Original Article

Investigation of the Emotional States and Future Plans of the Families of the Patients Waiting for a Kidney Transplant

Ayse Aydin, MSN
Assistant Professor in the Nursing Faculty Ataturk University, Erzurum, Turkey

Seher Erguney, MSN, RN
Associate Professor Erzurum, Turkey

Correspondence: Ayse Aydin, Contact address: Ataturk University Nursing Faculty Erzurum,Turkey Email: aysea@atauni.edu.tr

Abstract

Aim: This study was conducted descriptively, with the aim of investigating the emotional states and future plans of the families of the patients waiting for a kidney transplant.
Material and Method: Research data were collected between February 1, 2010 and May 31, 2013 in Ataturk University Yakutiye Research Hospital Dialysis Unit, Nephrology Clinic, Regional Training and Research Hospital Dialysis Unit and Serhat Private Dialysis Unit, subordinate to the Health Ministry, located in the Province of Erzurum, Turkey. The study population consisted of 154 patients that fit the research criteria. Data were obtained using "Questionnaire", "Future Plans Question Form" and "Level of Expressed Emotion Scale (LEE)". Percentage distribution and averages, t-test, Kruskal-Wallis, Mann Whitney U tests and Chi-square test were used in the data interpretations.
Results: The total LEE scale score of patients was found as 16.24±11.48. It was observed that the highest mean score was 5.60±3.42 in emotional sub-scale, and the lowest mean score was 2.39±3.74 in attitudes towards the disease sub-scale. As the score taken from the LEE scale increases the level of expression of emotions also increases.
Conclusions: Looking at the comparison of the LEE scale total and subscale score averages with age, occupation, employment status, family type, the number of people living at home, and their organ donation statuses, the difference was found statistically significant ($p < 0.05$). Based on these results, it is recommended that the patients waiting for a kidney transplant should be supported and the study should be repeated with a larger study population.

Keywords: Family, emotional state, renal, transplantation, future plans, nursing

Introduction

Rapid advances in science and technology have allowed a reduction in disease-induced mortality rate, better treatment and care facilities, widespread use of products that contribute to a healthy life, and a healthier environment. Thus, as the life expectancy at birth has increased, the number of individuals with chronic diseases has also increased (Talas, 2012).

Chronic Renal Failure (CRF) is a difficult to cure chronic disease that deeply affects individuals' lives, and has severe physiological, psychological and socioeconomic consequences for individuals, families and communities (Talas, 2012). Chronic diseases limit both the physical or spiritual lives of the individual and relatives. Patients try to cope with the psychological pressures and difficulties they have faced while trying to continue their lives with a long-term illness (Gulseren, 2002).

Transplantation is a form of treatment of choice for an end-stage renal disease (ESRD). This is because, in successful renal transplantations, performed via either cadaveric or living donors, not partial, but all of the renal functions become functional, as in the dialysis treatment (Akpolat, et al. 2007; Ozdag 2004). The quality of life is higher due to both the active renal functions and

the elimination of physical and psychological challenges caused by continuous dialysis processes (Akpolat, et al. 2007). In 2010, the ESRD point prevalence, requiring renal replacement therapy in Turkey, was found as 853 per million population (pediatric patients were included in this number). The number of renal transplantation (RTx) in 2010 was reported as 1164 (Serdengecti, et al. 2010).

CRF is one of the most important diseases leading to restrictions on patients as well as on the patient's family. CRF affects a family life in emotional, behavioral, social, cognitive and physical aspects (Aydemir, et al. 2002). Living with a CRF patient causes difficulties such as tension, stress, anxiety, hopelessness, diminishing social relationships, as well as the financial difficulties in the family; and in terms of the patient, there may be a lack of social support in the chronic period that the family is not functional (Ozcan, Basturk & Aslan, 2000). This course varies depending on the gender, age and social position of the patient. This can cause unemployment for a working person, role change for the head of the family, interruptions in housework and supportive role for a mother, self-blame of the parents for a child patient, as well as more despair (Asan, 2007; Kara & Iscan, 2006).

Since the health problem is a chronic disease that requires long-term management, this condition starts to become more difficult for patients and families. Family members may be forced to assume the role of the patient, in addition to maintaining their usual role behaviors. Taking unusual additional roles, can cause irritability, stress, gastric ulcers, heart attacks, loss of appetite, sleep disorders sexual problems in the family members (Erden, 1994). In addition, the problems such as emotional atmosphere in the family, lack of authority, nutrition, care may weaken the family unity.

Crying, sharing their feelings with family members and families in a similar situation, seeing the positive side of events, praying, self-suggestion are among the positive strategies used by families to cope with stress. Self-blame or blaming others, increasing regressions by acting overly tolerant towards the patient, despair and anger are among the negative strategies used by families to cope with stress (Yılmaz, 1998).

If the patient is a child, there may be feelings of hopelessness and uncertain future, and the stress faced in the child care may cause lack of quality time allocated to both each other and other healthy children and may affect the marriage relationship. And this can also lead to envy, hostility, uncertainty, neglect, deprivation the feeling of staying in the background in the other children (Erden, 1994).

