



## FULL LENGTH ARTICLE

# Measuring Patients' Level of Knowledge Regarding Kidney Transplantation in Eastern Hungary

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## ABSTRACT

Adequate knowledge is needed to make the correct decision regarding kidney transplantation. The purpose of this study was to measure the demographic, sociologic, economic, and cultural factors that may influence patients' decision-making regarding kidney transplantation and to explore patients' knowledge of renal replacement therapies. A total of 254 end-stage renal disease patients (predialysis, peritoneal dialysis, and hemodialysis) from 8 dialysis centers in eastern Hungary participated in our study. We developed a questionnaire that measures patients' knowledge of renal replacement therapies and the role of sociodemographic, economic, and cultural factors that may influence their knowledge. Factors influencing the knowledge scores were evaluated using a multivariate linear regression adjusted for 8 factors. We found a significant correlation between education level and knowledge score, where patients with greater education (greater than high school:  $\beta = 3.003$ ;  $P < .001$ ; high school:  $\beta = 1.906$ ;  $P < .001$ ) achieved higher knowledge scores than those without. Moreover, patients with a previous kidney transplant ( $\beta = -2.111$ ;  $P < .001$ ) had greater knowledge in the field. Our study identified a risk group where targeted, personalized patient education is essential.

**T**HE overall number of patients with end-stage renal disease (ESRD) receiving renal replacement therapy has increased steadily all over the world [1]. Hungary reported 999 patients with ESRD per million general population (PMP) in 2016. According to the United States Renal Data System 2018 Annual Data Report [2], Taiwan, the United States, the Jalisco region of Mexico, and Thailand showed the highest incidence of patients treated for ESRD, where the lowest incidence rate was approximately 346 PMP. However, it is closely followed by Hungary with 222 PMP. Dialysis is more common than other renal replacement therapies in the majority of countries, including Hungary [2], where the number of patients entering the dialysis program increases every year [3,4]. At the same time, the rate of increase in kidney transplantation is lower, though it is scientifically proven that this is the best available treatment choice [5]. According to the most recent data Hungary reported 53 kidney transplants per 1000 patients on dialysis in 2016 [2]. These trends support the increasing importance of educating

patients to enable them to actively participate in the decision-making process in selecting the modality for treatment of ESRD.

Beyond medical factors [6], there are many nonmedical factors that influence access to kidney transplantation such as the patient's demographic, sociologic, economic, or cultural background. Moreover, the patient's attitude and knowledge of treatment can also play a role [7]. Good decision making depends on correct knowledge [8], the lack of which may adversely influence the decision-making process [9]. The need to educate patients with ESRD is indisputable [10,11]. However, there are not many validated and standardized measurement tools specifically designed to measure patients' specific knowledge regarding renal replacement therapy [12,13].

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In the past few years the attitude of end-stage renal disease patients toward kidney replacement treatments have been explored using an attitude questionnaire developed specifically for this purpose [14]. The results of the study showed that patients with ESRD have a negative attitude toward kidney transplantation and are not yet motivated to change treatment modality [15]. However, patients' disease-specific knowledge was not measured.

## AIM

The present study is a continuation of the psychological attitude study by Illés et al [14, 15], which aimed to identify demographic, sociologic, economic, and cultural factors that may influence patients' decision-making regarding kidney transplantation. In addition, we aimed to explore patients' knowledge regarding renal replacement therapy, which, as a potentially modifiable factor, may influence the decision-making process.

## PATIENTS AND METHODS

Debrecen as a transplantation center is responsible for kidney transplantation in 3 counties (Hajdú-Bihar, Szabolcs-Szatmár-Bereg, and Borsod-Abaúj-Zemplén). The first data collection of our follow-up study started in September 2018 and lasted for a year. During this period the following patients were contacted: patients on the waiting list, patients undergoing medical evaluation, and patients who refused a kidney transplant. A total of 254 end-stage renal disease patients (pre-dialysis, peritoneal dialysis, and hemodialysis) from 8 dialysis centers in the region participated in our study.

A questionnaire was developed to assess knowledge regarding renal replacement therapy that measures patient knowledge and the role of socio-demographic, economic, and cultural factors that may influence it. The developed 15-item knowledge test included true-false and simple-choice

types of questions. To prevent patients from answering certain questions without actually knowing the correct answer, there was an "I do not know" option for each question. The questions on the knowledge test were grouped as follows: 4 questions on dialysis treatment, 5 questions on kidney transplantation, and 6 questions on living-donor kidney transplantation. After completing the questionnaire, patients received information about kidney transplantation from a health professional side and also from a kidney transplant patients' perspective. In addition, they received a handout where they were able to find answers to questions that would arise after the education. The second data collection will take place not earlier than 6 months after the patients have received the necessary education. This will provide information on both the effectiveness of our educational program and changes in patients' condition.

Statistical analysis was performed with SPSS version 22.0 statistic software package. Factors influencing knowledge scores were evaluated by univariate and multivariate linear regressions adjusted for 8 explanatory variables. In all cases, the outcome variable was the total score achieved. The explanatory variables included demographic (age, sex, ethnicity, educational background), patient-related (transplantation status, prior kidney transplantation), and care-related (dialysis treatment location and modality) factors.

