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Original Article

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How the Chronic Dialysis Patients Feel About Renal Transplantation

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Abstract

Objective: Chronic kidney disease has shown a gradual rise in prevalence. Kidney transplantation is the gold standard of renal replacement therapy and is associated with improved quality of life and decreased morbidity and mortality. The main goal of the present study was to understand the attitudes of patients with end-stage renal disease toward and apprehensions for renal transplantation.

Materials and Methods: This cross-sectional study included patients age >18 years without a history of transplantation who were receiving chronic dialysis for at least 1 month. A newly developed questionnaire form was used to obtain the necessary information on the attitudes of the patients. The questionnaire consisted of 59 questions, and the patients' answers were evaluated.

Results: A total of 85 patients who provided consent were included in the study. Of the 85 patients, 71 (83.5%) were on hemodialysis (HD), and 14 (16.5%) were on peritoneal dialysis. Most of the patients did not consider gender, race, belief, lifestyle of the donor, and the living or deceased status of the donor to be a barrier for their transplantation. Of the 85 patients, 37.6% reported that they had their family members screened to ascertain their suitability for donation.

Conclusion: Patients who have end-stage kidney disease should be informed about the renal transplantation preparation process, follow-up process, and post-transplantation treatment and care.

Keywords: Dialysis, end-stage kidney disease, renal transplantation

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INTRODUCTION

Chronic kidney disease is defined as a glomerular filtration rate (GFR)<60 mL/min/1.73 m^2 or the presence of kidney damage for at least 3 months. It is divided into stages, ranging from grade 1, representing normal to high kidney function with evidence of kidney disease, to grade 5, representing end-stage kidney disease (ESKD) (GFR<15 mL/min/1.73 m^2) (1). Chronic kidney disease in Turkey has become a major public health problem as it is worldwide. The Turkish Society of Nephrology conducted the CREDIT study, and the prevalence of chronic kidney disease in the adult age group in Turkey was reported to be 15.7% (2).

Patients with ESKD need renal replacement therapies (RRTs), such as hemodialysis, peritoneal dialysis (PD), and kidney transplantation. Kidney transplantation has emerged in the past decade as the gold standard of RRT as it is associated with improved quality of life and decreased morbidity and mortality (3, 4). Furthermore, transplantation is substantially more cost-effective than maintenance dialysis. However, a global shortage of available organs prevents kidney transplant from being a universally accessible treatment modality. While the kidney transplant waiting list offers patients the expectation of a normal life without dialysis, the transplant assessment work-up can be a

lengthy process, and for some patients, it takes 6 months-1 year to complete (3, 5).

The number of patients with ESKD in Turkey is also on the rise. Kidney transplantation offers better outcomes than dialysis but requires patients' access and adherence to an ongoing and complex self-management regimen. Gaining access to kidney transplantation is a complex process that involves treatment decisions made by patients, and some patients, despite significant advantages of kidney transplantation, choose to remain on dialysis treatment.

The main goal of the present study was to understand the attitudes of patients with end-stage renal disease toward and apprehensions for renal transplantation.

MATERIALS AND METHODS

This was a cross-sectional study. Patients age >18 years without a history of transplantation who were receiving chronic dialysis for at least 1 month were included in the study. A newly developed questionnaire form was used to obtain the necessary information on the attitudes of the patients. The questionnaire form consisted of 59 questions about renal transplantation. Of the 59 questions, 12 were on the socio-demographic characteristic of the patients, 3 on chronic illnesses, 10 on dialysis therapy, and 34 on transplantations. The form was applied to the patients by the same investigator during HD sessions for the HD patients and at the follow-up clinic for the PD patients.

The study was approved by the ethics committee of Bezmialem Vakif University on March 23, 2016 (71306642-050.01.04).

Statistical Analysis

Statistical data were analyzed using The Statistical Package for the Social Sciences (SPSS) for Windows 20.0 (IBM Corp.; Armonk, NY, USA). Descriptive statistics were used as the statistical method and are expressed as number, percentage, and mean±SD. Kruskal-Wallis H test was used to evaluate nonparametric differences between the groups. Chi-square test was used to compare categorical values. A $p<0.05$ was considered as statistically significant.