CRF can cause significant psychological problems in patients and their relatives (Micozkadıoglu, 2012). The difficulties and losses experienced by the patient may weaken the individual's coping resources over time, and cause various psychological problems (Kahraman, Cınar & Pınar, 2006). Depression and anxiety are seen in patients, and this affects the patient's family as well (Ozcurumez, Tanrıverdi & Zileli 2003; Erdem, et al. 2004; Kucuk, 2005; Salturk, 2006). In this context, the individual may experience depressive symptoms such as hopelessness, pessimism, helplessness, guilt, worthlessness, feel of inefficiency, lack of drive, loss of interest in life, thoughts of death, suicide (Micozkadıoglu, 2012).In the initial phase of the dialysis, it is observed that family members are overly concerned with the patient, and then they lose interest, and start not to call and ask friends and relatives. Studies performed on the spouses of the dialysis patients showed that the spouses are in aggression, as well as feeling responsible for being psychologically close to patients (Cimilli, 1997).Future plans are the targets put forward by an individual for the future. Although healthy people plan goals for the future, those with a chronic disease do plan for the future and consider themselves as hopeless for the future. The patients waiting for a kidney transplant cannot plan for the future, since they are getting a hemodialysis or peritoneal dialysis treatment, and in a long waiting period for transplantation, and these treatments cause emotional problems such as depression future uncertainty, hopelessness, feel of inefficiency, the idea of death, etc.. In order to improve the patient's positive expectations about the future, nurses direct the patient's thoughts towards the solvable problems and help to set goals for the next few days or weeks (Oz, 2004).

This study was conducted to investigate the familial emotional states and future plans of patients waiting for a kidney transplant.

Material and Method

This study was conducted descriptively, with the aim of investigating the familial emotional states and future plans of the patients waiting for a

kidney transplant. Research data were collected between February 1, 2010 and May 31, 2013 in Ataturk University Yakutiye Research Hospital Dialysis Unit, Nephrology Clinic, Regional Training and Research Hospital Dialysis Unit and Serhat Private Dialysis Unit, subordinate to the Health Ministry, located in the Province of Erzurum, Turkey. The study was conducted between September 20, 2009 and June 8, 2012. The study population consists of the 400 patients registered on the waiting list for a transplant, in Ataturk University Yakutiye Research Hospital Dialysis Unit and Nephrology Clinic, Regional Training and Research Hospital Dialysis Unit and Serhat Private Dialysis Unit.

No sampling was made in the study population, and 311 patients residing in the city center were included in the study, from the patients registered on the waiting list. The study was conducted with these patients that comply with research criteria, registered in the transplant list of the Ministry of Health, age over 18 years, literate, had no any psychiatric treatment, have communication abilities, easy to reach and accept the study on a voluntary basis. A total 164 patients were identified in this study population that meet these conditions, however 10 of these patients refused to contribute, and hence the study was carried out with 154 patients.

Variables of the Study

Independent Variables: Age, gender, marital status, occupational status, employment status, number of children, family type, number of people living at home, role in the family, organ donation status were among these variables.

Dependent Variable: These are the LEE Scale subscales, total score averages and the answers given to the questionnaire on the future plans.

Data Collection: In collecting the data "*Questionnaire*", "*Questionnaire Regarding the Future Plans*" and "*LEE Scale*" was utilized. Data collection instruments were applied by the researcher through 15 min. face-to-face interviews with each patient, registered in the kidney transplantation waiting list, and reading the forms to the patients after informing them about the research during the dialysis sessions every day in the dialysis centers, visited by the researcher.

Data Collection Instruments

Questionnaire: It was prepared by the researcher, using literature. It consists of a total of 16 questions on transplant-related characteristics and the socio-demographic characteristics of the patients (Ozsaker, 2002; Baktıroglu, 2010; Asan, 2007; Arat, 2006).

Questionnaire about the Future Plans (QAFP): In the study, the Questionnaire on the Future Plans consisting of 14 questions was developed by the researcher with the help of expert opinion and interviews with the patients, in addition to utilizing previous studies, to determine whether the patients waiting for a kidney transplant plan for the future (Erhan, 2005; Ada, 2013).

Level of Expressed Emotion (LEE Scale): LEE scale, which was developed in 1988 by Cole and Kazarian, is a 60-item scale. The reliability and validity study of the scale in Turkey was performed by Berk et al. in 1993. The internal consistency coefficient was 0.93 (by the Kuder-Richardson formula 20), and the test-retest reliability was 0.84 (Cole & Kazarian, 1988). In this study, the test-retest reliability of the scale was found as 0.83.

Evaluation of Data: Percentage distribution and averages, t-test, Kruskal-Wallis, Mann Whitney U tests and Chi-square test were used in the data interpretations.

Ethical Principles of the Study: The study was adhered to the Helsinki Declaration of Human Rights, since the use of human subjects in studies requires protection of individual rights. Before starting the study, written consent was obtained from hospitals and private dialysis center to be studied, and an approval was obtained by the Erzurum Provincial Directorate of Health, Directorate of Clinical Researches Ethics Committee. In order to protect the rights of the patients participated in the study based on the ethical principles, the aim of the study was explained to the patients to fulfill the "*informed consent*" principle before starting to collect study data, the "*Privacy and Protection of Privacy*" principle was met by stating that the information obtained will be kept confidential, and the principle of "*Respect for Autonomy*" was fulfilled by making the study on a voluntary basis. In addition, oral consent was taken from the patients before starting to collect data.

Results

The mean total scores of the patients in the LEE scale were shown as 16.24±11.48 in Table 1. It was observed that the highest mean score was

5.60±3.42 in emotional sub-scale, and the lowest mean score was 2.39±3.74 in attitudes towards the disease sub-scale.

Looking at the distribution of the descriptive characteristics of patients included in the study population (Table 2), it was found that 53.9% of the patients were male in the 40-60 age group, and 89% of them were married. 29.9% of the males were retired, 45.5% of the females were housewives and 96.8% were unemployed.

The difference between emotional reactions, attitudes towards the disease, tolerance-expectation and LEE scale total score averages of patients was found statistically significant according to age groups ($p < 0.05$). It was determined in the further analysis that the patients in the 61-81 age group has a higher emotional reaction, attitude toward disease, tolerance-expectations and LEE scale total score averages, compared to other age groups.

The difference between the tolerance-expectation score averages was statistically significant, according to the professional status of the patients ($p<0.05$). The tolerance-expectation score average of students was higher than the averages in other professions.

