

Awareness and Knowledge About Kidney Transplantation: A Reflection on the Current State Among Iranian Patients with End-stage Renal Disease (ESRD) Treated by Dialysis

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Introduction. Kidney transplantation is the treatment of choice in the majority of end-stage renal disease (ESRD) patients. However, most of the incident ESRD patients are not given the necessary information regarding kidney transplantation. The aim of this study was to evaluate awareness and knowledge about kidney transplantation in ESRD patients who were on dialysis.

Methods. In this cross-sectional study, a total of 300 ESRD patients who underwent hemodialysis or peritoneal dialysis and could be eligible for kidney transplant, were included. A questionnaire with 15 multiple choice questions (MCQs) was designed to collect the data. SPSS version 16 was used for data analysis and a *P* value less than .05 was considered statistically significant.

Results. Two hundred thirty- four patients participated in the study (response rate of 78%). Among them 58.1% were male with the mean age (SD) of 52.5 (12.1) years. The majority of the patients (94.0%) were on hemodialysis. About 87.6% wanted to receive kidney transplant; but despite the desire of the patients, this method was initially offered to about 11.5 % of the patients as a possible method of renal replacement therapy. Patients who had desire to receive kidney transplantation were significantly younger, male, married, employed, and had high level of education (*P* < .05).

Conclusion. Although most of the patients wanted to receive a kidney transplant, it was initially offered to a small population. Age, gender, marital status, employment condition, and level of education were significant factors for the patient's tendency to receive a kidney transplant.

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INTRODUCTION

Studies have shown that the global burden of ESRD is increasing, worldwide.^{1,2,3} From 1990 to 2013, the total number and age-standardized mortality rate of ESRD patients have increased substantially.³ ESRD could be fatal in the absence of renal replacement therapies (RRT) including dialysis or transplantation.¹

While the incidence and prevalence of ESRD

in our country is still lower than developed countries, data has shown a significant increase in the number of ESRD patients in recent years. The low reported rate of ESRD in our country could be multifactorial and be due to both low referral rate and under-diagnosis of patients with ESRD.⁴ Noteworthy, the cause of ESRD in the significant number of Iranian patients is unknown which might be mostly due to late referral of patients

with chronic kidney disease to specialized clinics.⁴

Like many countries, hemodialysis and kidney transplantation are the most common renal replacement therapy modalities (RRT) in Iran, respectively.^{4,5}

It is certain that in suited cases kidney transplantation is the preferred method of RRT and the patients who have a successful kidney transplant have higher survival rate and improved quality of life compared with the patients on maintenance dialysis and the patients who are on the waiting list.^{6,7,8,9} Moreover, the quality of hemodialysis procedure in some dialysis centers in our country might not meet the required standard and there might be various limitations in providing convenient service in some of these centers. Haghghi *et al* showed that as large as 42.5% of the patients who were candidate for hemodialysis three times a week underwent hemodialysis only twice a week, in some hemodialysis centers.⁵ This might indicate the inability of the health care system to provide sufficient services to meet the needs of growing numbers of hemodialysis patients.⁵ However, discussing the causes of these limitations is out of scope of this study.

It has been shown that ESRD patients' awareness about different modes of renal replacement therapy is not satisfactory.^{10,11} Studies also showed that in practice there is huge gap between patients' preference and the treatment started by their physician. This difference may be due to lack of education and awareness about the process of modality selection and RRT options available.¹²⁻¹⁴

Despite the important role of education and learning in the selection of RRT modalities and specially kidney transplantation, no multicenter study has been done yet in in our country regarding the current knowledge and awareness of ESRD patients about kidney transplantation. This study was designed to evaluate the awareness and knowledge of patients undergoing dialysis regarding kidney transplantation.

MATERIALS AND METHODS

Study Design

This was a cross-sectional study, which was approved by an institutional review board (IRB) and research ethics committee (REC) (Ref.no.IR.TUMS.MEDICINE.REC.1396.3201) of Tehran University of Medical Sciences (TUMS, Tehran, Iran). We

followed the declaration of Helsinki during the study process. Patients' autonomy was respected and written informed consent was obtained from participants before participation in this study.

