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Sociodemographic factors and patient perceptions are associated with attitudes to kidney transplantation among haemodialysis patients

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Abstract

Background. Treatment decisions made by patients with chronic kidney disease are crucial in the renal transplantation process. These decisions are influenced, amongst other factors, by attitudes towards different treatment options, which are modulated by knowledge and perceptions about the disease and its treatment and many other subjective factors. Here we study the attitude of dialysis patients to renal transplantation and the association of sociodemographic characteristics, patient perceptions and experiences with this attitude.

Methods. In a cross-sectional study, all patients from eight dialysis units in Budapest, Hungary, who were on haemodialysis for at least 3 months were approached to complete a self-administered questionnaire. Data collected from 459 patients younger than 70 years were analysed in this manuscript.

Results. Mean age of the study population was 53 $\pm$ 12 years, 54% were male and the prevalence of diabetes was 22%. Patients with positive attitude to renal transplantation were younger (51 $\pm$ 11 versus 58 $\pm$ 11 years), better educated, more likely to be employed (11% versus 4%) and had prior transplantation (15% versus 7%)($P < 0.05$ for all). In a multivariate model, negative patient perceptions about transplantation, negative expectations about health outcomes after transplantation and the presence of fears about the transplant surgery were associated, in addition to increasing age, with unwillingness to consider transplantation.

Conclusions. Negative attitudes to renal transplantation are associated with potentially modifiable factors. Based on this we suggest that it would be necessary to develop standardized, comprehensible patient information systems and personalized decision support to facilitate modality selection and to enable patients to make fully informed treatment decisions.

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Introduction

Successful kidney transplantation offers improved quality of life, increased life expectancy and greater physical and occupational rehabilitation compared to chronic dialysis for patients with end-stage renal disease (ESRD) [1–3]. Previous studies demonstrated sociodemographic differences in access to renal transplantation (Tx) [4–10]. A growing body of evidence, mainly from the United States, has shown that women, elderly individuals, and low-income and ethnic minority patients undergoing renal replacement therapy are less likely to receive waiting list and transplantation access than men, young, wealthy or white individuals [4–9]. This tendency may be observed at every step along the road to transplantation, even at the early listing phase [11]. Increasing attention has been recently directed to the organ allocation process and there is a considerable need for research assessing access to renal Tx [4,6,12].

Developing interest in renal transplantation is the first step in the transplantation sequence that precedes referral to a transplant centre, medical evaluation and—in the case of suitability—transplantation waiting list enrolment. However, patients' views about their desire for Tx and factors associated with choosing or not choosing Tx have not yet been studied closely.

Attitude is a hypothetical construct that represents an individual's like or dislike for an item. Attitudes are positive, negative or neutral views of an 'attitude object', i.e. a person, behaviour or event [13]. The results of a few previous studies about decision making of ESRD patients suggested that individual preferences, perceptions and sociodemographic characteristics influenced the attitudes of patients to renal transplantation and also their treatment decisions [12,14,15]. Lack of information and false

information about Tx and its risks may result in building or reinforcing fears, worries and negative attitudes [14,16]. Patients' attitudes, in turn, may influence treatment decisions and form a barrier to the access to transplantation and may explain in part the observed disparities in Tx rates [14,16,17].

Despite the growing number of dialyzed patients in Hungary, the number of transplantations has remained stagnant during the last 5 years and the proportion of waitlisted patients has been declining [18]. This cannot be fully explained by the increasing age and comorbidity of incident dialysis patients. Patients' perceptions and insufficient and false information about Tx might also be contributing factors resulting in decreased access to renal Tx among dialysis patients [14,16,19].

The primary objective of our study was to assess the associations between sociodemographic factors, perceptions regarding ESRD treatment options (dialysis versus Tx), information on Tx and willingness to consider renal Tx in ESRD patients on maintenance haemodialysis. We hypothesized that sociodemographic characteristics and also patients' perceptions and experiences would be associated with attitude, characterized by willingness and recommendation of renal Tx to others.