The difference between emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant, according to employment status of patients ($p<0.05$). The emotional reaction, tolerance-expectation and LEE scale total score averages of unemployed patients was found to be higher than the averages of the employed patients.

The difference between attitudes towards the disease, tolerance-expectation and LEE scale total score averages of patients was found statistically significant according to family type ($p < 0.05$). It was determined that attitude toward disease, tolerance-expectations and LEE scale total score averages was higher in extended family structures than the nuclear family structure.

The difference between emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant, according to the number of people that live in patients' houses ($p<0.05$).

The difference between patients' gender, marital status, number of children, place of residence, educational status, family status, income, social security status and LEE scale total and subscale mean scores was found statistically insignificant ($p>0.05$).

Looking at the transplant-related characteristics of the patients waiting for a kidney transplant (Table 3), it was determined that 43.5% of them were waiting for more than 3 years, 85.1% wanted to donate their organs if they could, and 60.4% were hoping to have a transplant.

The difference between intrusiveness, emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant, according to the donation status of patients' their own organs ($p<0.05$). The intrusiveness, emotional reaction, tolerance-expectation and LEE Scale total score averages of the patients that don't want to donate their organs was higher than the averages of the patients that want to donate their organs.

The difference between LEE scale total score and sub-scale averages was not statistically significant, according to the transplant waiting time and transplantation expectation of patients ($p>0.05$).

Looking at the future plans of the patients in Table 4, it was determined that 44.8% of them have health-related plans, 23.4% have family-related plans, 10.4% percent have business and social life related plans and 21.4% have no plan at all.

In Table 5, the answers given to future plans were compared according to the certain descriptive characteristics of patients. No relationship was found between age groups and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney", "reduction of expectations in life due to kidney disease", "concern/ anxiety status regarding the meeting future care needs" and "the fear of living economically dependent to someone in future" ($p> 0.05$).

There was a relation between gender and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney", "concern/ anxiety status regarding the meeting future care needs" and "the fear of living economically dependent to someone in future" ($p < 0.05$). There are dependencies between marital status and the variable of "reduction in expectations in life due to kidney disease" ($p<0.05$).

Table 1. Mean Scores Taken by the Patients in the LEE Scale

LEE Scale Subscales	The Lowest and Highest Scores of the Scale	The Lowest and Highest Scores taken in the Scale	X±SD
Intrusiveness 0-15		0-11	4.42±2.51
Emotional Reaction	0-15	0-14	5.60±3.42
Attitude Towards the Disease	0-15	0-15	2.39±3.74
Tolerance-Expectation	0-15	0-13	3.81±3.46
TOTAL	**0-60**	**0-48**	**16.24±11.48**

Table 2. Comparison of LEE Scale sub-scale mean scores and Mean Total Scores According to the Descriptive Characteristics of Patients

Descriptive Characteristics	n	%	Intrusiveness X±SD	Emotional Reaction X±SD	Attitude Towards the Disease X±SD	Tolerance-Expectation X±SD	LEE Scale Total Score X±SD
Age							
19-39	29	18.8	4.13±2.66	4.65±3.26	2.06±3.32	2.79±3.27	13.65±11.05
40-60	83	53.9	4.36±2.36	5.33±3.27	1.72±3.23	3.34±3.10	14.77±10.10
61-81	42	27.3	4.76±2.71	6.78±3.57	3.95±4.51	5.42±3.79	20.92±13.13
Test &			KW=0.752	KW=6.925	KW=13.630	KW=12.641	KW=9.254
p value			p=0.687	**p=0.031**	**p=0.001**	**p=0.002**	**p=0.010**
Gender							
Female	71	46.1	4.60±2.57	5.83±3.62	2.70±4.29	4.25±3.57	17.39±12.34
Male	83	53.9	4.27±2.46	5.40±3.25	2.13±3.20	3.43±3.35	15.25±10.66
Test &			t=0.808	t=0.760	t=0.944	t=1.467	t=1.155
p value			p=0.420	p=0.448	p=0.347	p=0.144	p=0.250
Marital status							
Married	137	89.0	4.45±2.57	5.73±3.46	2.45±3.80	3.99±3.53	16.64±11.71
Single	17	11.0	4.17±2.00	4.52±2.96	1.88±3.29	2.35±2.57	12.94±8.96
Test &			t=0.437	t=1.376	t=0.599	t=1.853	t=1.258
p value			p=0.662	p=0.171	p=0.550	p=0.066	p=0.210
Number of children							
0 child	25	16.2	4.44±2.21	5.00±2.90	2.24±3.75	2.96±3.22	14.64±10.71
1-4 children	76	49.4	4.30±2.44	5.23±3.42	2.22±3.67	3.48±3.39	15.25±11.30
5-8 children	45	29.2	4.73±2.87	6.53±3.77	2.82±4.04	4.73±3.65	18.82±12.59
9-12 children	8	5.2	3.87±1.95	5.75±1.98	2.12±2.94	4.37±3.20	16.12±7.64
Test &			KW=1.031	KW=5.118	KW=2.022	KW=6.063	KW=3.785
p value			p=0.794	p=0.163	p=0.568	p=0.109	p=0.286