Setting

We conducted this study in 5 dialysis centers from different regions in Tehran city, Iran. Eligible patients were included in the study via convenience sampling and recruitment was occurred between 22 July 2016 and 23 July 2017.

Participants

Inclusion criteria set as: both male and female subjects who aged over 18 years and underwent dialysis (hemodialysis or peritoneal dialysis). Patients who only underwent peritoneal dialysis catheter insertion and were eligible for kidney transplantation also included in the study. The patients who refused to continue the study and also patients with incomplete questionnaires were excluded from the analysis.

Variables and Measurements

The data were obtained by individual interview, patients' self-report and patients' clinical records at the dialysis center. Demographic and clinical information included: age, gender, ethnicity, Body mass index (BMI), marital status, employment condition, level of education and economic status, primary cause of ESRD, and KT/V.

In order to assess the awareness and knowledge regarding kidney transplantation, we applied a questionnaire which was used in the Mehrotra *et al* study in 2005.¹⁵ This questionnaire was translated to Farsi language by forward-backward translation method and its appearance and content validity was approved by two nephrologists affiliated to TUMS.

This questionnaire had 15 multiple choice questions (MCQs) which was completed by the main researcher through a face-to-face interview.

Statistical Analyses

In order to describe categorical data, frequency and partial frequency percent were used. Mean and standard deviation (SD) were used to describe continuous data. The answer to each question was reported by percent. In addition, we categorized the study population to two groups according

to the question number 10 “would you like to have a kidney transplant if it is possible?” which identified patients` desire to receive a kidney transplant. Categorical data were compared by chi squared test and in case of small frequency, the Fisher exact test was used. Continuous data were compared with independent sample t test between the two groups. SPSS software version

16 was used for data analysis and *P* less than .05 was considered as statistically significant.

RESULTS