Subjects and methods

Patient sample and study design

All patients who had been receiving haemodialysis therapy for ESRD in Budapest (in all eight dialysis centres in the capital) for at least 3 months were approached to participate in this multi-centre cross-sectional survey between May 2001 and April 2003. Patients with dementia were excluded. As the prevalence of peritoneal dialysis at these centres was very low (<5% in each centre), only haemodialysis patients were enrolled. Consenting patients were asked to complete the study questionnaire while waiting for their dialysis chair or while receiving dialysis treatment. The questionnaire was self-administered. A trained research assistant was available to address questions if needed.

The Institutional Review Board of the Semmelweis University Budapest approved the study protocol. All patients approached received detailed verbal and written information about the aims and methods of the survey.

Study questionnaire

A questionnaire was developed specifically for the purpose of this study and then modified during two focus-group sessions. During these sessions, dialysis patients (including patients with past experience of renal transplantation), nephrologists, psychiatrists and dialysis nurses generated additional items and also evaluated the items generated by the research team. A final questionnaire was constructed that contained items focusing on several domains that participants perceived as important related to renal transplantation: (1) patient characteristics, (2) attitudes to transplantation, (3) perceptions and expectations about kidney transplantation and (4) information about transplantation. This instrument was subsequently pilot tested for content and comprehensibility in a convenience sample of 15 dialysis patients in one centre. Participants of this pilot study found the questionnaire relevant and comprehensive and suggested only minor changes in the wording of two items. After slight modifications of wording, the final questionnaire was assembled.

We did not aim to develop a standard scale or profile where individual items would be combined to provide a composite score; instead we generated the items to be analysed individually.

Patient characteristics

We asked the patients to report their gender, age, level of education, employment and marital status. We also asked the participants to rate their overall financial situation on a five-point Likert scale (from 'very poor' to 'excellent'). We asked the patients about their transplantation and dialysis history, the presence of diabetes and knowledge about being on the transplantation waiting list (WL) and if they considered themselves suitable for renal transplantation. We confirmed the transplant list status, diabetes status and ESRD vintage from the medical records. Self-rated health status was assessed by a five-point Likert scale [20,21]. Patients were asked to rate their current health status from excellent to poor.

Study questionnaire: attitudes, perceptions, information and knowledge about Tx

Attitude to renal Tx, defined as willingness to accept and recommendation of Tx to others, was assessed by asking four questions with three possible answers (Table 1). Perceptions about Tx, potential fears and worries about transplantation were assessed by a similar method using a five-point Likert scale. Subsequently, we asked patients to estimate their overall health in 1 year if they stayed on dialysis and 1 year after a successful kidney transplant (Table 1). Information and knowledge about renal transplantation were also measured by five-point Likert scales ('fully agree', 'mostly agree', 'mostly disagree', 'fully disagree' or 'don't know') (Table 1). Patients were also asked to tell us who the most important source of information about transplantation would be for them (their nephrologist, nurses, fellow dialysis patients, transplanted patients, other). For any questions, when the proportion of patients answering 'don't know' was below 5%, 'don't know' answers were not analysed and were considered missing information.

Statistical analysis

Statistical analysis was performed using the SPSS statistical software SPSS Inc., (Chicago, IL, USA). In all cases, *P*-values are two-sided. Descriptive statistics were used to compare sociodemographic characteristics, perceptions, information and knowledge on Tx by willingness towards Tx (wants versus does not want groups) and recommendation of Tx to a 67-year-old woman (recommends versus does not recommend). Group differences were compared by using Pearson's chi-square test for categorical variables, the

Table 1. Items of the questionnaire assessing attitude towards renal transplantation, perceptions about treatment modalities and information about renal transplantation (Tx) with the corresponding answer options

Attitudes towards Tx	'Would you like to receive a kidney transplant?'	Yes	No	Don't know		
	'If you were offered a kidney transplant right after your dialysis now, would you accept that kidney?'					
	'Would you recommend Tx to a 67-year-old woman?'					
	'Would you recommend Tx to a 35-year-old man?'					
Information and knowledge about Tx	'I have received insufficient information regarding Tx.'	Fully agree	Mostly agree	Mostly disagree	Fully disagree	Don't know
	'The first transplanted kidney is usually rejected within the first year after Tx.'					
	'Tx is more successful in men than in women.'					
	'I have seen many sad and unsuccessful cases after Tx.'					
	'I have seen many successful cases after Tx.'					
Perceptions about Tx and dialysis	'Tx is the best possible solution for a patient on dialysis.'	Fully agree	Mostly agree	Mostly disagree	Fully disagree	Don't know
	'One can start a new life after Tx.'					
	'Tx causes more problems than benefits for the patient.'					
	'I am afraid of the transplant surgery.'					
	'I am concerned about the medical treatment following Tx.'					
	'What do you think your overall health will be like in one year if you stay on dialysis?'	Very poor—1	Poor—2	Fair—3	Good—4	Excellent—5
	'What do you think your overall health will be like in one year after a successful kidney transplantation?'					