Residential place							
Village	14	9.1	4.50±2.90	7.07±3.89	2.50±3.15	4.71±2.86	18.78±10.37
District	21	13.6	4.52±2.89	5.38±4.17	4.23±5.01	5.04±4.56	19.19±15.22
City center	119	77.3	4.40±2.41	5.47±3.20	2.05±3.47	3.48±3.26	15.42±10.80
Test &			KW=0.115	KW=3.793	KW=5.241	KW=3.792	KW=2.675
p value			p=0.944	p=0.150	p=0.073	p=0.150	p=0.263
Education status							
Illiterate	37	24.0	4.89±2.33	5.97±3.14	2.43±4.13	4.43±3.46	17.72±11.09
Literate	74	48.1	4.45±2.53	5.98±3.56	2.75±3.86	4.13±3.55	17.33±11.86
Primary School	20	13.0	3.85±2.99	4.65±3.74	2.10±3.71	2.90±3.12	13.50±12.15
High School	14	9.1	4.35±2.27	5.14±2.79	1.28±1.85	2.71±2.99	13.50±8.51
College/Postgraduate	9	5.8	3.66±2.34	3.77±2.99	1.66±3.53	2.33±3.67	11.44±11.60
Test &			KW=3.045	KW=5.826	KW=3.593	KW=7.468	KW=5.592
p value			p=0.550	p=0.213	p=0.464	p=0.113	p=0.232
Occupation							
Student	3	1.9	4.66±2.51	5.33±4.16	5.33±5.50	4.66±4.61	20.00±15.87
Officer	3	1.9	2.66±3.05	1.00±1.00	0.33±0.57	0.00±0.00	4.00±4.00
Self-employed	32	20.8	3.78±2.13	5.03±3.28	1.65±2.00	2.81±3.20	13.28±9.18
Retired	46	29.9	4.67±2.58	5.76±3.09	2.41±3.69	3.91±3.33	16.76±11.06
Housewife	70	45.5	4.62±2.59	5.97±3.61	2.68±4.30	4.32±3.57	17.61±12.39
Test &			KW=4.672	KW=7.565	KW=2.383	KW=10.408	KW=7.384
p value			p=0.323	p=0.109	p=0.666	**p=0.034**	p=0.117
Employment status							
Employed	5	3.2	2.80±1.78	2.60±1.14	0.60±0.89	0.80±1.30	6.80±2.77
Unemployed	149	96.8	4.48±2.51	5.70±3.42	2.45±3.78	3.91±3.47	16.55±11.53
Test &			MWU=211.50	MWU=163.00	MWU=277.50	MWU=157.50	MWU=166.50
p value			p=0.098	**p=0.032**	p=0.310	**p=0.027**	**p=0.036**
Family type							
Core	125	81.2	4.28±2.50	5.53±3.47	1.97±3.37	3.57±3.45	15.36±11.24
Large	29	18.8	5.06±2.47	5.89±3.24	4.20±4.68	4.82±3.40	20.00±11.91
Test &			MWU=1477.50	MWU=1685.00	MWU=1188.00	MWU=1396.00	MWU=1394.50
p value			p=0.119	p=0.554	**p=0.002**	**p=0.052**	**p=0.053**
Number of people living at home							
1-4	80	51.9	4.00±2.35	4.83±3.27	1.71±2.93	3.25±3.38	13.80±10.44
5-8	66	42.9	4.95±2.63	6.56±3.47	3.27±4.56	4.66±3.58	19.45±12.43
9-12	8	5.2	4.37±2.44	5.37±2.82	2.00±1.85	2.37±1.40	14.12±6.57
Test &			KW=5.442	KW=9.686	KW=3.253	KW=7.464	KW=9.206
p value			p=0.066	**p=0.008**	p=0.197	**p=0.024**	**p=0.010**
Role in the family							

Mother							
Father	52	33.8	4.67±2.66	6.25±3.77	3.19±4.68	4.75±3.74	18.86±13.27
Child	64	41.6	4.26±2.57	5.40±3.41	2.12±3.10	3.43±3.42	15.23±10.73
Other (daughter in	13	8.4	4.38±1.93	4.76±3.32	2.53±3.57	2.76±2.83	14.46±9.74
law, spouse, etc.)	25	16.2	4.36±2.39	5.20±2.59	1.36±2.88	3.36±2.99	14.28±9.62
Test &			KW=0.482	KW=2.429	KW=3.190	KW=5.342	KW=2.708
p value			p=0.923	p=0.488	p=0.363	p=0.148	p=0.439
Income level							
Income is lower than							
expenses	36	23.4	4.30±2.70	6.11±3.67	2.72±4.25	4.00±3.58	17.13±12.60
Balanced	112	72.7	4.51±2.40	5.53±3.24	2.29±3.51	3.81±3.35	16.16±10.75
Income is higher	6	3.9	3.50±3.56	3.83±4.95	2.33±5.24	2.66±5.20	12.33±18.11
than expenses							
Test &			KW=1.083	KW=2.930	KW=0.916	KW=2.470	KW=2.562
p value			p=0.582	p=0.231	p=0.633	p=0.291	p=0.278
Has a social							
security							
Yes	146	94.8	4.42±2.51	5.56±3.44	2.46±3.81	3.76±3.50	16.21±11.67
No	8	5.2	4.50±2.67	6.37±3.02	1.12±1.72	4.75±2.76	16.75±7.51
Test &			MWU=571.50	MWU=483.50	MWU=501.50	MWU=448.00	MWU=504.00
p value			p=0.918	p=0.411	p=0.481	p=0.264	p=0.515

Table 3. The comparison of LEE Scale Sub-Scales and Total Score Averages of the Patients Waiting for a Kidney Transplant According to Transplant Related Characteristics