RESULTS

One hundred thirteen patients who provided consent were included in the study. A total of 85 patients with complete answers were selected for the final analysis. The study included 40 female and 45 male patients. The mean age of the patients was 57±13.3 years. None of the patients on the present study was currently employed. Of the 85 patients, 71 (83.5%) were on HD, and 14 (16.5%) were on PD. The duration of dialysis was 2.5±5.90 (0.10-22) years.

The vast majority of the patients (77%) were generally satisfied with the current dialysis treatment and believed in destiny and religious appropriateness of organ transplants. Most patients (64%) believed in the presence of the organ mafia. Most of these patients (87.1%, n=74) stated that if they were healthy, they would have donated their kidney. If their relatives had volunteered to donate, 71.8% (n=61) of the patients would accept a kidney. On the other hand, only 37.6% of the patients had their family members screened for suitableness for donation. Most of the patients did not consider gender, race, belief, lifestyle of the donor, and living or cadaveric status of the donor to be a barrier for their transplantation. The majority of the patients (84.7%, n=72) felt psychologically ready for transplantation.

Of the 85 patients, 34 (40%) were afraid of rejection after transplantation, whereas more than half of the patients were willing to have a second kidney transplantation if their first kidney transplant failed. Of these patients, 63 (74.1%) were not worried about being on medication after transplantation, and they reported that changes that may occur in their appearance due to steroid use after transplantation are not significantly important (Table 1).

Of the 85 patients, 49 (57.6%) stated that they did not receive any education/information about transplantation. Patients who were informed about the procedure stated that they know the transplantation process and received enough education ($p<0.001$). Moreover, they were aware of the adverse situations that might occur after transplantation ($p<0.001$), as well as the benefits of the transplantation ($p<0.001$) (Table 2).

The quality of life was scored from 1 to 10. The mean score of the quality of life was 7±2.60. The level of patients' satisfaction with dialysis affects the quality of life of the patients, χ^2 SD: 2 (n=85)=10.779 ($p<0.05$). Patients who have done their follow-ups for transplantation regularly (44.7%) found that the preparation process is exhausting ($p<0.001$).

DISCUSSION

The purpose of the present study was to learn the patients' thoughts on transplantation, to evaluate whether patients with chronic renal disease have knowledge on the issue, if there is any factor affecting their will to have the transplantation and if there is, to know what those factors are together with the degree of the effect. There was no current scale in the literature examining patient views on renal transplantation. For this reason, researchers established a new questionnaire form.

The first finding is that the patients did not receive enough information on transplantation and do not know the necessary details regarding the procedures. Knowledge gaps were identified, such as transplantation process and medications that are used after transplantation. In accordance with our study, Gorgel et al. (6) have shown that 60% of kidney transplantation patients do not have enough information.

Another study displayed that when patients received information from other patients, it was often out of date and inaccurate (7). Kazley et al. (4) reported similar results of the lack of knowl-