t-test for normally distributed continuous variables and the Mann–Whitney test for continuous variables with skewed distribution, as appropriate. Variables associated with willingness at a *P*-value ≤ 0.05 were then entered into a binary logistic regression model to examine the independent association of sociodemographic factors, patients' treatment perceptions and information about Tx on willingness.

Model building was performed in a backward stepwise algorithm based on the Wald statistics and variables with a *P*-value <0.15 were kept in the final model. Variance influence factors (VIF) were used to indicate collinearity between independent variables.

Results

Of 648 patients approached, 591 (91%) agreed to participate. Non-responders were significantly older ($P < 0.001$) and more likely to be female ($P = 0.008$). No other data were collected from those who refused to participate due to lack of consent. Patients who were older than 70 years were excluded from our analyses, since the oldest patient on the Tx WL was 70 years old in our study population and Tx rates are very low above this age [22]. Thus, the final sample included 459 patients.

Attitudes for renal transplantation

Of the 459 patients included in this analysis, 325 (71%) reported yes for the question of whether they wanted to be transplanted and practically the same group of patients (320, 70%) said that they would accept a kidney immediately. Thus, we did not analyse answers for this latter question to avoid redundancy. Two hundred and eighty patients (61%) would have recommended Tx to a 67-year-old woman, while 91% would have recommended Tx for a 35-year-old man. Because of the large proportion of concordant answers for the last question, we did not perform group comparisons analysing this question, since further analyses would have had low explanatory power.

Demographic and baseline characteristics of the study population are shown in Table 2 by answers for the questions "Would you like to receive a kidney transplant?" and "Would you recommend renal transplantation for a 67-year-old woman?"

In bivariate comparisons, those who wanted a transplant were younger (51 ± 11 versus 58 ± 11 years, $P < 0.0001$), more likely male (56% versus 46%, $P = 0.056$) and employed (either full time or part time) (11% versus 4%, $P = 0.04$) and more likely to have spent >8 years in formal education (70% versus 56%, $P = 0.006$) than those who did not want to consider the procedure. They were also more likely to have had a prior transplantation (15% versus 7%, $P = 0.035$). The likelihood of being definitely interested in transplantation decreased with increasing age (87%, 76%, 49% for ages 18–44, 45–64 and over 65 years, respectively, $P < 0.001$). The groups with positive versus negative attitudes to Tx did not differ in the proportion of diabetic patients (21% versus 25%, $P = 0.403$, for those who wanted versus did not want, respectively) and marital status.