Transplant Related Characteristics	n	%	Intrusiveness X±SD	Emotional Reaction X±SD	Attitude Towards the Disease X±SD	Tolerance-Expectation X±SD	LEE Scale Total Score X±SD
Transplant waiting time							
0-11 months	24	15.6	5.12±2.19	6.58±3.14	2.75±3.87	4.70±3.18	19.16±10.56
1-3 years	63	40.9	4.33±2.71	5.65±3.62	2.82±4.04	3.95±3.73	16.76±12.80
3 years and above	67	43.5	4.26±2.40	5.20±3.29	1.86±3.37	3.35±3.28	14.70±10.33
Test & p value			KW=2.314 p=0.314	KW=3.265 p=0.195	KW=3.387 p=0.184	KW=3.890 p=0.143	KW=3.671 p=0.160
Has Donated Organs							
Yes	131	85.1	4.21±2.53	5.23±3.36	2.19±3.61	3.46±3.29	15.11±11.11
No	23	14.9	5.65±2.03	7.69±3.06	3.52±4.30	5.78±3.86	22.65±11.67
Test & p value			MWU=1010.00 **p=0.011**	MWU=899.50 **p=0.002**	MWU=1257.50 p=0.186	MWU=970.50 **p=0.006**	MWU=895.00 **p=0.002**
Transplant Expectation							
Hopeful	93	60.4	4.45±2.57	5.43±3.56	2.35±3.66	3.73±3.54	15.96±11.76
Hopeless	61	39.6	4.39±2.43	5.86±3.20	2.45±3.88	3.93±3.37	16.65±11.12
Test & p value			t=0.140 p=0.889	t=-0.777 p=0.43	t=-0.168 p=0.867	t=-0.355 p=0.723	t=-0.363 p=0.717

Table 4. Future Plans of the Patients

Plans	S	%
Health Related Plans		
Being healthy again	64	41.6
Drinking lots of water	5	3.2
Family Related Plans		
To have quality time with my children and family	27	17.6
To get married	6	3.9
To marry my children	3	1.9
Occupation and Social Life Related Plans		
To return to my old job	5	3.2
To ranch	3	1.9
To help people	4	2.6
To plant trees	1	0.8
Travel the world	3	1.9
I have no plans	33	21.4

Table 5. Comparison of the Future Plans According to the Certain Descriptive Characteristics of the Patients

Descriptive Characteristics	Afraid of not being able to find a proper kidney		Afraid of body's rejecting of the found kidney		Reduction in expectations in life due to kidney disease		Concerns/worries on meeting the future care need in the future		Afraid to live economically dependent on someone in the future	
	Yes S %	No S %	Yes S %	No S %	Yes S %	No S %	Yes S %	No S %	Yes S %	No S %
Age										
19-39	9 31.0	20 69.0	15 51.7	14 48.3	17 58.6	12 41.4	14 48.3	15 51.7	18 62.1	11 37.9
40-60	28 33.7	55 66.3	39 47.0	44 53.0	67 80.7	16 19.3	46 55.4	37 44.6	56 67.5	27 32.5
61-81	13 31.0	29 69.0	14 33.3	28 66.7	32 76.2	10 23.8	23 54.8	19 45.2	34 81.0	8 19.0
Test and p value	X^2=0.132	p=0.936	X^2=2.939	p=0.230	X^2=5.672	p=0.059	X^2=0.459	p=0.795	X^2=3.528	p=0.171
Gender										
Female	32 45.1	39 54.9	42 59.2	29 40.8	57 80.3	14 19.7	46 64.8	25 35.2	57 80.3	14 19.7
Male	18 21.7	65 78.3	26 31.3	57 68.7	59 71.1	24 28.9	37 44.6	46 55.4	51 61.4	32 38.6
Test and p value	X^2=9.543	**p=0.002**	X^2=12.019	**p=0.001**	X^2=1.742	p=0.187	X^2=6.290	**p=0.012**	X^2=6.481	**p=0.011**
Marital status										
Married	48 35.0	89 65.0	60 43.8	77 56.2	108 78.8	29 21.2	76 55.5	61 44.5	98 71.5	39 28.5
Single	2 11.8	15 88.2	8 47.1	9 52.9	8 47.1	9 52.9	7 41.2	10 58.8	10 58.8	7 41.2
Test and p value	X^2=3.735	p=0.053	X^2=0.065	p=0.798	X^2=8.214	**p=0.004**	X^2=1.244	p=0.265	X^2=1.166	p=0.280
Occupation										
Student	0 0.0	3 100.0	1 33.3	2 66.7	0 0.0	3 100.0	0 0.0	3 100.0	0 0.0	3 100.0
Officer	0 0.0	3 100.0	0 0.0	3 100.0	2 66.7	1 33.3	1 33.3	2 66.7	0 0.0	3 100.0
Self-employed	9 28.1	23 71.9	14 43.8	18 56.3	26 81.3	6 18.7	13 40.6	19 59.4	25 78.1	7 21.9
Retired	9 19.6	37 80.4	12 26.1	34 73.9	32 69.6	14 30.4	24 52.2	22 47.8	25 54.3	21 45.7
Housewife	32 45.7	38 54.3	41 58.6	29 41.4	56 80.0	14 20.0	45 64.3	25 35.	58 82.9	12 17.1
Test and p value	X^2=12.254	**p=0.016**	X^2=14.507	**p=0.006**	X^2=11.528	**p=0.021**	X^2=9.381	p=0.0527	X^2=25.946	**p=0.000**
Role in the family										
Mother	23 44.2	29 55.8	28 53.8	24 46.2	43 82.7	9 17.3	34 65.4	18 34.6	42 80.8	10 19.2
Father	15 23.4	49 76.6	20 31.3	44 68.7	46 71.9	18 28.1	29 45.3	35 54.7	39 60.9	25 39.1
Child	1 7.7	12 92.3	5 38.5	8 61.5	7 53.8	6 46.2	5 38.5	8 61.5	8 61.5	5 38.5
Other (daughter in law, spouse, etc.)	11 44.0	14 56.0	15 60.0	10 40.0	20 80.0	5 20.0	15 60.0	10 40.0	19 76.0	6 24.0
Test and p value	X^2=10.818	**p=0.013**	X^2=9.019	**p=0.029**	X^2=5.449	p=0.142	X^2=6.281	p=0.099	X^2=6.261	p=0.100
Income level										
Income is lower than expenses	14 38.9	22 61.1	22 61.1	14 38.9	26 72.2	10 27.8	21 58.3	15 41.7	32 88.9	4 11.1
Balanced	36 32.1	76 67.9	45 40.2	67 59.8	87 77.7	25 22.3	61 54.5	51 45.5	75 67.0	37 33.0
Income is higher than expenses	0 0.0	6 100.0	1 16.7	5 83.3	3 50.0	3 50.0	1 16.7	5 83.3	1 16.7	5 83.3
Test and p value	X^2=3.567	p=0.168	X^2=6.754	**p=0.034**	X^2=2.591	p=0.274	X^2=3.647	p=0.161	X^2=14.770	**p=0.001**