Table 1. Patient's attitudes and apprehensions to renal transplantation

	N=85 (%)
Religious appropriateness	
Yes	79 (92.9)
No	2 (2.4)
No idea	4 (4.7)
Do you believe in destiny?	
Yes	77 (90.6)
No	6 (5.9)
No idea	2 (2.4)
If you were healthy, would you donate your organs?	
Yes	74 (87.1)
No	5 (5.9)
No idea	6 (7.1)
Do you believe in the existence of the organ mafia?	
Yes	64 (75.3)
No	9 (10.6)
No idea	12 (14.1)
Does it feel frightening to be carrying someone else's organ?	
Yes	18 (21.2)
No	65 (76.5)
No idea	2 (2.4)
Do you receive psychological support?	
Yes	14 (16.5)
No	71 (83.5)
Have you checked the appropriateness of anybody in your family for donation?	
No	3 (3.5)
I thought but we did not control	23 (27.1)
Yes	32 (37.6)
No one wants to be a donor	11 (12.9)
Some of my relations wanted to be a donor, I did not accept	16 (18.8)
Would you accept kidney donation from your relatives?	
Yes	61 (71.8)
No	20 (23.5)
No idea	4 (4.7)
Did you receive any education regarding transplantation?	
Yes	36 (42.2)
No	49 (57.8)
Do you have surgery phobia?	
Yes	10 (11.8)
No	63 (74.1)
No idea	12 (14.1)
Do race, belief, and lifestyle of the donor matter?	
No	75 (88.2)
Some	4 (4.7)
Yes, they are important	5 (5.9)
No idea	1 (1.2)
Importance of cadaveric or living donor	
I do not want transplantation	2 (2.4)
I would accept only from a living donor	2 (2.4)
I would accept only from a cadaveric donor	12 (14.1)
Both donors are okay for me	69 (81.2)
Are you psychologically ready for transplantation?	
Yes	72 (84.7)
No	7 (8.2)
No idea	6 (7.1)
Do you know all the procedures related to pre-transplant evaluation?	
No, I do not know	37 (43.5)
I have some unclear knowledge	8 (9.4)
Yes, I know	40 (47.1)
Are your follow-ups for transplantation regularly performed?	
Yes, regularly	38 (44.7)
I am not fully prepared for transplantation	13 (15.3)
No, I am not following it up regularly	34 (40)
Is the preparation process exhausting?	
No	21 (24.7)
Some	9 (10.6)
Yes	20 (23.5)
Not completely ready for transplantation	35 (41.2)
Are all your tests up-to-date for transplantation?	
Yes	37 (43.5)
No	43 (50.6)
No idea	5 (5.9)
Did you receive adequate education about transplantation?	
Yes	22 (25.9)
Some	11 (12.9)
No	52 (61.2)
Are you afraid of rejection?	
No, I am not scared	33 (38.8)
I am a bit scared	13 (15.3)
I am really afraid of it	34 (40.0)
No idea	5 (5.9)
What if you got the organ and rejected it, would you still want to try your chance for retransplant?	
Yes	49 (57.6)
No	25 (29.4)
No idea	11 (12.9)
Are you worried about being on medication after transplantation?	
Yes	16 (18.8)
Some	6 (7.1)
No	63 (74.1)

edge about the process of transplantation and the requirements for listing. Their study also showed that the minority of the patients have discussed the transplantation process with their doctors, but these were also outdated or were not enough (4).

Similarly, in our study, most patients (64%) reported to believe that the organ mafia exists in Turkey. However, in our country,

Table 2. Comparison of education status with adverse situation and benefit of transplantation

	Education		
	Yes (%)	No (%)	p
Know adverse situations after transplantation			
Yes	22 (61.1)	8 (16.3)	χ^2:17.198
No	7 (19.4)	6 (12.2)	<0.001*
Not sure	7 (19.4)	35 (71.4)	
Know benefit of transplantation			
Yes	20 (55.6)	9 (31)	χ^2:23.846
No	9 (25)	34 (69.4)	<0.001*
Not sure	7 (19.4)	6 (12.2)	
Enough education			
Yes	19 (52.8)	3 (6.1)	χ^2:34.970
No	9 (25.0)	43 (87.8)	<0.001*
Not sure	8 (22.2)	3 (6.1)	

Chi-square test *p<0.01

organ transplantations have long been regulated by laws and strict regulations. We believe that the patients' thoughts of an organ mafia originate from the conversations they had with other patients.

Sufficient patient education is necessary for arranging potential recipients for kidney transplantation. For this reason, more effective training strategies in the pre-transplant setting are being considered. Healthcare providers play a vital role in education and can identify gaps in patient understanding (8). Sources of knowledge should include nephrologists, dialysis nurses, or coordinators (7).

Some participants in the present study were afraid of the surgery and the following medications, and many of them were worried of complications after surgery, such as rejections. Herlin and Wann-Hansson showed similar findings in their phenomenological study (9).

We could not find a valid reason for patients who do not want to have transplantation and who did not register to list or neglect their follow-ups. Furthermore, we realize that there are multiple factors affecting their decisions. The striking finding is that when we ask the reason for not registering to list, some of them stated their old age and wanted the younger patients to have a transplant. They further expressed that they are satisfied as it is and are used to going to dialysis. A previous study has examined the reasons and found similar findings to those of our study. They believe that dialysis was not bad, they were scared of getting surgery, they were worried about waiting for a kidney for a long time, and they were anxious about not passing the medical tests (4). Reasons for refusing transplantation may vary and are certainly deserving of further study.

