

Level of Daily Life Activities and Learning Needs in Renal Transplant Patients

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Abstract

Objectives: Transplantation affects the patient's psychological state and daily life activities. Although there are various studies regarding the quality of life of patients, there are limited studies on the daily life activities and learning needs of patients after renal transplant. Here, we investigated the daily life activities and learning needs of patients after renal transplant.

Materials and Methods: This descriptive and cross-sectional study was conducted on 120 renal transplant recipients. Data were collected using the "Patient Information Form," the "Nottingham Extended Activities of Daily Living Scale," and the "The Patient Learning Needs Scale." Data were evaluated with t test, analysis of variance, and Pearson correlation analyses. **Results:** In our patient group, the mean general health score was 6.8 ± 2.34 , and the fatigue score was 4.53 ± 2.88 . Although 66.7% of our patients reported that they had information about the drugs that they used, 58.3% could not answer questions regarding the most important adverse effects of their drugs. We found that 20% of the patients had a respiratory problem, 34.2% had sexual problems, and 26.7% had sleep problems. The average Nottingham Extended Activities of Daily Living Scale levels were lower in patients with only primary school education, patients who did not work, and patients with other illnesses. Learning needs of patients were as follows in order: quality of life, feelings related to the conditions, treatment, and complications.

Conclusions: Our study patients reported that their overall daily life activities and quality of life, given the

holistic approach to treatment and care, were good. However, when we examined each activity separately, our findings showed that patients lacked information regarding how to cope with stress, emotions, and the effects of renal transplant on their life.

Key words: Kidney transplantation, Nursing, Quality of life

Introduction

In addition to serious physiologic, psychologic, and socioeconomic implications for the individual, family, and community, end-stage renal disease (ESRD) has profound effects on a patient's life and is difficult to treat.^{1,2} Renal transplant is the best treatment option for patients with ESRD compared with dialysis. Renal transplant is less stressful and causes less life style restrictions.³⁻⁵ However, immunosuppressive drugs, which should be used continuously, may present adverse effects. Complications after renal transplant, including infection, organ rejection, weight gain, and side effects of immunosuppressive drugs (eg, hirsutism, cataract, neuropathy, and osteoporosis), may adversely affect the psychologic and social status of patients.^{1,5,6}

Illness affects a patient's level of daily life activity,^{7,8} including routine chores that normally healthy individuals can achieve without the need for assistance. Caregivers commonly note that functionality declines.⁹ As highlighted by Procópio and associates,¹⁰ the enhancement of daily activities in renal transplant recipients is vital. Renal transplant is a chronic condition, and patients are likely to face various difficulties, including stress, depression, fear of dying, and limited physical activity post-transplant. These potential difficulties may bring some burden to patients and their families. Thus, diagnosing the needs of patients is important to health and daily life of the patient.¹⁰

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After kidney transplant, patients require treatment and follow-up because they live with the risk of organ rejection and infection. A mutual collaboration between the patient and health care provider is significant to report any symptoms and signs correctly and on time.¹¹ The nurse's role is to facilitate a patient's return to health. Nurses are in the position to counsel patients and make recommendations to improve patient quality of life. Both health promotion and disease prevention could be easily applied to renal transplant recipients given that preventive care, patient education, and training are needed. Therefore, nurses play a key role in screening, support, and education at all stages of the renal transplant process. Training activities provided to patients after renal transplant are considered key for return of patients to normal daily life.^{1,12}

Transplantation affects the patient's psychologic state, quality of life, and daily life activities. Both quality of life and daily life activities are important variables to determining the general health status of the patient.⁴ Liu and associates found that physical and mental quality of life decreased as the side effects of immunosuppressive drugs increased.¹³ Alavi and colleagues found that the daily activity level of renal transplant recipients was better than patients who underwent hemodialysis.⁴ Because of the effects of transplant and because recipients are afraid of losing a new organ, patients may encounter several problems in daily life activities, especially in social life. These problems could be prevented by tailoring training programs to the needs of the patient. Training of patients can improve compliance with treatment and quality of life through control of side effects and complications.¹⁴ Many studies have examined the patient's perspective on life or quality of life after renal transplant.^{1,4,15} However, to our knowledge, few studies have addressed daily life activities and learning needs of renal transplant recipients. In this study, we investigated daily life activities and learning needs of renal transplant recipients in Turkey.

