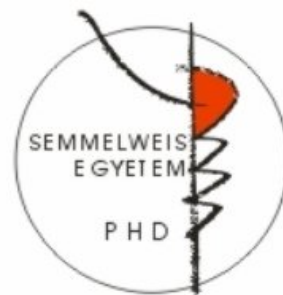


# Quality of life and the role of psycho-social factors in the treatment of patients with chronic renal failure

Thesis abstract

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## **INTRODUCTION**

Chronic disease management represents one of the major challenges for future health care systems. The tremendous technical and scientific improvements that took place in the XX. century allow long-term treatment of patients who earlier died due to chronic renal failure. However, considering the increased life expectancy of these patients, the question arises, how the presence of the disease and its complications will influence the quality of life of patients with chronic renal failure. The aspect of quality of life has received increasing attention in chronic disease management and clinical guidelines mention the improvement of quality of life amongst the primary objectives of treatment strategies.

Since significant improvements in the technology of renal replacement therapy cannot be expected in the near future, the extensive examination of quality of life and factors influencing quality of life has particular importance in the improvement of life perspectives of this patient group. Kidney transplantation is the treatment of choice for patients with end-stage renal disease (ESRD), because compared with maintenance hemodialysis it offers a longer life span, superior quality of life and lower health care costs. Although there are a growing number of studies examining quality of life at an international level, there are only very limited data available on this issue in Hungary.

Significant inequalities in access to kidney transplantation have been identified in the last two decades. Although equitable and efficient organ allocation is an essential goal of health care systems and policy-makers, the benefits of transplantation do not appear to be shared equally among patients with ESRD. Substantial evidence demonstrates significant disparities in access to renal transplantation indicating that non-medical factors, such as demographic, socioeconomic and psycho-social characteristics influence the likelihood of receiving a transplant. The medical literature has examined intensively the distinct steps which constitute the transplantation process. There are, however, only very few studies available on patients' preferences and factors associated with decision-making towards renal transplantation.

## **PURPOSE OF THE STUDY, HYPOTHESES**

### *1. Quality of life of patients on maintenance hemodialysis*

- 1.1. Psychometric validation of the KDQOL-HU questionnaire in hemodialysed patients

Due to the increasing interest in quality of life measurement, methodological guidelines have been available on the development, validation, adaptation and application of quality of life instruments. Prior to the nationwide use of an instrument, it is important to evaluate the psychometric characteristics (validity, reliability) of this tool. The most widely used questionnaires are developed in English language and the validation process takes place with the English version. In Hungary, no translated, adapted and validated quality of life instrument has been available so far. The psychometric validation of the versions translated into several different languages of the KDQOL-SF<sup>TM</sup> have been recently published. These studies confirmed the reliability of all generic and most disease-specific subscales. It is essential, however, to validate and run a psychometric evaluation of the questionnaire in each language and patient population that it is used in. Firstly I will report on the psychometric properties of the validated KDQOL-SF<sup>TM</sup> questionnaire.

I verified the following hypothesis in this study:

- The Hungarian version of the Kidney Disease Quality of Life quality of life questionnaire (KDQOL-SF<sup>TM</sup>) is a reliable and valid tool for the assessment of quality of life in patients on hemodialysis – the results of the psychometric validation of the KDQOL-HU

## 1.2. Study assessing factors associated with quality of life in patients on maintenance hemodialysis

Identification of factors associated with quality of life of patients on maintenance hemodialysis has received increasing attention in recent years in order to improve the life expectancy and quality of life of this patient population. In this study we examined by means of the developed questionnaire the association between the different aspects of quality of life and socio-demographic characteristics, clinical parameters and comorbid conditions.

I verified the following hypotheses in this study:

- Elderly patients on maintenance hemodialysis report worse quality of life compared with younger counterparts, particularly along physical and disease-specific dimensions.

- Women on maintenance hemodialysis report worse quality of life compared with their men counterparts both along generic and disease specific dimensions.
- Serum albumin level of patients on maintenance hemodialysis, which is a marker of general clinical status in this patient population, is correlated with physical dimension quality of life scores.
- The number of comorbid conditions of patients on maintenance hemodialysis shows significant correlation with physical dimension quality of life scores.
- The Kt/V, which is a measure of dialysis dose, shows association with disease specific domains of quality of life patients on maintenance hemodialysis.