Kidney transplantation extends the length of and improves the quality of life for most patients on the waiting list undergoing dialysis (10). Donor organs for kidney transplant are available from either a living or a deceased donor. Our study showed that it is not important for patients to have whether living or deceased kidney. Living donor transplantation is significantly higher than deceased donor transplantation in Turkey (11). Kidney transplants are performed mostly from living donors. The number of cadaveric transplants has not yet reached the desired level. Similarly, in our study, most relatives of the patients are willing to donate their organs. Patients included in the study stated that if they were healthy, they would have donated their kidneys after death. To increase the number of cadaveric donations, we believe that our community should be informed about this issue.

In our findings, only a small percentage of the patients did not find the preparation process onerous. While the kidney transplant waiting list offers patients expectations of a normal life without dialysis, the burdensome demands of completing the transplant assessment work-up, uncertainty about waiting times and eligibility, and that exceed expectations can be discouraging and impel patients to disappointment (12). Qualitative studies that have examined the experiences of patients on dialysis who are waiting for a cadaveric donor have shown that symptoms of depression and anxiety rise during the waiting period (13).

CONCLUSION

If earnings of transplantation are explained wholly and objectively, i.e., together with cons, and if patients are followed up for the continuity of their enlistment by either doctors or the organ transplantation coordinators of the hospital which they are listed, the number of donors and chances of transplantation will increase in our country.

Ethics Committee Approval: Ethics committee approval was received for this study from the Ethics Committee of Bezmialem Vakif University on March 23, 2016 (71306642-050.01.04).

Informed Consent: Written informed consent was obtained from the patient who participated in this study.

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REFERENCES

1. Anderson J, Glynn LG. Definition of chronic kidney disease and measurement of kidney function in original research papers: a review of the literature. Nephrol Dial Transplant 2011; 26: 2793-8. [CrossRef]
2. Suleymanlar G, Utas C, Arinsoy T, Ates K, Altun B, Altiparmak MR, et al. A population-based survey of chronic renal disease in Turkey-the CREDIT study. Nephrol Dial Transplant 2011; 26: 1862-71. [CrossRef]
3. Tang E, Bansal A, Novak M, Mucsi I. Patient-reported outcomes in patients with chronic kidney disease and kidney transplant-part 1. Front Med (Lausanne) 2018; 15: 254. [CrossRef]
4. Kazley AS, Simpson KN, Chavin KD, Baliga P. Barriers facing patients referred for kidney transplant cause loss to follow-up. Kidney Int 2012; 82: 1018-23. [CrossRef]
5. Vassalotti JA, Centor R, Turner BJ, Greer RC, Choi M, Sequist TD. Practical approach to detection and management of chronic kidney disease for the primary care clinician. Am J Med 2016; 129: 153-62. [CrossRef]
6. Gorgel A, Yilmaz T, Kesler F, Aydin G, Yavuz Coskun Y, Demircioglu D, et al. Hemodialysis patients' perspective on renal transplantation. 2016 Turk Neph Dial Transpl 2016; 25: 269-72. [CrossRef]
7. Landreneau KJ, Ward-Smith P. Perceptions of adult patients on hemodialysis concerning choice among renal replacement therapies. Nephrol Nurse J 2007; 34: 513-9.
8. Rosaasen N, Mainra R, Shoker A, Wilson J, Blackburn D, Mansell H. Education before kidney transplantation: what do patients need to know? Prog Transplant 2017; 27: 58-64. [CrossRef]
9. Herlin C, Wann-Hansson C. The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. Scand J Caring Sci 2010; 24: 693-9. [CrossRef]
10. Chopra B, Sureshkumar KK. Changing organ allocation policy for kidney transplantation in the United States. World J Transplant 2015; 5: 38-43. [CrossRef]
11. http://www.tsn.org.tr/folders/file/2016_REGISTRY.pdf Erişim tarihi: 03.02.2018.
12. Tong A, Hanson CS, Chapman JR. 'Suspended in a paradox'-patient attitudes to wait-listing for kidney transplantation: systematic review and thematic synthesis of qualitative studies. Transpl Int 2015; 28: 771-87. [CrossRef]
13. Corruble E, Durrbach A, Charpentier B, Lang P, Amidi S, Dezamis A, et al. Progressive increase of anxiety and depression in patients waiting for a kidney transplantation. Behav Med 2010; 36: 32-6. [CrossRef]