Materials and Methods

In this descriptive and cross-sectional study, we enrolled a convenience sample of renal transplant recipients from Turkey (from May 2016 to December 2016; n = 120). Patients who were willing to participate in this study were followed up in renal

transplant clinics. Patients who had inpatient treatment and patients who did not complete the questionnaires during the period of this study were excluded.

Data collection and instruments

Data were collected through 3 types of instruments: (1) the Patient Information Form, which was prepared by the authors of this research, (2) the Nottingham Extended Activities of Daily Living Scale (NEADLS), and (3) the Patient Learning Needs Scale.

Patient information form

There were 50 questions on sociodemographic and disease characteristics of the patients, as well as activities of daily living, which were prepared by the researchers of this study. In the present study, drawing on a 2000 study from Roper and associates, we developed a questionnaire that consisted of 12 daily life activities: maintaining a safe environment, communicating, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobilizing, working and playing, expressing sexuality, sleeping, and dying.^{7,8} The following aspects were assessed using a 10-cm visual analogue scale: general health status (0: very bad, 10: very good), pain (0: no pain, 10: severe pain), fatigue (0: never, 10: exhaustion), quality of sleeping (0: very bad, 10: very good), and fear of death (0: no fear, 10: a lot of fear).

The Nottingham extended activities of daily living scale

Validity and reliability assessments of the Turkish version of NEADLS had been previously conducted by Şahin and associates.¹⁶ The NEADLS has 4 subsections and includes 22 items: mobility (6 items), kitchen (5 items), domestic tasks (5 items), and leisure activities (6 items). Responses to all questions are evaluated as follows: not performed (0 points), with help (1 point), on my own with difficulty (2 points), and on my own easily (3 points). For each subsection total, and with the summation of all scores, the final total NEADLS scores are obtained, which can range from 0 to 66 points.¹⁶

The patient learning needs scale

The Patient Learning Needs Scale was developed by Bubela and colleagues in 1990, with the Turkish

version of the scale validated by Çatal and Dicle in 2008.^{17,18} The scale consists of 50 items and 7 sections. The 7 subscales are as follows: medications (8 items), activities of living (9 items), feelings related to the condition (5 items), community and follow-up (6 items), treatment and complications (9 items), enhancing the quality of life (8 items), and skin care (5 items). Scores gained from the scale range from 50 to 250. The Cronbach alpha was 0.93 for the 50-item scale.¹⁸

Surveys were collected from participants through a face-to-face meeting to clarify any questions that the participants may ask. Completing the survey took approximately 25 to 30 minutes.

Ethical approval

Ethical approval was obtained from the Clinical Research Ethical Committee, Faculty of Medicine, Uludag University (date: May 10, 2016; no. 2016-9/12). Written informed consent was collected from participants.

Statistical analyses

We used *t* tests, analysis of variance, and Pearson correlation analysis to analyze the data using the SPSS software (SPSS: An IBM Company, version 24.0, IBM Corporation, Armonk, NY, USA). *P* < .05 was considered significant.

Results

Sociodemographic characteristics of patients are shown in Table 1. Mean age of patients was 41.65 ± 10.65 years, mean duration of disease was 10.58 ± 6.26 years, and mean duration posttransplant was 4.59 ± 4.19 years. Of total patients, 50% had another chronic disease, including hypertension (*n* = 31), diabetes mellitus (*n* = 12), osteoporosis (*n* = 8), thyroid disease (*n* = 7), familial Mediterranean fever (*n* = 7), heart disease (*n* = 3), avascular necrosis (*n* = 3), and disc hernia (*n* = 3). The median number of medications used by patients was 5.65 ± 1.88 , and the mean general health score was 6.8 ± 2.34 . The patients with accompanying diseases had a higher number of drugs that they used and lower general health score (*P* < .05). The findings showed that there was a reverse correlation between general health score, age (*r* = -0.208; *P* = .023), and pain score (*r* = -0.200; *P* = .028).