There is a relation between occupations and the variables of "fear of not being able to find proper kidney", "fear of body's rejecting of the found kidney", "reduction of expectations in life due to kidney disease" and "the fear of living economically dependent to someone in future" ($p<0.05$).

There is a relation between the role in the family and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney" ($p<0.05$). And there was a relation between income status and the variables of "fear of not being able to find proper kidney" and "the fear of living economically dependent to someone in future" ($p <0.05$).

Discussion

In this study, future plans and emotional states in a family of the patients waiting for a kidney transplant were investigated and the findings were discussed in accordance with the literature.

Patients' LEE scale score average was 16.24±11.48. Perceived level of expressed emotion increases as the scores increase. LEE scale score averages of the patients was 15.4±9.7 in Arat's study (Arat, 2006). This finding is in line with the findings of Arat.

The difference between emotional reactions, attitudes towards the disease, tolerance-expectation and LEE scale total score averages of patients was found statistically significant, according to age groups, when the LEE scale total score and subscale mean scores were compared according to the descriptive characteristics of patients. It was determined that the patients in the 61-81 age group has a higher emotional reaction, attitude toward disease, tolerance-expectations and LEE scale total score averages, compared to other age groups. Accordingly, it can be said that patients have increased levels of perceived emotion expression, have negative emotional responses and have decreased tolerance-expectations as the age advances. And this is consistent with the results stating that the family members lose their interest to the patient after an initial period of intimate care at the beginning of dialysis (Cimilli, 1997).

The difference between the tolerance-expectation score averages was statistically significant, according to the professional status of the patients. The tolerance-expectation score average of students was higher than the averages in other professions. Young patients can perceive the attitudes and reactions of their relatives as intolerant and negative. Beliefs such as "diseases are related to advanced age" affect patients' responses and coping manners, as well as making adaptation to the disease difficult (Kocaman, 2008). Humankind assumes or desires to assume that there is a chronological order for death, illness and such. And the patient compares his/her age with the others' (mother, father, brother/sister, etc.) ages and may develop thoughts such as "why he/she is not sick and I'm sick?". In this case, they somehow express their suppressed emotions (Arat, 2006). Therefore, the tolerance-expectations score may be increased because of the denial of disease by the individuals that have a chronic disease at a young age.

The difference between emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant according to employment status of patients. The emotional reaction, tolerance-expectation and LEE scale total score averages of unemployed patients was found to be higher than the averages of the employed patients. Patients cannot perform their everyday functions as before due to the dialysis treatment. The work efficiency decreases depending on the physical losses and mental problems (depression, anxiety, feelings of worthlessness, etc.) in patients (Kumbasar, 2005). Loss of jobs and loss of labor force, as well as the treatment costs and obligation to live in big cities that have dialysis centers also leads to economic burden in the family (Cimilli, 1997). Krespi, et al. (2008) have stated that dialysis patients feel a loss of power, they cannot perform the thing that they are capable of before, they are forced to rest frequently and become tired in a short time. The loss of labor force may have raised their emotional expressiveness of the patients.

It was determined that attitude toward disease, tolerance-expectations and LEE scale total score averages were higher in extended family structures than the nuclear family structure, when the LEE scale total score and subscale mean scores were compared according to family types of patients. The difference between emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant, when the LEE scale total score and subscale mean scores were compared according to the number of people that live in patients' houses.

The changes occurring in the life of one family member inevitably affect the lives of other family members as well, if we consider a family as a system. In this context, it can be stated that not the individuals, but the families have a chronic disease. A family member that has a chronic disease becomes dependent to other family members (Mutlu, 2007). This dependence that also occurs in dialysis patients may be the cause of the statistical significance observed in the study.

The difference between patients' gender, marital status, number of children, place of residence, educational status, family status, income, social security status and LEE scale total and subscale mean scores was not found statistically significant. These findings have similarities with the findings of Arat's study (Arat, 2006).

The difference between intrusiveness, emotional reaction, tolerance-expectation and LEE scale total score averages was statistically significant, according to donation status of their organs, when the LEE scale total score and subscale mean scores were compared according to the transplant-related characteristics of the patients. The intrusiveness, emotional reaction, tolerance-expectation and LEE Scale total score averages of the patients that don't want to donate their organs was higher than the averages of the patients that want to donate their organs. One of the reasons that prevent people from donating organs is their psychologies (Parlak, 2009). It is frequently observed that family members give up donating their kidneys, despite the initial willingness (Cimilli, 1997). This adversely affects the psychology of patients waiting for an organ transplant, and can cause to consider their organs more valuable.

Looking at the future plans of the patients, it was determined that 44.8% of them have health-related plans, 23.4% have family-related plans, 10.4% percent have business and social life related plans and 21.4% have no any plans. In a study conducted by Mutlu (2007) on the expectations of hemodialysis patients for the future, the expectations on having an organ transplant was at the first place by 62.5%, and this followed by family-related expectations by 39.3%, expectations on employment by 14.3%, and marriage related expectations by 7.1% respectively.