## *2. The association between non-medical factors and attitude towards renal transplantation in patients on maintenance hemodialysis*

Patient preferences have been shown to be a major predictive factor of referral for evaluation, enrolment on a waiting list and receiving a transplant in patients on maintenance hemodialysis. Despite the importance of this issue there are only a very few studies available on the attitude of hemodialysed patients towards a renal transplantation and non-medical factors associated with patients' decision-making. In Hungary, there have not been studies published on factors associated with the choice of renal replacement therapy in hemodialysed patients. The aims of this study were to examine the association between socio-demographic characteristics, perception of patients towards different ESRD modalities, information on transplantation and willingness towards renal transplantation.

I aimed to test the following hypotheses:

- lower socio-economic status (increasing age, female gender, lower education, worse financial situation, unemployment) is associated with unwillingness to consider renal transplantation as a renal replacement therapy option.
- the association between socio-demographic characteristics and attitude towards renal transplantation remains independent after adjustment for several covariables.
- patients with more and more accurate information are more likely to express willingness towards renal transplantation
- patients who saw many sad and unsuccessful cases amongst counterparts are less likely, patients who saw counterparts with favorable outcomes are more likely to report willingness towards renal transplantation

- fear of surgery and medical treatment, misperceptions about transplantation are associated with negative attitude towards renal transplantation
- perceptions associated with transplantation and hemodialysis are associated with attitude towards renal transplantation; patients who expect better health status after a transplant are more likely to desire for one and those who expect worse health status after a transplant are more likely to report unwillingness towards renal transplantation.

## **METHODS**

### *1. Quality of life of patients on maintenance hemodialysis*

#### 1.1. Psychometric validation of the KDQOL-HU in patients on hemodialysis

The Hungarian version of the KDQOL-SF<sup>TM</sup> was prepared from the original US version by the Functional Assessment of Chronic Illness Therapy (FACIT) translation group (Center on Outcomes, Research and Education, (CORE) Evanston, IL, USA) which followed the FACIT translation methodology. During the analysis of the data collected in the linguistic testing pilot project, two revisions were made utilizing patients' comments to obtain the final version of the Hungarian KDQOL-SF<sup>TM</sup>.

For pilot testing of linguistic validity of the Hungarian version of KDQOL-SF, 15 patients receiving maintenance dialysis treatment in a single dialysis center in Budapest, Hungary, completed the questionnaire. Subsequently, test-retest reliability was evaluated in a convenience sample of 63 patients receiving maintenance hemodialysis in another dialysis unit in Budapest. After the above pre-testing phase psychometric characteristics and validity of the Hungarian version of the KDQOL-SFTM were tested in patients on maintenance hemodialysis. For this purpose, a convenience sample of patients receiving maintenance dialysis for more than 3 months was recruited from 9 dialysis units in Budapest (n=418).

The patients enrolled in this study also received a battery of questionnaires including the KDQOL-SF<sup>TM</sup> along with other validated instruments, including the Center for Epidemiologic Studies - Depression (CES-D) scale. In addition to the questionnaires, basic demographic and laboratory data (serum albumin - alb, hemoglobin – Hb, single pool Kt/V – spKt/V) were also tabulated.

#### 1.2. Study assessing factors associated with quality of life in patients on maintenance hemodialysis

In this study all 257 patients from four dialysis units in Budapest who were not on the transplantation list completed a battery of questionnaires, which included the Hungarian version of the KDQOL-SF™. Furthermore, 214 waitlisted patients of nine dialysis centres who were enrolled in the TransQol-HU cross-sectional study completed a similar battery of questionnaires between August 2002 and February 2003.

Demographic characteristics (age, gender) and anamnesis (primary cause of kidney failure, comorbidity) were tabulated. Patients completed the questionnaires either during dialysis sessions or waiting for them. Data on dialysis treatment (single pool Kt/V) and time spent on dialysis were recorded from patient files. The number of comorbidities were determined based on data from patients.

### Statistical analyses

Group differences were compared by using Pearson's Chi-square test for categorical variables, t-test for normally distributed continuous variables and Mann-Whitney test for continuous variables with skewed distribution, as appropriate. Pearson correlation coefficients between the test and retest scores were computed. Cronbach's alpha was computed as the index of internal consistency of the individual dimensions/domains of the KDQOL-SF™ questionnaire. When examining the association between categorical and continuous variables, Bonferroni correction was used. In order to examine the independent association between variables, linear regression analysis was applied. Student's t-test was used to compare quality of life scores of patients in the lowest and the highest tertiles of age and of serum albumin. Analysis was carried out with SPSS v.12.1 statistical software.