Table 2. Patient characteristics by attitude to renal transplantation

		Wants a transplant			Recommends Tx to a 67-year-old woman		
	Total ($n = 459$)	Yes ($n = 325$)	No ($n = 116$)	*P*-value	Yes ($n = 280$)	No ($n = 132$)	*P*-value
Mean age ± SD, year	53 ± 12	51 ± 11	58 ± 11	<0.001	53 ± 12	54 ± 11	NS
Age groups, *n* (%)				<0.001			NS
18–44 years	105 (23)	87 (27)	13 (11)		66 (24)	27 (20.5)	
45–64 years	265 (58)	196 (60)	60 (52)		158 (56)	78 (59)	
65 years and over	89 (19)	42 (13)	43 (37)		56 (20)	27 (20.5)	
Male, *n* (%)	245 (54)	182 (56)	53 (46)	0.056	154 (55)	67 (51)	NS
Married, *n* (%)	262 (57)	192 (59)	64 (55)	NS	182 (65)	65 (49)	0.038
Poor self-rated financial status, *n* (%)	170 (37)	124 (38)	41 (35)	NS	109 (39)	50 (38)	NS
Employed, *n* (%)	41 (9)	36 (11)	5 (4)	0.04	20 (7)	9 (7)	NS
10 years or more in education, *n* (%)	303 (66)	228 (70)	65 (56)	0.006	185 (66)	81 (61)	0.046
ESRD time (months), median (min–max)	34 (3–240)	31 (3–228)	39 (3–240)	NS	36 (3–228)	34 (3–240)	NS
Diabetes, *n* (%)	101 (22)	68 (21)	29 (25)	NS	64 (23)	25 (19)	NS
Previous transplant, *n* (%)	55 (12)	49 (15)	8 (7)	0.035	42 (15)	9 (7)	0.035
Medically suitable, *n* (%)	239 (52)	211 (65)	16 (14)	<0.001	165 (59)	44 (33)	<0.001
Considers himself or herself suitable for Tx, *n* (%)	270 (61)	231 (73)	26 (24)	<0.001	190 (68)	57 (43)	<0.001
Wants a transplant, *n* (%)	325 (71)	NA	NA		235 (84)	58 (44)	<0.001
Recommends Tx to a 35-year-old man, *n* (%)	416 (91)	316 (99)	90 (83)	<0.001	273 (99)	112 (89)	<0.001

Three-quarters of the patients (73%) who wanted, whereas only 24% of those who did not want Tx, considered themselves suitable for transplantation ($P < 0.001$).

As for the second question assessing transplant-related attitudes ("Would you recommend renal transplantation for a 67-year-old woman?"), a somewhat different picture was seen. Neither age nor gender was different between those who would versus would not recommend Tx. Similarly to the previous question, however, patients with previous transplant experience, or those who considered themselves suitable for Tx were more likely to recommend Tx for others (Table 2).

Perceptions and expectations

Most study participants, 390 persons (85%), mostly or strongly agreed with the statement that renal transplantation is the best possible solution for a patient on dialysis. Those who did not want transplantation were less likely to agree with this statement (74% of patients who did not want versus 95% of those who wanted Tx, $P < 0.001$). Interestingly, 35% of the participants believed that transplantation brings more problems than benefits. Fifty-two percent of the patients who did not want transplant versus only 24% of those who wanted a transplant agreed with this statement ($P < 0.001$) (Table 3). Responses to the questions "Renal transplantation is the best possible solution for a patient on dialysis" and "One can start a new life after kidney transplantation" defined practically the same group of individuals.

To assess if attitudes to renal transplantation are associated with different expectations in health outcomes delivered by the different treatment modalities, patients were asked to rate their current health, their expected health status 1 year later if they stayed on dialysis and their expected health status 1 year later if they received a renal transplant (Table 3). The current self-rated health (SRH) score was similar between the groups with different attitudes. Patients who wanted a Tx expected a decline in SRH if they stayed on dialysis but expected a substantial improvement after renal Tx ($P < 0.001$ for both comparisons). In contrast, patients who did not want Tx expected their health to remain unchanged on dialysis and did not expect a significant improvement after Tx either ($P =$ NS for both cases). While almost three-quarters of the patients (72.3%) who wanted a Tx expected their health to improve after Tx and only 4% expected a decline, less than half of the patients who did not want Tx (43.5%) expected an improvement and one out of four (26.1%) expected a decline. Qualitatively similar trends are seen in patients who recommended Tx to others versus the ones who did not (not shown).

To further explore potential factors that are associated with attitudes to transplantation, we analysed the fears and worries patients may have about renal Tx. Almost half of the respondents reported to have significant fears about the transplant surgery (46%) and the immunosuppressive medications (45%). This proportion was 38% and 37%, respectively, in the group that wanted Tx, whereas it was almost twice as much (72% and 68%, respectively) in the group that did not want Tx ($P < 0.001$ for both comparisons). Again, qualitatively similar trends are seen in patients who recommend Tx to others versus the ones who did not (Table 3).