At the end of the study, 234 out of 300 eligible ESRD patients participated in the study giving a response rate of 78%. The baseline characteristics of the study population was presented in **Table 1**.

Table 1. Baseline Characteristics of the Study Population

| Variables | Total Frequency (%) (n = 234) | Patients Want to Receive Transplantation | | P |
|-----------------------|----------------------------------|--|----------------|-------|
| | | Yes (n = 205) | No (n = 29) | |
| Age, y | 52.5 (12.1) | 51.7 (12.1) | 57.9 (10.8) | < .05 |
| Gender | | | | |
| Male | 136 (58.1) | 126 (61.5) | 10 (34.5) | < .05 |
| Female | 98 (41.9) | 79 (38.5) | 19 (65.5) | |
| Ethnicity | | | | |
| Fars | 154 (65.8) | 131 (63.9) | 23 (79.3) | > .05 |
| Turk | 52 (22.2) | 48 (23.4) | 4 (13.8) | |
| Others | 28 (12.0) | 26 (12.7) | 2 (6.9) | |
| BMI | 24.2 (4.5) | 24.2 (4.5) | 24.5 (4.3) | > .05 |
| Marital Status | | | | |
| Single | 25 (10.7) | 21 (10.2) | 4 (13.8) | < .05 |
| Married | 176 (75.2) | 160 (78.1) | 16 (55.2) | |
| Divorced/ Widowed | 33 (14.1) | 24 (11.7) | 9 (31.0) | |
| Employment Status | | | | |
| Employed | 61 (26.0) | 59 (28.8) | 2 (6.9) | < .05 |
| Retired | 44 (18.8) | 38 (18.5) | 6 (20.7) | |
| Unemployed | 39 (16.7) | 37 (18.0) | 2 (6.9) | |
| Homemaker | 90 (38.5) | 71 (34.7) | 19 (65.5) | |
| Level of Education | | | | |
| Illiterate | 43 (18.4) | 32 (15.6) | 11 (37.9) | < .05 |
| Elementary school | 99 (42.2) | 88 (42.9) | 11 (37.9) | |
| High school | 64 (27.4) | 60 (29.3) | 4 (13.9) | |
| Academic | 28 (12.0) | 25 (12.2) | 3 (10.3) | |
| Economic status | | | | |
| High | 7 (3.0) | 6 (2.9) | 1 (3.4) | > .05 |
| Medium | 96 (41.0) | 85 (41.5) | 11 (37.9) | |
| Low | 131 (56.0) | 114 (55.6) | 17 (58.6) | |
| Primary Cause of ESRD | | | | |
| Diabetes Mellitus | 83 (35.5) | 73 (35.6) | 10 (34.5) | > .05 |
| Hypertension | 78 (33.3) | 69 (33.7) | 9 (31.0) | |
| Infectious Diseases | 11 (4.7) | 10 (4.9) | 1 (3.4) | |
| ADPKD | 8 (3.4) | 7 (3.4) | 1 (3.4) | |
| Glomerulonephritis | 7 (3.0) | 6 (2.9) | 1 (3.4) | |
| Unknown | 26 (11.1) | 23 (11.2) | 3 (10.3) | |
| Others | 21 (9.0) | 17 (8.3) | 4 (13.8) | |
| KT/V | 1.3 (0.4) | 1.3 (0.4) | 1.3 (0.4) | |
| Type of Dialysis | | | | |
| Hemodialysis | 220 (94.0) | 194 (94.6) | 26 (89.7) | > .05 |
| Peritoneal Dialysis | 14 (6.0) | 11 (5.4) | 3 (10.3) | |