### *2. The association between non-medical factors and attitude towards renal transplantation in patients on maintenance hemodialysis*

All patients who had been receiving hemodialysis therapy for ESRD in Budapest (in all 8 dialysis centers in the capital) for at least 3 months were approached to participate in this multi-center cross-sectional survey between May 2001 and April 2003. Patients with dementia were excluded. As the prevalence of peritoneal dialysis at these centers was very low (less than 5% in each centers), only hemodialysis 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.

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. Patients were asked to rate their current health status from excellent to poor.

### Study questionnaire

A questionnaire was developed specifically for the purpose of this study and then modified in 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 which 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, (4) information about transplantation. This instrument was subsequently pilot tested for content and comprehensibility in a convenience sample of 15 dialysis patients in one center. 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 analyzed individually.

Attitude to renal Tx, defined as willingness to accept and recommendation of Tx to others, was assessed by four questions with three possible answers (“Would you like to receive a kidney transplant?”, “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?”). Perceptions about Tx, potential fears and worries about transplantation were assessed by a similar method using a 5-point Likert scale. Subsequently we asked patients to estimate their overall health in one year if they stayed on dialysis and one year after a successful kidney transplant („Tx is the

best possible solution for a patient on dialysis.”, “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.”). Information and knowledge about renal transplantation was also measured by 5-point Likert scales (“I have received insufficient information regarding Tx”, The first 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”). 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 analyzed, those were considered missing information.

#### Statistical analysis

Statistical analysis was performed using the SPSS statistical software (SPSS Inc., version 16.0). In all cases p values are 2-sided. Descriptive statistics were used to compare socio-demographic characteristics, perceptions, information and knowledge on Tx by willingness towards Tx (wants vs. does not want groups) and recommendation of Tx to a 67-year old woman (recommends vs. does not recommend). Group differences were compared by using Pearson’s Chi-square test for categorical variables, t-test for normally distributed continuous variables and Mann-Whitney test for continuous variables with skewed distribution, as appropriate. Variables associated with willingness at a P-value  $\leq 0.05$  were then entered into a binary logistic regression model to examine the independent association of socio-demographic factors, patients’ treatment perceptions and information about Tx on willingness.

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



## RESULTS

### *1. Quality of life of dialysed patients*

#### 1.1. Descriptive statistics of the Hungarian KDQOL-SF<sup>TM</sup>

The mean scores and standard deviations for the Hungarian dialysis group were overall similar to the means and standard deviations obtained with the original US version of the KDQOL-SFTM, and also to mean scores obtained with a Dutch version of the instrument (kidney disease targeted dimensions only). For some of the kidney disease targeted sub-scales („effects of kidney disease”, „sexual function”, „staff encouragement”) and for some of the generic dimensions („social support”), however, the Hungarian scores seemed to be substantially higher.

#### Test-retest and internal consistency

Test-retest correlation was above 0.60 for 7 out of 11 kidney disease targeted domains and for 7 out of 8 of the generic dimensions. The lowest test-retest correlation was seen for the sub-scales assessing "quality of social interactions" (0.40) and "cognitive function" (0.48). Relatively low correlations were also found for the sub-scales measuring „staff encouragement” (0.54), „general health perception” (0.56) and „patient satisfaction” (0.58).

Internal consistency of the domains was assessed by computing Cronbach's alpha for the individual sub-scales. First internal consistency was assessed to confirm reliability of the Hungarian version of the instrument. The overall reliability pattern of the domains was remarkably similar to the pattern observed with the original US version. Alpha values were above 0.70 (Nunnally 1978) for all of the generic dimensions and for all but four of the kidney disease targeted domains (quality of social interaction - 0.54; cognitive function – 0.62; social support – 0.64; work – 0.64).