Table 1. Sociodemographic Characteristics of Patients Along With the Nottingham Extended Activities of Daily Living Scale and the Patient Learning Needs Scale Scores

Parameter	Number of Patients (%)	NEADLS (mean ± SD)	PLNS (mean ± SD)
Sex			
Female	63 (52.5)	57.09 ± 8.72	2.46 ± 0.90
Male	57 (47.5)	54.92 ± 9.59	2.39 ± 0.86
<i>P</i> value		.198	.692
Educational status			
Primary school	55 (45.8)	52.87 ± 10.06	2.59 ± 0.80
Secondary school	18 (15.0)	59.44 ± 7.42	2.15 ± 0.63
High school	28 (23.3)	57.35 ± 8.35	2.40 ± 1.06
University	19 (15.9)	60.21 ± 5.70	2.24 ± 0.95
<i>P</i> value		.003	.215
Marital status			
Married	86 (71.7)	55.52 ± 9.13	2.43 ± 0.82
Single	34 (28.3)	57.44 ± 9.26	2.40 ± 1.02
<i>P</i> value		.304	.868
Place of residence			
Village	10 (8.4)	56.00 ± 9.20	2.73 ± 1.11
Town	43 (35.8)	54.04 ± 11.03	2.28 ± 0.85
City	67 (55.8)	57.37 ± 7.63	2.47 ± 0.88
<i>P</i> value		.179	.291
Economic status			
Good	18 (15.0)	59.66 ± 6.24	2.26 ± 0.50
Medium	91 (75.8)	55.78 ± 8.82	2.45 ± 0.95
Bad	11 (9.2)	52.54 ± 14.00	2.46 ± 0.76
<i>P</i> value		.106	.684
Working			
Yes	19 (15.8)	60.63 ± 4.87	2.10 ± 0.84
No	101 (84.2)	55.20 ± 9.54	2.49 ± 0.87
<i>P</i> value		.017	.076
History of other disease			
Yes	60 (50.0)	54.36 ± 9.52	2.40 ± 0.82
No	60 (50.0)	57.76 ± 8.55	2.45 ± 0.93
<i>P</i> value		.042	.768
Total	120 (100.0)	56.06 ± 9.17	2.43 ± 0.88

Abbreviations: NEADSL, Nottingham Extended Activities of Daily Living Scale; PLNS, Patient Learning Needs Scale; SD, standard deviation

Activities of daily life

Findings for activities of daily life are presented in Table 2. Although 66.7% of the patients reported that they had knowledge about the drugs that they used, 58.3% did not answer the question regarding the most important side effect of their drug. The findings showed that patients only knew the side effects that they experienced, which included infection, osteoporosis, weight gain, hirsutism, avascular necrosis, hair loss, dizziness, tremors, and allergies. A risk of infection was reported by 48.3% of patients. A number of patients reported pain (41.7%), with pain having a visual analogue scale score of 5.07 ± 1.92 . The findings showed that there was a negative correlation between patient pain score and fatigue and sleep scores.

One-fifth (20%) of patients had a respiratory problem, with half of these patients at a level that challenged daily activities. Body mass index was 26.06 ± 5.53 kg/m², 72.5% of patients had 3 meals per day, 12.5% had a nutritional problem, and 57.5% had

a weight change. Mean daily urinary frequency of patients was 7.41 ± 2.76 , and 8.3% had problems with urination. More than half of the patients (58.3%) defecated once per day, with 16.7% noting problems. With regard to cleanliness, 56.7% bathed 2 to 3 times per week, 50% brushed their teeth twice per day, and 39.2% practiced frequent hand washing; only 8 patients had problems with personal care. In 28.3% of the patients, sometimes body temperatures rose, with applications made in these cases, including taking a shower, going to a doctor, and wearing thinner clothes.

The average score for tiredness was 4.53 ± 2.88 . Of total patients, 65.8% reported practicing leisure activities, including walking ($n = 22$), crafts ($n = 20$), watching television ($n = 17$), and reading books ($n = 14$). Greater than one-third of patients (34.2%) had sexual problems, and 26.7% had trouble sleeping. There was an inverse relationship between fear of death and illness duration.

The average level of activities of daily living was lower in patients who only had primary school education, patients who did not work, and patients

with other illnesses. There was a reverse correlation between age ($r = -0.365$; $P < .001$), body mass index ($r = -0.253$; $P = .005$), and learning needs ($r = -0.217$; $P = .017$).

Learning needs

The mean learning need score was 2.43 ± 0.88 , and the learning need priorities were as follows: quality of life, feelings related to the situation, treatment, and complications (Table 3). When 50 items of the scale of learning needs were examined, the expression "how this disease will affect my future" had the highest significance (3.24 ± 1.51).

Other items above the scale's total score average included "how can I stay away from the stress?" (3.21 ± 1.50), "how can I cope with the stress?" (3.22 ± 1.41), and "where can I get help to cope with my feelings of illness?" (3.00 ± 1.57). No differences were shown among sociodemographic characteristics and learning needs (Table 1).