Information about transplantation

A series of questions were asked from the patients to help us understand how informed they were about renal transplantation, what the sources of their information were and whom they felt was the most important source of information for

Table 3. Patient perceptions by attitude to renal transplantation

		Wants transplant			Recommends transplant to a 67-year-old woman		
	Total	Yes	No	*P*-value	Yes	No	*P*-value
Transplant is the best solution, *n* (%)				<0.001			<0.001
Fully or mostly agree	390 (85)	306 (94)	75 (65)		257 (92)	99 (75)	
Fully or mostly disagree	46 (10)	16 (5)	27 (23)		17 (6)	22 (17)	
Don't know	23 (5)	3 (1)	14 (12)		6 (2)	11 (8)	
Transplant causes more trouble, *n* (%)				<0.001			
Fully or mostly agree	147 (32)	80 (25)	60 (52)		76 (27)	55 (42)	<0.001
Fully or mostly disagree	280 (61)	233 (72)	37 (32)		193 (69)	62 (47)	
Don't know	32 (7)	12 (4)	19 (16)		11 (4)	15 (11)	
Mean SRH ± SD	2.88 ± 0.9	2.89 ± 0.9	2.87 ± 0.8	NS	2.84 ± 0.9	2.88 ± 0.8	0.066
Mean SRH in 1 year on dialysis ± SD	2.64 ± 0.9	2.58 ± 0.9	2.83 ± 0.9	0.022	2.55 ± 0.9	2.78 ± 0.9	0.035
Mean SRH 1year after transplant ± SD	3.78 ± 0.8	3.96 ± 0.6	3.1 ± 0.9	0.001	3.91 ± 0.7	3.52 ± 0.9	0.001
Fear of transplant, fully or mostly agree, *n* (%)	206 (46)	120 (37)	82 (72)	<0.001	98 (35)	86 (65)	<0.001
Fear of medication, fully or mostly agree, *n* (%)	198 (45)	123 (38)	79 (68)	<0.001	106 (38)	81 (61)	<0.001

Table 4. Patient information and knowledge by attitude towards renal transplantation

		Wants transplant			Recommends transplant to a 67-year-old woman		
	Total	Yes	No	*P*-value	Yes	No	*P*-value
Saw successful Tx cases, fully or mostly agree, *n* (%)	312 (71)	249(77)	63 (55)	<0.001	216 (77)	73 (55)	<0.001
Saw many sad cases, fully or mostly agree, *n* (%)	140 (32)	81 (25)	57 (50)	<0.001	115 (28)	57 (43)	0.009
Received insufficient information	250 (56)	179 (55)	70 (60)	NS	154 (55)	81 (61)	NS
Tx is more successful for men							
Fully or mostly agree	73 (16)	52 (16)	22 (19)	0.043	39 (14)	32 (24)	0.042
Fully or mostly disagree	219 (48)	166 (51)	44 (38)		140 (50)	58 (44)	
Don't know	167 (36)	107 (33)	50 (43)		101 (36)	42 (32)	
Graft is rejected within 1 year, *n* (%)							
Fully or mostly agree	92 (20)	46 (14)	41 (35)	<0.001	51 (18)	36 (27)	0.013
Fully or mostly disagree	308 (67)	244 (75)	50 (43)		204 (73)	78 (59)	
Don't know	59 (13)	35 (11)	25 (22)		25 (9)	18 (14)	

them. Although the overwhelming majority of the patients (>90%) suggested that the most important source of information would have been their nephrologist, 114 (24.8%) of patients reported not to have heard about Tx from their doctor. Out of these patients, 58 (51%) reported to have heard about Tx from other dialyzed or kidney-transplanted patients. The distribution of the answer to this question did not differ between the groups with different attitudes (not shown).

Almost one-third of the study population reported to have seen unfavourable outcomes (32%) and 71% of them saw favourable examples regarding Tx. Seventy-seven percent versus 55% of the patients who wanted versus did not want Tx, respectively, said that they had seen many successful transplant cases and 25% versus 50%, respectively, admitted that they had seen many sad and unsuccessful cases ($P < 0.001$ for both) (Table 4).

Importantly, 56% of the participants suggested that they received insufficient information about the transplant, with no difference between the groups (Table 4). Patients with a positive attitude to Tx, however, had more accurate knowledge about transplantation. Seventy-five percent versus 43% of the patients who wanted versus did not want Tx disagreed with the statement that the transplanted kidney would be rejected within 1 year ($P < 0.001$), and 51% versus 38% disagreed with the statement that transplantation is more successful in men versus women ($P = 0.043$).