Values are either mean ± SD or n (%).

Abbreviations: ESRD, end-stage renal disease; ADPKD, autosomal dominant polycystic kidney disease

*Statistically Significant

The mean age of participants was 52.5 ± 12.1 years. The majority of the patients were male (58.1%), and more than 75% of them were married. Only 12% of them had academic education and more than half of these patients described themselves as low socioeconomic status (56%) and homemaker (38.5%). Diabetes Mellitus was the most common cause of ESRD (35.5%) and hemodialysis was the most common mode of dialysis (94.0%) (Table 1).

We categorized the patients based on whether they desired to have a kidney transplant or not. Our results showed that 87.6% of the subjects had

preference of having kidney transplant (205 vs. 29 subjects). Patients who will to have a kidney transplantation were significantly younger than other group (51.7 vs. 57.9 years). Interestingly male subjects were more willing to have a kidney transplantation (61.5%) compared to female subjects (38.5%). The frequency distribution of response to the survey questions has been indicated in Table 2. Most of the patients (45.3%) found out about their kidney failure only one month before starting the dialysis. Also, about (48.3%) of them visited a nephrologist only one month before

Table 2. Frequency Distribution of Responses to the Survey Questions

| Questions | Total Frequency (%) (n = 234) | Patients Want to Receive Kidney Transplant | | P |
|--|----------------------------------|--|----------------|-------|
| | | Yes (n = 205) | No (n = 29) | |
| "How long have you known that you have kidney failure?" | | | | |
| < 1 month | 106 (45.3) | 94 (46.0) | 12 (41.4) | > .05 |
| 1 to 12 months | 39 (16.7) | 33 (16.0) | 6 (20.7) | |
| 1 to 5 years | 53 (22.6) | 43 (21.0) | 10 (34.5) | |
| > 5 years | 36 (15.4) | 35 (17.1) | 1 (3.4) | |
| "How long were you seeing a nephrologist before you started dialysis?" | | | | |
| < 1 month | 113 (48.3) | 102 (49.8) | 11 (38.0) | > .05 |
| 1 to 12 months | 33 (14.1) | 28 (13.7) | 5 (17.2) | |
| 1 to 5 years | 66 (28.2) | 54 (26.3) | 12 (41.4) | |
| > 5 years | 22 (9.4) | 21 (10.2) | 1 (3.4) | |
| "When were the different type of treatment options first presented & explained to you?" | | | | |
| Not until dialysis was started | 160 (68.3) | 136 (66.3) | 24 (82.8) | > .05 |
| 1 to 3 months before beginning dialysis | 28 (12.0) | 26 (12.7) | 2 (6.9) | |
| 4 to 6 months before beginning dialysis | 10 (4.3) | 10 (4.9) | 0 (0.0) | |
| > 1 year before beginning dialysis | 32 (13.7) | 29 (14.1) | 3 (10.3) | |
| Not Explained | 4 (1.7) | 4 (2.0) | 0 (0.0) | |
| "Which of the following options were initially offered to you as possible methods of treatment?" | | | | |
| Hemodialysis | 183 (78.2) | 158 (77.0) | 25 (86.2) | > .05 |
| Peritoneal Dialysis | 24 (10.3) | 20 (9.8) | 4 (13.8) | |
| Kidney Transplant | 27 (11.5) | 27 (13.2) | 0 (0.0) | |
| "Who discussed your treatment option with you?" | | | | |
| Internal Specialist | 4 (1.7) | 4 (2.0) | 0 (0.0) | > .05 |
| Nephrologist | 139 (59.4) | 125 (61.0) | 14 (48.3) | |
| A Nurse from the Dialysis Center | 7 (3.0) | 6 (2.9) | 1 (3.4) | |
| Don't Know/ Don't Remember | 84 (35.9) | 70 (34.1) | 14 (48.3) | |
| "Please indicate the types of materials used to explain your treatment options" | | | | |
| Face to Face Discussion (s) with Doctor/ Nurse | 131 (56.0) | 119 (58.0) | 12 (41.4) | > .05 |
| Discussion with Other Patients Already on Hemodialysis | 2 (0.9) | 2 (1.0) | 0 (0.0) | |
| Discussion with Other Patients with Kidney Failure Who Received Kidney Transplant | 2 (0.9) | 1 (0.5) | 1 (3.4) | |
| All of the Above | 17 (7.2) | 15 (7.3) | 2 (6.9) | |
| Treatment Options Were NOT Given to Me | 82 (35.0) | 68 (33.2) | 14 (48.3) | |
| "How satisfied with the information you obtained on the kidney transplant in different ways?" | | | | |
| Very Satisfied | 12 (5.1) | 11 (5.4) | 1 (3.4) | > .05 |
| Somewhat Satisfied | 92 (39.3) | 85 (41.5) | 7 (24.1) | |
| I am not satisfied | 89 (38.0) | 72 (35.1) | 17 (58.6) | |
| I am not satisfied at all | 41 (17.5) | 37 (18.0) | 4 (13.8) | |

