



# Analysis of hemodialysis patients' thoughts about kidney transplantation and the national organ transplant system in terms of organ transplantation services management

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## ABSTRACT

**Introduction:** Kidney transplantation is the most effective treatment of end-stage renal failure. Although many patients continue to wait for a kidney transplant, there are constraints in organ supply. This situation needs to be analyzed and to be managed effectively.

**Objective:** The objective of this study was to determine the status of information regarding kidney transplants provided to patients treated with hemodialysis, the patients' thoughts regarding kidney transplants and the national organ transplant system as well as assessing their registration status at transplant centers.

**Methods:** 273 patients receiving hemodialysis treatment at 4 private dialysis centers in Ankara/Turkey were evaluated within the scope of this descriptive study. The data were collected through a survey method. The survey consisted of 18 questions in total which had been developed by the authors.

**Results:** It was determined that the hemodialysis patients responding to the survey were in the 20-95 age group with an average age of  $58,64 \pm 15,64$  years. 87,9% of the patients reported that they had been briefed about kidney transplants, 32,2% of those had been briefed said that the information had been delivered by the dialysis physician, 77,7% stated that they wanted a kidney transplant from a cadaver, 49,5% did not want a kidney transplant from a live donor and 35,5% indicated that the national organ transplant system operated adequately. Furthermore, it was noted that 50,9% of the responders were registered on the waiting lists of kidney transplant centers.

**Conclusions:** It was concluded that it is necessary to provide sufficient information to hemodialysis patients about kidney transplants and the national organ transplant system to steer them to transplant centers. It is anticipated that the results of this study will assist officers of the Ministry of Health, politicians involved in health issues, decision makers and health professionals.

**Key words:** Health management, hemodialysis, kidney transplant, national organ transplant system

## Introduction

Although hemodialysis is the most commonly preferred treatment method for patients with end-stage renal failure [1,2], the fundamentally desired method is

a kidney transplant [3,4]. Compared to hemodialysis, kidney transplants are more advantageous in terms of patient survival, quality of life and cost [5-7]. Kidney transplants come from two sources - live donors and

cadavers. Kidneys that are collected for transplant from cadavers are taken from brain dead patients and kidneys collected from live donors are obtained from a healthy relative who donates a kidney to the patient [8].

The number of patients receiving hemodialysis treatment in Turkey in February 2016 was 59,428. 846 dialysis centers serve these patients with 15,467 hemodialyzers. The number of current patients who are registered at kidney transplant centers and are waiting for kidneys is 22,340. The National Organ and Tissue Transplant System is managed by the Republic of Turkey Ministry of Health and 9 regional coordination centers have been established with a view on the geographical, economical and technological structure of the country. The number of centers carrying out kidney transplants in the country is 74 [9,10].

In 2015, brain death was determined in 1969 cases and the organs of 472 donors were donated. The million per capita donation rate (p.m.p.) is approximately 6.0. The total number of kidney transplants carried out per year is 3,204.

The objective of this study was to determine the status of information provided to patients treated with hemodialysis regarding kidney transplants, their thoughts regarding kidney transplants and the national organ transplant system while also assessing registration status in transplant centers.

### Methods

This study was qualified as descriptive and carried out in four private dialysis centers operating in Ankara between 01 January 2016 - 10 February 2016. The inclusion criteria of the study were receiving hemodialysis treatment, being 18 years old or older, freedom from psychiatric ailment, consciousness, the ability to communicate robustly and willingness to volunteer for the study. 273 patients had been recruited for the study.

A survey method was used as a data collection tool. The first part of the survey contained eight questions involving socio-demographical features, such as age, gender, marital status, income level, employment status, dialysis duration, education level and other chronic ailments. The second part consisted of 10 questions which were developed by the authors through taking advantage of information in the literature and presenting it from the view of an expert regarding the brief-

ing status for kidney transplant operations, opinions regarding kidney transplants and the national organ transplant system and registration status with the transplant centers. The SPSS 21.0 (IBM Corporation, New York, USA) program was used for the statistical analyses of the data. The descriptive data were presented as frequency and percentage.