When we repeated our analyses in the whole patient population involving patients over the age of 70 years, all bivariate comparisons regarding willingness towards Tx

Table 5. Factors associated with positive attitude to renal transplantation (dependent variable: 'Would you want to be transplanted?')

	Odds ratio (95% CI)	*P*-value
Age, years (for 1-year increase)	0.94 (0.89–0.98)	0.015
More than 8 years of formal education (versus 8 years or less of formal education)	2.27 (0.95–5.41)	0.064
Health condition in 1 year on dialysis (reference: decline)		0.108
Improve	0.25 (0.06–0.95)	0.042
Same	0.47 (0.18–1.25)	0.131
Health condition in 1 year after transplant (reference: decline)		0.102
Improve	4.23 (1.09)	0.036
Same	2.76 (0.61)	0.186
Considers himself or herself suitable for Tx (reference: no)	5.08 (2.14)	$P<0.001$
Saw many unsuccessful cases (reference: no)	0.42 (0.18)	0.047
Are you afraid of the transplant surgery? (yes, reference: no)	0.31 (0.13)	0.007
Transplant is the best solution (reference: no)	12.9 (2.7)	0.001

Variables entered but removed as non-significant ($P > 0.15$): gender, employment status, prior Tx, saw successful Tx cases, Tx causes more problems, first kidney is rejected in 1 year.

produced qualitatively similar results showing the same associations to be significant for the entire patient group as for the study population (i.e. patients <70 years old).

Adjusted associations with willingness towards renal transplantation

Independent association of factors described above with attitude to transplantation was tested in multivariate logistic regression models (Table 5). In this analysis, perception of transplantation as the best solution for patients on dialysis remained the strongest predictor of a positive attitude to Tx (OR = 12.98, $P = 0.001$). Patients who considered themselves suitable for transplantation (OR 5.08, $P < 0.001$) and also those who expected an improvement in their health after transplant (OR 4.23, $P = 0.036$) were also more likely to want a transplant. Increasing age was associated with decreasing odds to want Tx. Being afraid of the surgery and having seen many sad cases after Tx and expecting an improving overall health on dialysis were significant negative predictors of positive attitude. Finally, having 8 years or less education was also near-significant negative predictor of willingness to consider renal transplantation (Table 5).

Discussion

Developing and maintaining interest in renal transplantation is the first step in the transplantation process. In this paper, we have shown that, in addition to increasing age, negative patient perceptions about transplantation, negative expectations about health outcomes and the presence of fears about the transplant surgery are associated with unwillingness to consider transplantation as a treatment option. This is important as many of these factors are potentially modifiable with effective and systematic patient education and this would improve the chance for the patients to make fully informed treatment decisions about renal replacement therapy.

Several previous papers, mainly from the United States, suggested that social inequalities exist in the access to renal transplantation [4–8,12,15]. In our analysis of more than 400 dialysis patients, disadvantaged social status (poor self-reported financial situation or low education) was not or only marginally associated with willingness to consider renal transplant after adjustment for co-variables. We did not, however, assess access to waiting list or actual transplantation in this manuscript. In a different analysis of a larger sample of non-selected Hungarian dialysis patients, we found that patients with only basic education had a significantly smaller chance to be on the waiting list than patients with more education (Szeifert *et al.*, unpublished observation).

We analysed answers to two questions to assess attitudes to transplantation: "Would you like to receive a kidney transplant?"; "Would you recommend renal transplantation for a 67-year-old woman?" Overall, a similar distribution of the answers was seen in the analyses and the same predictors of attitudes were found in multivariate models. A few points about these two questions, however, deserve comments. Substantially more patients wanted a transplant than would have suggested transplantation to a 67-year-old woman. This clearly reflects the age dependence of the transplant attitude, as 91% of the respondents would have recommended Tx for a young patient. It has been demonstrated that transplantation carries benefit even for the elderly both in terms of survival and quality of life compared to dialysis [1,23]. In our sample, less than half of the patients between 60 and 70 years of age considered themselves suitable for transplantation, and >40% of the patients in this age group versus 22% of the patients between 18 and 45 years thought that transplantation would bring more trouble than benefit. An individual older than 60 years is generally considered 'old' in Hungary. This opinion may well be held by the physicians who are the main source of information and also the main decision makers about transplantation in a traditional, still paternalistic health care system.