No relationship was found between age groups and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney", "reduction of expectations in life due to kidney disease", "concern/ anxiety status regarding the meeting future care needs" and "the fear of living economically dependent to someone in future". In a study conducted by Gok, et al. (2009) to determine the level of despair of the hemodialysis patients, it was found that the level of hopelessness of the patients over 46 years age was higher than the patients from age 17 to 45. The suggested reason for the high level of hopelessness of patients in the older age group was the thinking about death more at advanced ages, and the thinking that the emergence of chronic diseases at these advanced ages complicates the treatment process. Okanli, et al. (2008) have found no relationship between the level of despair and education level and age groups of the hemodialysis patients in their study. These findings support the study findings.

There is a relation between gender and the variable of "fear of not being able to find proper kidney". It was found that females are afraid of not finding a proper kidney more than males. There was a relation between gender and the variables of "fear of body's rejection of the found kidney", "concern/ anxiety status regarding the meeting future care needs" and "the fear of living economically dependent to someone in future". Females are more concerned for the future of their children and spouses, since they have more responsibilities in a family. Therefore, they are afraid of not being able to find a proper kidney.

There are dependencies between marital status and the variable of "reduction in expectations in life due to kidney disease". It was found in married patients that suffering from kidney disease reduces their life expectancies. Family and marriage stress is evident among patients with organ failure. Spouses of patients are forced to change role and become a nurse or caregiver (Ozcurumez, Tanrıverdi & Zileli, 2003). In addition to the change of roles within the family, the major cause of the negative feelings developed by the spouses of the dialysis patients is the loss of sexual function of patients (Arat, 2006). Dialysis patients who suffered a loss of sexual function are not able to fulfill their responsibilities to their spouses. Therefore, being unable to fulfill the responsibilities due to disease can reduce the expectations of married patients in life.

There is a relation between occupations and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney", "reduction of expectations in life due to kidney disease" and "the fear of living economically dependent to someone in future". ESRD disease significantly affects a person's professional life (Mutlu, 2007). It can be said that the loss of labor force occurred in patients due to various reasons negatively affects their professional lives, their economic status and future plans on occupation accordingly.

There is a relation between the role in the family and the variables of "fear of not being able to find proper kidney", "fear of the body's rejecting of the found kidney". If there is a patient with organ failure in a family, changes in roles of family members and interaction between family members occur (Mutlu, 2007). Long-term dialysis treatment increases the patient's dependency, and causes a decrease in physical abilities, as well as decrease in quality of life of the patients and causes changes in roles within their families (Unal, Bilge, 2005)

And there was a relation between income status and the variables of "fear of not being able to find proper kidney" and "the fear of living economically dependent to someone in future". Patients with low income are afraid to live economically dependent on someone in the future. Individuals that have a lower income are unable to plan for the future for themselves and their children. Family income level is an important factor affecting the level of despair (Erhan, 2005). In a study by Gok, et al. (2009), it was found that the level of despair in patients with negatively-imbalanced incomes was higher than others. Economic dependence and difficulties in coping with the family responsibilities lead to pessimism and despair in patients and affect their life perspectives (Erdem, et al. 2004).

The patients waiting for a kidney transplant exhibit a negative emotional expression against the family members since they receive an inadequate support from their families. And since the loss of labor force in patients affect their working lives they are afraid of being economically dependent in the future.

Conslusion: As the score taken from LEE scale increases, the level of revealing emotion scale also increases. When score averages of LEE scale total and subdimension were compared in terms of age, profession, working situation, type of family, the number of people living at home and their wish to donate their organs, it was found out that the distinction between them was statistically significant ($p<0.05$). In accordance with these results, it is suggested that the patients who are waiting for a renal transplantation should be supported and that the research should be repeated in a greater study group.

Based on the study findings, these recommendations can be made:

- Since the level of expressed emotion perceived by patients waiting for a kidney transplant is increased, the family members can be directed to be involved in care at home, as well as care at the health center.
- Informative meetings can be organized on the patient reactions that occurred as a result of chronic diseases, in order prevent patients' attitudes and behaviors to some extent, and relatives of patients can be informed regarding the patients' reactions are not personal.
- Activities such as supportive psychotherapies, meetings with other patients waiting for a kidney transplant or with the patients that have kidney transplants, and group activities, in order to increase the prospects of patients for the future.
- Similar studies can be repeated by working in larger samples.
- The validity and reliability tests of the Questionnaire on Future Plans can be performed in a scaled form by studying with a larger sample and extending the questions.

Limitations of the Study: The study is limited to the patients that can be reached, since the study population consists of the patients registered in the transplant list of the Ministry of Health, the Ministry of Health. The small sample size is the only limitation of the study.

Acknowledgements: We greatfull for our participants.

References

Ada S. (2013). Expert Opinion. Educational Administration, Supervision, Planning and Economy Department. Kazım Karabekir University, Education Faculty.

Akpolat T., Utas C., Suleymanlar G. & Erek E. (2007). *Nephrology Handbook*, 4th Edition. Istanbul: Nobel Medicine Bookstores 300-337.

Arat Z. (2006). Burnout Syndrome in Hemodialysis Patients and Their Relatives, Evaluation of the Quality of Life of the Relatives of the Patients and the Affecting Factors. Institute of Health Sciences, Master's Thesis. Ankara: Baskent University.

Asan T. (2007). Assessment of the Families of Patients Diagnosed with Chronic Renal Failure. Health Sciences Institute, Department of Surgical Nursing. Master Thesis. Istanbul: Halic University.

Asan T. (2007). Assessment of the Families of Patients Diagnosed with Chronic Renal Failure. Institute of Health Sciences, Nursing Department. Master Thesis, Istanbul: Halic University.