### Results

It was determined that the hemodialysis patients responding to the survey were in the range of 20-95 years of age and that their average age was  $58,64 \pm 15,64$  years. 46,5% of the responders were in the 62-95 age group, 54,9% were male, 48,7% had income levels less than

**Table 1.** Socio-demographical features of the responders.

	n	%
Gender		
Female	123	45,1
Male	150	54,9
Age		
20-41 age group	42	15,4
42-61 age group	104	38,1
62-95 age group	127	46,5
Income level		
Less than 1300 TL	133	48,7
Between 1301-2500 TL	107	39,2
2501 TL and over	33	12,1
Marital status		
Married	224	82,1
Single	49	17,9
Employment status		
Yes	38	13,9
No	235	86,1
Dialysis duration		
0-5 years	155	56,8
6-10 years	80	29,3
11 years and over	38	13,9
Education level		
Illiterate	57	20,9
Primary education	110	40,3
Secondary education	35	12,8
High school	42	15,4
University or more	29	10,6
Other chronic ailments		
None	156	57,1
Yes	117	42,9

**Table 2.** Briefing status of hemodialysis patients.

	n	%
Have you been briefed about kidney transplant surgery?		
Yes, sufficiently	189	69,2
Yes, but insufficiently	51	18,7
No	33	12,1
Which of these health personnel made the briefing?		
Nephrologist	68	24,9
Dialysis physician	88	32,2
Transplant surgeon	10	3,7
Nurse	58	21,2
Transplant coordinator	16	5,9

1300 TL, 82,1% were married, 86,1% did not work, the dialysis duration of 56,8% was in the 0-5 year range and 40,3% were primary school graduates. Furthermore, 57,1% were found to have other chronic ailments, like hypertension, diabetes, coronary disease and respiratory failure respectively (Table 1).

69,2% of hemodialysis patients indicated that they had been adequately briefed about kidney transplants, 18,7% reported that the briefing had been inadequate and 12,1% stated that they had not been briefed at all. Most of the patients had been informed by the dialysis physician (36,7%) while the transplant surgeon had been the least involved in briefings (4,2%) (Table 2).

52,0% of hemodialysis patients specified that they wanted a kidney transplant to be independent from dialysis. 77,7% said that they wanted a kidney transplant from a cadaver, 49,5% did not want to have a kidney transplant from a live donor, 69,2% indicated that there were no suitable live donors for transplantation and 60,1% said that they took a dim view on kidney transplantation from a live donor fearing that the health of the relative could deteriorate in the future (Table 3).

35,5% of the responders believed that the National Organ Transplant System managed by the R.T. Ministry of Health had the organizational capacity and competency to provide a kidney from a cadaver. 50,9% of hemodialysis patients indicated that they were registered for a kidney transplant at a transplant center. Out of the registered patients, 64,7% stated that they were on the waiting lists of transplant centers of public or university hospitals (Table 4).

**Table 3.** Thoughts about kidney transplants of hemodialysis patients.

	n	%
Why do you want a kidney transplant?		
To be free of dialysis	142	52,0
To work, return to work	16	5,9
To be more healthy and active	93	34,0
Other	22	8,1
Do you want a kidney transplant from a cadaver?		
Yes	212	77,7
No	48	17,6
Not sure	13	4,8
Do you have a relative who wants to donate a kidney for a live transplant?		
Yes	84	30,8
No	189	69,2
Should any of your relatives be suitable donors, do you want a kidney transplant from a live donor?		
Yes	112	41,0
No	135	49,5
Not sure	26	9,5
What is your main reason for having a negative outlook on kidney transplants from live donors?		
I want to spare my relatives the fear/pain of surgery	24	8,8
I think that the health of my relatives could deteriorate in the future	164	60,1
I do not want to feel guilt or gratitude towards my relatives	18	6,6
I believe that a suitable kidney will be available from a cadaver in the near future	18	6,6
Other	49	17,9