Table 2. Continued

| Questions | Total Frequency (%) (n = 234) | Patients Want to Receive Kidney Transplant | | P |
|---|----------------------------------|--|----------------|--------|
| | | Yes (n = 205) | No (n = 29) | |
| "Have you yourself chosen your treatment option for kidney failure or has the doctor made the decision for you?" | | | | |
| I chose it myself | 17 (7.3) | 14 (6.8) | 3 (10.3) | > .05 |
| My doctor has chosen it | 200 (85.4) | 176 (85.9) | 24 (82.8) | |
| Both my doctor and I have been involved in decision making | 17 (7.3) | 15 (7.3) | 2 (6.9) | |
| "Generally, how satisfied are you with the current form of treatment?" | | | | |
| Very Satisfied | 91 (38.9) | 85 (41.5) | 6 (20.7) | < .05 |
| Neither Satisfied Nor Dissatisfied | 111 (47.4) | 96 (46.8) | 15 (51.7) | |
| Very Dissatisfied | 32 (13.7) | 24 (11.7) | 8 (27.6) | |
| "Have you ever been referred to a kidney transplant center in order to be evaluated for a kidney transplant?" | | | | |
| Yes | 117 (50.0) | 112 (54.6) | 5 (17.2) | < .001 |
| No | 117 (50.0) | 93 (45.4) | 24 (82.8) | |
| "What kind of kidney transplant has been considered for you?" | | | | |
| A kidney transplant from a donor who died | 32 (13.7) | 32 (28.6) | 0 (0.0) | > .05 |
| A kidney transplant from a living donor who is your relatives | 19 (8.1) | 19 (17.0) | 0 (0.0) | |
| I don't know / I don't remember" | 183 (78.2) | 178 (86.4) | 5 (100.0) | |
| "In your opinion, if you receive a kidney transplant, to what extent can this treatment have a positive effect on your quality of life" | | | | |
| Not at all | 14 (6.0) | 1 (0.5) | 13 (44.8) | < .001 |
| Very little | 1 (0.4) | 1 (0.5) | 0 (0.0) | |
| Somewhat | 67 (28.6) | 55 (26.8) | 12 (41.4) | |
| Very large | 152 (65.0) | 148 (72.2) | 4 (13.8) | |
| "Have you ever been on a kidney transplant list?" | | | | |
| Yes | 50 (21.4) | 50 (24.4) | 0 (0.0) | < .05 |
| No | 184 (78.6) | 155 (75.6) | 29 (100.0) | |

starting the modality. The majority of the patients (68.3%) declared that different types of RRT was not presented to them before starting dialysis. Most of the patients (78.2%), reported that hemodialysis was the first method of RRT offered to them by a nephrologist and in most cases (59.4%) patients believed that the decision on treatment selection was made by their doctor rather than them. The majority of the participants (56.0%) reported that doctor / nurse used face to face discussion to explain the treatment options to them and only 5.1% were satisfied with the information received. About 38.9% of the patients were satisfied with the current form of their RRT (Table 2).

Most of the patients (87.6%) tended to receive a kidney transplantation and half of them were referred to be evaluated for kidney transplantation. The majority of the patients (65%) believed that kidney transplantation could have huge effect on their quality of life. Just 21.4% of the patients were included in the kidney transplantation list and 6.4% were excluded from the transplant list because of a specific reason (Table 2).

DISCUSSION

Kidney transplantation is regarded as the first successful RRT for ESRD subjects, however some drawbacks including shortage of available organs, adverse effects of required medications and possible immunological rejection limited its application. In this cross-sectional study we evaluated the knowledge and desire of Iranian ESRD population on dialysis regarding kidney transplantation.

Interestingly, we found that patients were not fully informed about the availability of various RRT options and the maintenance hemodialysis was offered as the primary modality to most of them (78.2%). Considering that we collected data from various centers, it is plausible that our finding of the neglecting of health care providers to present kidney transplant as a primary choice for most ESRD subjects is a representative of the general practice in our country. Due to the existence of limitation in providing tools and material for hemodialysis in many centers in our country and also since many studies showed the optimal outcomes in kidney transplanted subjects in both

terms of patients and survival, the policy maker should consider it more seriously and try to make plan for changing this policy.

While the number of ESRD patients is increasing, patients should be informed about the risks and benefits of various RRT options prior to their initiation. They also should be engaged in their disease management^{18,19} in order to choose the best choice. It is obvious that information should be spoken and taught based on available medical facilities and methods in each country. For example, nowadays in Iran peritoneal dialysis has many barriers such as providing dialysis solutions and its application has been limited so far and obviously this modality might not be the choice one for many physicians and patients.

This study also has shown that most of the patients found out about their kidney failure only one month before modality initiation. The same scenario was reported for referring to a nephrologist. In fact, most patients visited the nephrologist when they lost their kidney function.

Mehrotra *et al.*,¹⁵ showed a lower percentage of patients who knew about their kidney failure for less than a month compared to our study. Moreover, the percentage of patients who visited a nephrologist only 4 months or less before starting the dialysis was lower compared to our study.

