it is common for patients to experience anxiety associated with surgery and after. In a qualitative study conducted by Amerena and Wallace (2009), patients were concerned about the effects of cancellation of the transplantation, death, disability, organ rejection and immunosuppressive drugs before transplantation; similarly, in the study of Crawford, et al. (2017:1205), patients were reported to be afraid of rejection. In this study, it was found that the participants were afraid of death related to the planned transplant, similar to the previous studies, afraid of returning to dialysis as a result of the kidney not working after the transplant, life will be limited after transplant, cancellation of the transplantation for any reason and damage in the donor after the transplantation. In addition to the fact that organ transplantation frees patients from various limitations, the result obtained regarding the sense of uncertainty and fears in patients in terms of surgical risks and a new life experience can be considered as an expected and ordinary situation. Nurses' encouraging patients to express their fears and ask questions during the preparation for transplantation may facilitate compliance with the surgical intervention and thus increase the success rate.

In the success of the transplant, what the patient expects from the operation is as important as the management of the treatment and care process. In one study, patients thought that after transplantation they would be good again and their lives would return to some sort of normality; however, it was observed that these expectations of the patients were not realistic after the surgery (Crawford, et al. 2017: 1204-1207). In another study, it was found that the expectations of healthcare providers from transplantation and patients who received RTx were significantly different. In the same study, patients anticipated their transplants to last longer and to live longer than expected (average 80-71 years of age) for typical patients (Maass, et al. 2019: 990-997). In this study, it can be interpreted as the usual result that all participants express that organ transplantation means a more qualified life, that the participants hope that their quality of life will increase after a successful organ transplant and see the transplant as salvation. Being aware of the expectations of the patients who are in the waiting period or who are preparing for the transplant, and supporting them to have realistic expectations are important components in increasing the adaptation to the new life after the operation and the success of the transplant.

Being on the RTx waiting list can be seen by patients as a road to normality and an escape from the dialysis program (Crawford, et al. 2017: 1204-1207). In the research of Sağduyu et al. (2006), 40.0% of the patients who received dialysis treatment stated the reason for requesting transplant as "getting rid of dependence to dialysis". In Moran et al. (2010)'s study, the following statement is made by a patient; "*I see life as on hold until transplantation. Because you can't do anything you want to do. Dialysis dominates your working condition and your normal routine. It is like being dependent on dialysis and you will get rid of handcuffs when transplantation is made*". In this study, it

was determined that kidney transplantation means freedom/non-obstruction for the participants. While RTx means getting rid of dialysis, it also brings different difficulties. Before the transplantation decision is made, the patient should be explicitly talked about what awaits them after the transfer and, when appropriate, they can be brought together with their peers who have positive experiences for experience sharing.

Conclusion

It is known that the process of waiting for transplantation is a long and uncertain process, and the psychosocial lives of patients are negatively affected by ESRD. In this research, the participants used various emotional methods of coping, where they experienced different losses in their lives, they felt depressed, they felt despair and uncertainty about the future, they were stigmatized due to the disease, and that they considered themselves different from the society, their self-esteem and body images were negatively affected by the disease, it was found that were distrustful towards healthcare professionals, they experienced fear of death related to the planned transplant, fear of returning to dialysis as a result of a non-functioning kidney after the transplant, that their lives would be limited, the transplant could be canceled for any reason and that the donor could be damaged after the transplant.

With a multidisciplinary approach in end-stage renal failure, supporting patients to adapt to the disease by being aware of their needs during the indefinite waiting period, providing patients with realistic expectations for transplantation, and applying treatment and care on the basis of their individual needs, is of vital importance for patients trying to cope with a physical/psychosocial problem of different qualities and dimensions. It is thought that the results obtained from this research will form the basis and guide in this direction.

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