Table 2. Activities of Daily Life

Daily Life Activity	Yes, No. (%)	No, No. (%)
I. Maintaining a safe environment		
Sensory problem	44 (36.7)	76 (63.4)
Smoking	9 (7.5)	111 (92.5)
Alcohol use	5 (4.2)	115 (95.8)
Information about drugs	80 (66.7)	40 (33.3)
Infection risk	58 (48.3)	62 (51.7)
Pain	50 (41.7)	70 (58.3)
II. Communication		
Hearing/speech problem	1 (0.8)	119 (99.2)
III. Breathing Problem	24 (20.0)	96 (96.0)
IV. Eating and drinking		
Problem	15 (12.5)	105 (87.5)
Weight change	69 (57.5)	51 (42.5)
V. Elimination		
Urine problem	10 (8.3)	110 (91.7)
Defecation problem	20 (16.7)	100 (83.3)
VI. Washing and dressing		
Personal care problem	8 (6.7)	112 (93.3)
VII. Controlling temperature		
Problem	28 (23.3)	92 (76.7)
VIII. Mobilization		
Problem	32 (26.7)	88 (73.3)
Utility vehicle use	7 (5.8)	113 (94.2)
IX. Working and playing		
Problem	22 (18.3)	98 (81.7)
Leisure activity	79 (65.8)	41 (34.2)
X. Expressing sexuality		
Sexual problem (mean \pm SD)	41 (34.2)	79 (65.8)
XI. Sleeping (mean \pm SD)	7.2 \pm 2.7	
Problem	32 (26.7)	88 (73.3)
XII. Death and dying		
Fear of death (mean \pm SD)	3.16 \pm 3.12	

Abbreviations: SD, standard deviation

Table 3. Patient Learning Needs Scale

Subscale	Mean \pm SD
Medications	2.15 \pm 1.06
Activities of living	2.32 \pm 0.94
Community and follow-up	2.16 \pm 0.89
Feelings related to condition	2.70 \pm 1.09
Treatment and complications	2.53 \pm 1.01
Enhancing quality of life	2.88 \pm 1.00
Skin care	2.18 \pm 1.08

Discussion

Although we found that daily life activities of patients seemed to be good according to NEADLS point average, when examined individually, we observed problems in some activities. The most notable of these activities were maintaining a safe environment, eating and drinking, working and playing, and sexuality. We found that education status, working status, and accompanying illness affected the daily lives of patients. A need for patient education was found in the areas of quality of life, feelings about the situation, treatment, and complications.

Daily living in transplant recipients is different from daily living in those who do not undergo the procedure due to excessive care required to prevent infection, requirements of healthy and proper food, need for weight maintenance, and the need for continuous administration of medication. Hence, teamwork among health care providers is significant

given that care is effectively required and has a strong social effect on the lives of patients. However, we should highlight that available studies have so far focused on clinical findings and quality of life with comparisons versus dialysis treatment.¹⁹⁻²¹ Alavi and associates⁴ investigated anxiety, depression, quality of life, and activities of daily living among 63 hemodialysis versus 100 renal transplant patients. They used the same questionnaire that we used in this research (the Nottingham Extended Activities of Daily Living Scale). In addition, the Symptom Checklist-90 subscales of depression and anxiety and the Duke Health Profile questionnaire were used to collect data from the transplant and hemodialysis patients. Given that our research focused on NEADLS, the work from Alavi and colleagues regarding that renal replacement therapy significantly accounting for 35.3% of the variance of the NEADLS score ($P < .001$) is important. The mean NEADLS score (51.4 ± 10.2) of the transplant patients was significantly higher than the score for patients on hemodialysis (31.7 ± 14.8). Determinants for NEADLS were as follows: young age, male sex, and having higher education level.⁴ In our study, the mean NEADLS score of the patients was 56.06 ± 9.17 , which is consistent with the findings of Alavi and associates regarding age, educational status, and presence of additional disease.

Despite the increased number of kidney transplant procedures performed in 2016 in Turkey, this number is still below the need. Of note, the most important potential source of donors (deceased donations) has not increased to desired levels, and the continuous low rate of deceased donors is alarming. Increasing the number of kidney transplant procedures, which is the most appropriate treatment for cost-effectiveness, is important for our patients' health and the economy of our country. The most important cause of death in renal transplant recipients is infection (33.3%),²² which is caused by the increased risk of infection with immunosuppressive therapies used for treatment. In our study, only about half of the patients (51.7%) reported an infection risk, and only 20 patients reported that the medication had side effects of infection, suggesting that patients had insufficient knowledge regarding adverse effects.