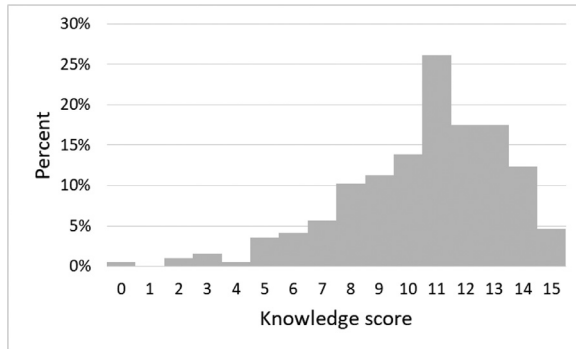
## RESULTS

### Sociodemographic and Clinical Characteristics

As shown in Table 1, the mean age of the participants was 48.75 years (SD = 13.24). The female:male ratio was 1.82 (females: 35.4%; males: 64.6%). There were 42 Roma in the sample (16.5%). Most participants had a high school equivalency diploma (less than high school: 20.2%; high school equivalent: 67.2%; greater than high school: 12.6%). Kidney transplantation was rejected by 63 participants (24.8%). Forty-four (17.5%) patients had a previous kidney transplant. The proportion of patients from the 3 counties was similar (Hajdú-Bihar: 32.3%; Szabolcs-Szatmár: 32.3%; Borsod-Abaúj-Zemplén: 35.4%). With

**Table 1. Sociodemographic and Clinical Characteristics of the Study Population**

| Characteristics          |                        | Mean (SD)     | SD    |
|--------------------------|------------------------|---------------|-------|
| Age                      | Year                   | 48.75 (13.24) | 13.24 |
|                          |                        | n             | %     |
| Sex                      | Female                 | 90            | 35.4  |
|                          | Male                   | 164           | 64.6  |
| Ethnicity                | Roma                   | 42            | 16.5  |
|                          | Non-Roma               | 212           | 83.5  |
| Education level          | Less than high school  | 51            | 20.2  |
|                          | High school            | 170           | 67.2  |
|                          | More than high school  | 32            | 12.6  |
| Transplantation status   | Refused                | 63            | 24.8  |
|                          | Did not refuse         | 163           | 64.2  |
| Previous transplantation | No                     | 207           | 81.8  |
|                          | Yes                    | 44            | 17.5  |
| Location of dialysis     | Szabolcs-Szatmár-Bereg | 82            | 32.3  |
|                          | Hajdú-Bihar            | 82            | 32.3  |
|                          | Borsod-Abaúj-Zemplén   | 90            | 35.4  |
| Modality of dialysis     | Hemodialysis           | 211           | 83.0  |
|                          | Peritoneal dialysis    | 29            | 11.4  |
|                          | Pre-dialysis           | 14            | 5.6   |



**Fig 1.** Histogram of knowledge scores in the study population.

respect to the modality of dialysis, the majority of patients receive hemodialysis treatment (83.0%; peritoneal dialysis: 11.4%; predialysis: 5.6%).

#### Knowledge Level

Patients achieved 10.6 points out of a maximum of 15 points (SD = 2.76) in the knowledge test (Fig 1). After analyzing each question group, lack of patient knowledge was observed regarding living-donor kidney transplantation (3.5 out of 6 possible points). They had the most information about dialysis treatment (3.6 out of 4 possible points). Patient knowledge regarding kidney transplantation was good (3.7 out of 5 possible points).

Table 2 shows the results for univariate descriptive statistics. No significant association was found ( $P = .485$ ) when we compared knowledge scores between females and males (females: median = 11, IQR = 4; males: median = 11, IQR = 4). There was no significant relationship between patients who refused

(median = 11, IQR = 4) and those who accepted (median = 11, IQR = 5) kidney transplantation. Similar results were found when comparing the median for the location (county;  $P = .601$ ) and modalities of dialysis ( $P = .210$ ). Borderline significance was observed for age ( $P = .050$ ). Moreover, a significant relationship was found between knowledge scores and education levels ( $P < .001$ ), previous kidney transplantations ( $P < .001$ ), and ethnicity ( $P = .006$ ).

Table 3 shows the results of multivariate linear regression. Patient knowledge regarding renal replacement therapy was not affected ( $P > .05$ ) by sex, ethnicity, transplantation status, location of dialysis, or modality of dialysis. However, patients with greater than high school education ( $\beta = 3.003$ ;  $P < .001$ ) and high school education ( $\beta = 1.906$ ;  $P < .001$ ) achieved higher knowledge scores compared with patients with less education. Patients who had a previous kidney transplant also achieved higher scores ( $\beta = -2.111$ ;  $P < .001$ ).