Patients who do not want a transplant were more likely to report having seen sad cases after Tx, and they believe that a transplant brings more trouble. They hope for their health to remain stable or even improve on dialysis and they fear of their health getting worse after transplant. Expecting improved health on Tx and foreseeing a decline in health on dialysis is associated with positive attitude. This finding is in agreement with the results of previous studies [19,24].

Our results suggest that individuals who feel that they are not suitable for a transplant, or who for some unknown reason do not want a transplant, try to adjust to this stressful situation (since many of these individuals still consider transplantation the best treatment for renal patients) by constructing a negative image about transplantation. Providing personalized, evidence-based patient information could break this cycle and could help patients to better understand their options, the risks and benefits involved in the transplantation process.

Overall almost half of the patients reported fears and worries about the transplant surgery and also about medications used after transplantation. Significantly more patients with negative attitudes than individuals with positive attitudes admitted having such concerns. Part of these worries is probably 'fear of the unknown' as patients who were afraid of the surgery or the transplant medications were significantly more likely to report that they had received insufficient information or to have false knowledge about Tx (not shown).

Importantly, about half of the respondents said that they had received insufficient information about Tx. Similar results have been reported by others [19,24]. One-third to one-half of the patients seemed to have false knowledge or uncertainties about basic facts about transplantation. Even the patients who did not feel the need for additional information had, in several instances, false knowledge. These results clearly demonstrate that the current system of providing patient information needs substantial improvement. Multidisciplinary approach to patient care is very rarely utilized in nephrology in Hungary. There is currently no comprehensive, standardized system in place that would help nephrologists to provide well-balanced, comprehensible and evidence-based patient information to either predialysis or dialysis patients [25]. The lack of this system may, in part, also explain that it takes quite long for the patients to go on the waiting list. In an analysis, we found that patients get waitlisted on average 20 months after starting dialysis, which is longer than in countries participating in the Dialysis Outcomes and Practice Patterns Study (Szeifert *et al.*, unpublished observation). We suggest that investing resources in creating multidisciplinary clinics for predialysis care and in developing standardized, comprehensible and evidence-based patient information systems to facilitate modality selection and self-management would enhance the standards of care and would likely improve outcomes [25].

This would also be essential to facilitate the utilization of living donor transplantation [18]. Effective patient education would be a key component to the success of a living donor transplant program in Hungary and in countries in a similar situation.

We decided to include all patients younger than 70 years treated in the participating dialysis units regardless of medical suitability and waiting list status, in order to understand factors that may form the views about transplantation in this patient group. Previous surveys investigating patients' choice and preferences in the transplantation process examined only medically eligible persons [14,16,17]. Dialysis patients treated in one centre form a very intimate community. Experiencing unsuccessful transplantation cases may directly influence patients' opinion on transplantation and may have a direct effect on the decision-making process as suggested by our result.

Our study is notable for the number of enrolled patients from a number of dialysis centres and for the broad range of factors and aspects of patient perceptions assessed. Although our sample is not formally a representative of the dialysis population in Hungary, the main sociodemographic characteristics of the sample seem to be similar to the total dialysis population in the country.

Several limitations of this survey, however, also need to be taken into account when interpreting our results. The cross-sectional design certainly prevents us from drawing any conclusions about the directionality of the observed associations. We also have no information about the potential association of attitudes and patient perceptions and rates of actual transplantation. Furthermore, we have not analysed medical information and actual waitlisted status as we wanted to focus on the patient perspective only.

In summary, we reported here that patient perceptions, fears, preferences and knowledge are associated with attitudes to renal transplantation in a large sample of Hungarian dialysis patients. Furthermore, a large proportion of the patients reported the need for more information about transplantation, and many patients had false knowledge or uncertainty about basic facts about Tx. Based on these results, we suggest that it would be necessary to create multidisciplinary clinics for predialysis care and to develop standardized, comprehensible and evidence-based patient information systems to facilitate modality selection and self-management and to enable patients to make fully informed treatment decisions.

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