Patients reported that fear of deterioration was their most pressing concern. They feared that their health condition could remain unstable, not improve,

or even worsen. Most of the patients worried about a reduction in renal function due to rejection or through a recurrence of their disease, resulting in kidney loss.¹⁵ The concerns of patients also seemed to affect their social activities. Although our patients reported that they did not have problems in their daily activities, our study group reported limited leisure activities. Although 65.8% of our study patients stated that they engaged in spare time activities, the activities that they performed were limited to those performed alone, including walking, everyday household chores, and reading books.

End-stage renal disease has a strong effect on sexual functioning in men and women, which affects quality of life. Sexual dysfunction in dialysis patients has multifaceted causes and includes physiologic changes, comorbid conditions, treatment-related factors, and psychologic states. Several studies have shown that renal transplant recipients experience better sexual functioning than patients undergoing dialysis.^{23,24} The sexual function of patients post-transplant was observed to be significantly better versus patients on dialysis ($r = 0.693$; $P < .001$), although 79% of the patients were diagnosed with sexual dysfunction.²⁵ Özdemir and colleagues²⁶ found that 68 patients (69.4%) had sexual dysfunction, with prevalence rates of 56.9% for men and 93.4% for women. Among single patients, numbers were higher than those among married patients. Subjects with sexual dysfunction were more depressed ($P = .001$) and less educated (for female patients, $P = .02$). The study also showed that sexual dysfunction was common in Turkish patients, especially women. In line with these results, it has been emphasized that assessment of sexual dysfunction should be integrated into routine examination throughout the transplant process, and, when needed, treatment management should include education regarding sexual life complaints.²⁶ In our study, 34.2% of the patients stated that they had sexual problems. This percentage is low compared with previous studies. However, we should keep in mind that sexuality is considered as a taboo in Turkey and that data were collected through the survey.

Although there are many studies on quality of life for renal transplant patients, surprisingly few studies have investigated the learning needs of Turkish patients after renal transplant. Using a questionnaire and interviews, Talas and Bayraktar¹ explored problems, knowledge, practices, and healthy living practices of 125 renal transplant recipients in Turkey.

The patients reported that they encountered physiologic problems and other diseases, including urinary and respiratory tract infections, hypertension, and hypercholesterolemia. A surprising finding was that 68.8% of the patients did not have any training on transplantation from a health care provider. Overall, the study indicated how patient quality of life was negatively affected and that knowledge and practices of patients were inadequate to lead healthy lives.¹

The important education areas for renal transplant patients may be categorized into 3 main domains: prescribed medication, rejection, and lifestyle.²⁷ In our study, learning needs in the order of priority were as follows: quality of life, feelings about the situation, treatment, and complications. Although we found no differences among socio-demographic characteristics with regard to learning needs, there was a positive correlation between activity of daily living scores. Our findings were similar to those reported in previous studies in the literature, which could be explained by increased need for information in patients as problems experienced in daily activities increase.

There are published studies on training programs that facilitate patients' daily life activities. For example, Tsay and colleagues² focused on the effectiveness of an adaptation training program in 57 ESRD patients to deal with various problems, including stress and depression, to enhance daily life. Their research was conducted over 8 weeks, in which data were collected using the Hemodialysis Stressor Scale, the Beck Depression Inventory, and the Medical Outcomes Study SF-36. Their findings showed that patients encountered problems regarding time and place, employment, physical activities, and transport limitations on fluid intake. The 3-month training showed a beneficial effect on patients to address their problems.²

One of the main responsibilities of nursing is to improve daily life activities of patients, thus helping them through posttransplant issues. In light of our findings, we have several recommendations to enhance survival after renal transplant and improve daily activities of patients. For example, although the daily activity levels of patients seemed adequate when we examined the average scale point, we noted problems in daily activities of patients, with priorities of learning needs shown to be quality of life, feelings related to the conditions, treatment, and complications. Given the association between the

NEADLS and the Patient Learning Needs Scale, the planned and regular training protocols regarding learning needs of patients are highly likely to help deal with any potential problems that they may encounter regarding daily activities.

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