#### DISCUSSION

Based on the results of the knowledge test, the overall knowledge of end-stage renal disease patients on renal replacement therapy is acceptable. However, when we analyzed the measure scores of the questions in the 3 question groups (dialysis, kidney transplant, and living-donor kidney transplant), we found that patients lacked knowledge regarding living-donor kidney transplantation. Lack of knowledge regarding the essentials of renal replacement therapies has been noted previously in patients with chronic disease [12,13]. Identifying gaps in patients' knowledge can help health care professionals to tailor health education messages to the needs and capacity of the patient in order to improve compliance and outcomes. Incomplete knowledge can have several negative consequences.

**Table 2. Univariate Descriptive Statistics Results**

| Variables                |                        | Mean (SD)     | P Value |
|--------------------------|------------------------|---------------|---------|
| Age                      | Year                   | 48.75 (13.24) | .050    |
|                          |                        | Median (IQR)  | P Value |
| Sex                      | Female                 | 11 (4)        | .485    |
|                          | Male                   | 11 (4)        |         |
| Ethnicity                | Roma                   | 11 (4)        | <.001   |
|                          | Non-Roma               | 10 (3)        |         |
| Education level          | Less than high school  | 9 (4)         | <.001   |
|                          | High school            | 11 (4)        |         |
|                          | More than high school  | 12 (2.5)      |         |
| Transplantation status   | Refuse                 | 11 (4)        | .145    |
|                          | Do not refuse          | 11 (5)        |         |
| Previous transplantation | No                     | 13 (2.5)      | <.001   |
|                          | Yes                    | 11 (3)        |         |
| Location of dialysis     | Szabolcs-Szatmár-Bereg | 11 (3)        | .601    |
|                          | Hajdú-Bihar            | 11 (4)        |         |
|                          | Borsod-Abaúj-Zemplén   | 11 (4)        |         |
| Modality of dialysis     | Hemodialysis           | 11 (4)        | .210    |
|                          | Peritoneal dialysis    | 11 (2)        |         |
|                          | Pre-dialysis           | 10.5 (4)      |         |

IQR, interquartile range.

Table 3. Multivariate Linear Analysis Results

| Variables                |   | Coeff. | P Value |
|--------------------------|---|--------|---------|
| Age                      | Year  | −0.021 | .094    |
| Sex                      | Female/male                                 | 0.382  | .264    |
| Ethnicity                | Roma/non-Roma                               | −0.248 | .636    |
| Education level          | High school/less than high school           | 1.905  | <.000   |
|                          | More than high school/less than high school | 3.003  | <.000   |
| Transplantation status   | Refused/did not refuse                      | −0.538 | .145    |
| Previous transplantation | No/yes                                      | −2.111 | <.000   |
| Location of dialysis     | Szabolcs-Szatmár-Bereg/Hajdú-Bihar          | −0.443 | .265    |
|                          | Borsod-Abaúj-Zemplén/Hajdú-Bihar            | 0.808  | .115    |
| Modality of dialysis     | Peritoneal dialysis/hemodialysis            | 0.807  | .115    |
|                          | Pre-dialysis/hemodialysis                   | −0.737 | .361    |

According to Waterman and his colleagues it can cause kidney function to deteriorate as well [16]. Moreover, it can prevent the possibility of choosing transplantation as a treatment option [17]. The number of living-donor kidney transplants performed in Hungary, which has increased in recent years, is still below the European average [18]. Moreover, cross-over kidney transplantation is supported by local legal acts, however no transplantation of this type has been executed yet in Hungary. [19]. For patients with ESRD, living-donor kidney transplantation is the best available treatment choice because it offers longer graft survival [20]. Taking into consideration these data and the results of our study, the primary task would be the dissemination of information to encourage living donation among patients' relatives. This could be achieved by involving health care professionals specializing in the field and living donor pairs. Appropriate dissemination of information can increase patient knowledge, which may have a positive effect on the number of living-donor transplants performed.

There are 2 main factors influencing patients' knowledge regarding renal replacement therapy. The results of the present study show that there is a significant relationship between knowledge and education level. Moreover, a significant difference was found for a higher level of knowledge among previous kidney transplant recipients. In our study we identified a risk group for whom targeted, personalized patient education is essential. To determine that age is not an influencing factor, further studies are needed that take into account the results of univariate descriptive statistics and multivariate linear regression analysis. Targeted, personalized education is essential, especially among patients with lower education levels and those who have not previously undergone kidney transplantation. There is a need to develop an educational program that is tailored to the needs of patients in which current renal transplant recipients play a key role. It is important to note that inadequate knowledge is not the only factor that influences patients' preferences for renal replacement therapies and that adequate knowledge will not result in a direct behavioral change. However, knowledge is a critical and modifiable factor, because previous research showed that misconceptions are frequent [7-9].

## CONCLUSIONS

The results of our study provide insight into the knowledge gaps and important factors influencing decision making among patients with ESRD. Health care professionals, such as physicians and nurses, could use our questionnaire in the pretransplant setting to identify areas of patient misunderstanding so that they can provide appropriate information according to the needs of the patients. Our disease-specific questionnaire can easily be implemented in clinical practice improvement or other research to measure the effect of educational interventions focused on supporting informed decision making. Further use of the questionnaire in other patient subgroups such as people with kidney transplant can also provide a better understanding of the kidney transplantation process.

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