Early patient education, as an essential component, can contribute significantly to slow the progression of kidney failure and improve patient survival and may help to make the best decision.^{16,17,18} In the present study, the majority of the patients (68%) mentioned that different types of RRT were not presented to them. and just dialysis was started which was significantly higher than the number reported in Mehrotra *et al.* study (30%).¹⁵ Contrary to our study, in Morton *et al* study; 84% of the patients received information about different types of renal replacement therapy prior to commencing treatment.¹⁶

A qualitative study in 2017 with staff and patients about pre-dialysis education confirmed that patients eagerly waiting for improvement on teaching materials and methods and focusing on a much more individualized approach to include patients' interests and better acceptance of their treatment choice.²⁰ In our study, face to face discussion with the doctor and/or nurse was the most common type of material used to explain

treatment options to the patients and 39.3% of the patients were somewhat satisfied with the information received.

In contrast, according to Mehrotra *et al.* study, 68% of the patients were satisfied with the information received and only 17% indicated that little or no information was given¹⁵. The high level of dissatisfaction regarding the amount of information given to patients in our study may be due to the method of training, duration of disease awareness and the short duration of time that patient visited a nephrologist before starting the modality.

In the present study, we found that the majority of the patients wanted to receive kidney transplant and believed that it could have huge effect on their quality of life. While, half of the patients were referred for evaluation of kidney transplantation. In Gordon study, 68% of the patients reported that they were encouraged by nephrologists to have kidney transplantation.²² The low percentage reported in other studies^{15,21} may be due to inadequate information of the patients about kidney transplantation and poor communication between nephrologist / dialysis physicians and the patients.²¹ Indeed, in good training course and the information which is given to the patients the pros and cons of all methods should be mentioned and the patients must have participation in the selecting the best choice for themselves and they should know about the possibility of preemptive kidney transplantation in the country, as well.

In our study, patients who wanted to receive a kidney transplant were younger than who did not. According to Chanouzas *et al.* study, age is one of the non-modifiable factors that influence patient choice of treatment modality at the pre-dialysis stage.²³ In addition, male patients were more interested than female patients to receive kidney transplant, which was consistent with Morton *et al.* study.¹⁶ While, in Chanouzas study, gender has no significant role among the patients with different renal replacement therapies.²³ We have shown that the patients who were homemaker and had low level of education were less interested to receive a kidney transplant. Ghahramani *et al.* had shown that patient's social support, understanding and age were the most important factors that a nephrologist considered for referring the patients for kidney transplantation.²⁴ Robert *et al.* in 2017

indicated that poverty and African-American race were independently associated with a lower pre-ESRD care.²⁵ Age, presence of co-morbidity, being married and employed, and having another person living at home were among the significant factors which affect the mode of treatment.²³ While, younger age, male gender, married status, employment status and high level of education were the significant factors for choosing a kidney transplant as a treatment option in our study. It is obvious that men are more breadwinners at home and they want to pursue a kidney transplant and to have time to work and to be more active in the community. Garg *et al.* recently in a study showed that there are different barriers for kidney transplantation and patient related factors were included as poor transplant knowledge and fear or uncertainty about kidney transplantation. They applied a cluster randomized clinical trial which finally resulted in about 7% rise in 1 year kidney transplantation referral in ESRD patients.²⁶ This study emphasizes the role of education of CKD and ESRD patients toward kidney transplantation.

CONCLUSION

Although most of the patients wanted to receive a kidney transplant, kidney transplant was offered initially to a small number of patients and half of them were referred to a kidney transplant center in order to be evaluated and finally just 21% of the patients were included in the kidney transplantation list. Assessing the reasons why kidney transplant was not offered to large proportions of ESRD patients was out of scope of this study, however it could be an important issue and calls for future educational interventions. Age, gender, marital status, employment status, and high level of education may affect patient desire to receive kidney transplantation. Actually, education and giving relevant information would be helpful in active participation of the patients in selecting the best method of RRT for themselves.

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CONFLICT OF INTEREST

None.

DISCLOSURE

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