**Table 4.** The opinions of the responders regarding the national organ transplant system and registration status at the transplant center.

	n	%
Do you think that the R.T. Ministry of Health National Organ Transplant System has the organization and competency to provide you with a suitable kidney from a cadaver?		
Yes	97	35,5
No	94	34,4
Not sure	82	30,0
Are you registered at any transplant center?		
No	134	49,1
Yes	139	50,9
Type of transplant center of registration (n=139)		
Public or university hospital	90	64,7
Private hospital	49	35,3

## Discussion

As a result of a review of the socio-demographic characteristics of the hemodialysis patients who participated in our study, it was evident that most were of advanced age with low educational and income levels. The results were consistent with the literature and the great proportion of hemodialysis patients of an advanced age was considered to be higher than that of other age groups [11-13].

The results of our study indicated that briefing patients who received hemodialysis treatment on kidney transplants was performed to a large extent and that the main source of the briefings had been dialysis physicians and nephrologists. The reason for the high level of information is attributed to the fact that the Ministry of Health mandates that dialysis centers brief the patients [14]. Patients waiting for organ transplants generally live in fear, anger, despair, hopelessness, uncertainty, fatigue and anxiety [15-17]. Most of these emotions are generated by insufficient briefings [18]. Therefore, it is anticipated that ensuring patients are informed about subjects such as the organ transplant system, its function, kidney transplant surgery and its complications by the relevant health staff will contribute to the quality of life and psychological status of the patients.

In terms of types of transplants, approximately 75,0% of all kidney transplants in Europe are conducted with kidneys from cadavers while approximately 75,0% of all kidney transplants performed in Turkey are from live donors. Turkey has the highest rate of kidney transplants from live donors in the world. Out of 3,205 kidney transplants carried out in 2015, 79,1% were from live donors (n=2534) and 20,9% (n=670) were with kidneys from cadavers [9,19]. While 77,7% of the responders of our study wanted to have a kidney transplant from a cadaver, at the same time, 41,0% preferred to have a kidney transplant from a live donor. The results are consistent with those of other studies [20,21]. The inability to provide organs from cadavers is considered to influence patients such that they become in favor of transplants from live donors. The main reason that the responders wanted a kidney transplant was to end dependency on dialysis. Other studies have also found similar results [20,22]. Usually, a session of hemodialysis takes 4 hours and 3 sessions per week are

prescribed, causing fatigue and burnout and decreasing quality of life. Education, work and family life must be reorganized. Therefore, it is considered that the elimination of dependency on dialysis is the most important justification for a kidney transplant.

The first kidney transplant in Turkey from a live donor was carried out in 1975 while the first cadaveric kidney transplant was later carried out in 1978 [23]. The National Organ Transplant System was established in 2000 and revised in 2007 and 2011. 35,5% of the responders felt that the national system was competent. A review of the types of transplants conducted, the number of transplants and organ donation suggested that organ transplantation in Turkey is gradually increasing to a robust level.

Almost half of the hemodialysis patients who participated in this study were on the organ waiting list. All dialysis patients, except for those who chose not to have an organ transplant or those who cannot have an organ transplant as a consequence of medical contraindications, must be directed to register at the cadaver pool of a transplant center which is actively involved in kidney transplants. This is considered a necessity in order to ensure equality among patients and an important task falls on health personnel in this regard.

Overall, it is considered a requisite that hemodialysis patients are briefed adequately about kidney transplants as well as the national organ transplant system and that they are directed to transplant centers. It is recommended that education, campaigns and policies that increase organ donations are established. It is anticipated that the results of this study will assist the officers of the Ministry of Health, politicians involved in health issues, decision makers and health professionals.

## Conflict of interest statement

The authors have no conflicts of interest to declare.

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