Aydemir C., Kasım I., Cebeci S., Goka E. & Tuzer V. (2002). The quality of life and psychiatric symptoms of the relatives of patients with chronic renal failure. *Crisis Journal*, 10, 29-39.

Baktıroglu G. (2010). Comparison of Depression and Anxiety Levels of the Hemodialysis Patients and Non-Hemodialysis Patients With Chronic Renal Failure. Institute of Social Sciences, Department of Psychology, Master Thesis. Istanbul: Maltepe University.

Berksun O.E. (1993). Expressed emotion scale: A pilot study on the adaptation of the scale. *Turkish Journal of Psychology, 8,* 10-15.

Cimilli C. (1997). Psychiatric aspects of hemodialysis. *Turkish Nephrology, Dialysis and Transplantation Journal, 3,* 88-92.

Cole J.D. & Kazarian S.S. (1988). The level of expressed emotion scale: a new measure of expressed emotion. *Journal of Clinical Psychology, 44,* 392-397.

Erdem N., Karabulutlu E., Okanlı A. & Tan, M. (2004). Hopelessness and life satisfaction in hemodialysis patients. *Journal of Human Sciences,* ISSN:1303–5134.

Erden G. (1994). The Impact of Chronic Diseases.on Families. Sivas: Cumhuriyet University, Nursing Institute.

Erhan G.G. (2005). Investigation of Hopelessness, Pessimism, Social Support Perceptions and Future Plans of the Mothers with Mentally Retarded Children. Institute of Education Sciences, Department of Special Education, Master Thesis, Ankara: Ankara University.

Gok O.F., Tascı B.K.D., Cengiz S. & Kiper, S. (2009). Hopelessness levels of hemodialysis patients. *Fırat Health Services Journal, 4,* 123-136.

Gulseren L. (2002). Schizophrenia and the family: challenges, burdens, feelings, needs. *Turkish Journal of Psychiatry, 13,* 143–151.

Kahraman A., Cınar S. & Pınar R. (2006). Does the social support affect depression in hemodialysis patients? *Journal of Nephrology Nursing, 5,* 46-53.

Kara B. & Iscan, B. (2006). Stressors perceiveby nurses in hemodialysis patients. *Journal of Nephrology Nursing,* 57-65.

Kocaman N. (2008). Factors affecting the psychosocial responses of patients. *Ataturk University Nursing School Journal, 11,* 101-112.

Krespi M.R., Bone M., Ahmad R., Worthington B. & Salmon, P. (2008). Assessment of lives of the hemodialysis patients. *Turkish Journal of Psychiatry, 19,* 365-372.

Kumbasar H. (2005). Consultation-Liaison Psychiatry. Included in Ozkan S (ed.). Psychiatric Problems Encountered in Patients with Chronic Renal Failure and Approaches Applied. Istanbul.

Kucuk L. (2005). Frequent mental health problems in dialysis patients. *Turkish Nephrology, Dialysis and Transplantation Journal, 14,* 166–170.

Micozkadıoglu I. (2012). Living with chronic renal failure. http://www.psikolog.org.tr/Belgeler/brosurler/kronik-bobrek-yetmezligi-ile-yasamak . 20.03.2012.

Mutlu E. (2007). Socio-Demographic Characteristics of Hemodialysis Patients, Their Social Support Resources and the Impact of the Disease on Self-Esteem. Institute of Social Sciences, Social Services Department. Master Thesis. Ankara: Hacettepe University.

Okanlı A., Erdem N. & Yılmaz K.E. (2008). Control of emotions and factors affecting this control in hemodialysis patients. *Anatolian Journal of Psychiatry, 9,* 156-161.

Oz F. (2004). Basic Concepts in Health. Ankara: Imaj Ic ve Dıs Ticaret Inc.

Ozcan Y., Basturk M. & Aslan S.S. (2000). Psychiatric morbidity and quality of life in patients undergoing hemodialysis and continuous peritoneal dialysis. 36th National Congress of Psychiatry, Proceedings Book, 63.

Ozcurumez G., Tanrıverdi N. & Zileli L. (2003). Psychiatric and psychosocial aspects of chronic renal failure. *Turkish Journal of Psychiatry, 14,* 72–80.

Ozdag N. (2004). Perceptions of people regarding organ donation and transplantation. *Journal of Nephrology Nursing, 1,* 46-50.

Ozsaker E. (2002). Investigation of the Factors Affecting the Quality of Life of Patients and Relatives of the Patients with Renal Transplant. Health Sciences Institute, Department of Surgical Nursing. Master's Thesis. Izmir: Ege University.

Parlak S. (2009). Organ donation and the problems encountered in transplantation. *Turkey Bar Association Journal, 83,* 189-222.

Salturk D. (2006). The Relationship between Quality of Life and Dialysis Adequacy in Hemodialysis Patients. Republic of Turkey Ministry of Health, Istanbul Goztepe Training and Research Hospital, IIIrd Internal Medicine Clinic, Medical Specialization Thesis, Istanbul.

Serdengecti K., Suleymanlar G., Altıparmak M.R. & Seyahi N. (2010). Nephrology, dialysis and transplantation in Turkey. *Publication of Turkish Society of Nephrology*.

Talas S. (2012). Determination of the Challenges Experienced by the Patients with Renal Transplant. Health Sciences Institute, Department of Surgical Nursing. PhD Thesis. Ankara: Hacettepe University

Unal G. & Bilge, A. (2005). Assessment of mental status and quality of life of the end-stage renal failure patients that underwent hemodialysis treatment. *Ege Journal of Medicine*, *44*, 35-38.

Yılmaz M. (1998). Investigation of the Stress-Coping Strategies of the Spouses of Patients Diagnosed with Chronic Schizophrenia and Patients Diagnosed with Chronic Renal Failure. Health Sciences Institute, Department of Psychiatric Nursing. Master Thesis, Izmir: Ege University.