#### Concurrent validity

To assess the validity of the KDQOL-SF<sup>TM</sup> in kidney transplant patients, age and gender adjusted correlations between the generic dimensions and also the disease-targeted domains versus an overall health rating scale, that was also included in the questionnaire, were computed. As hypothesized, the overall health rating score correlated positively with most of the disease targeted and all of the generic dimensions of the KDQOL-SF<sup>TM</sup> (higher scores on the sub-scales of the instrument indicate better health-related quality of life). Of the generic domains the strongest correlation was seen for the „general health perception”

sub-scale ( $r=0.57$ ,  $p<0.001$ ), whereas the weakest association was found for the „role emotional” sub-scale ( $r=0.36$ ,  $p<0.01$ ). Of the kidney disease targeted domains the strongest correlation was demonstrated for the „burden of kidney disease” ( $r=0.49$ ,  $p<0.001$ ) and the „symptoms, problems list” ( $r=0.48$ ,  $p<0.001$ ) sub-scales, whereas negligible or non-significant correlation was seen for the „social support” ( $r=0.15$ ,  $p<0.05$ ), „sexual function” ( $r=0.14$ ,  $p<0.05$ ) and „staff encouragement” ( $r=0.07$ ,  $p=NS$ ) domains.

Depression has been shown to interact with chronic illness to determine different aspects of HRQOL in several chronic conditions. Accordingly, concurrent validity of the Hungarian version of the KDQOL-SF<sup>TM</sup> was also assessed computing age and gender adjusted correlations between the KDQOL-SF<sup>TM</sup> domains versus the CES-D scores (higher scores on the CES-D scale reflect more psychological distress). We found significant, moderate to strong negative correlations between most of the KDQOL-SF<sup>TM</sup> domains and the CES-D scores. As expected, the correlations were the strongest with KDQOL-SF<sup>TM</sup> dimensions reflecting different aspects of mental health: „emotional well being” ( $r=-0.74$ ,  $p<0.001$ ); „role emotional” ( $r=-0.53$ ,  $p<0.001$ ); „vitality” ( $r=-0.70$ ,  $p<0.001$ ); sleep ( $r=-0.56$ ,  $p<0.001$ ); „burden of kidney disease” ( $r=-0.57$ ,  $p<0.001$ ). The observed correlations, similarly to what was seen with the „overall health rating” were the weakest for „sexual function”, „staff encouragement”, „work status”, „social support” and „patient satisfaction”.

Some of the disease targeted dimensions („sexual function”, „staff encouragement”, „social support”, „patient satisfaction”) showed no substantial correlation with any of the scales used to assess concurrent validity.

## 1.2. Assessment of quality of life related factors in dialysed patients

This study examined the association between health related quality of life and socio demographic and certain clinical parameters.

Out of the valid and reliable subscales found in the process of psychometric validation, four were included in the analysis („symptoms”, „effects of kidney disease”, „burden of kidney disease” and „sleep”).

As expected, the assessment of the association between gender and quality of life showed better quality of life for males than females across all studied general subscales. This difference proved to be statistically significant in three out of four subscales („energy”, „emotional wellbeing” and „vitality”). Males showed higher average quality of

life scores across three out of four kidney disease specific dimensions („symptoms”, „effects of kidney disease” and „sleep”). The difference in case of the „symptoms” and „sleep” subscales was statistically significant.

With increasing age, all general quality of life scale scores decreased, proving age to be associated with worse quality of life. The strongest negative correlation was found in case of „energy” ( $r=-0.443$ ,  $p<0.001$ ) and „vitality” ( $r=-0.253$ ,  $p<0.001$ ) subscales. In case of „emotional wellbeing” ( $r=-0.145$ ,  $p<0.05$ ) and „general health” ( $r=-0.161$ ,  $p<0.05$ ) subscales the association was weaker. The difference was less marked or not significant on the mental sub-scales („emotional well being”, „role emotional”, „vitality”).

Regarding illness specific subscales, „burden of kidney disease” ( $r=-0.210$ ,  $p<0.001$ ) and „sleep” ( $r=-0.203$ ,  $p<0.001$ ) showed a stronger negative correlation with age, meaning that older patients reported worse quality of life than younger counterparts. „Burden of kidney disease” showed a statistically significant, but weak negative correlation ( $r=-0.141$ ,  $p<0.05$ ). No significant correlation could be shown between average „effect of kidney disease” subscale points and age.

The association between serum albumin levels, reflecting the general clinical status of patients and quality of life was examined by comparison of attained points on the quality of life subscale and serum albumin tertiles. As expected, differences between low and high tertiles were more marked for the domains related to physical functioning („energy” and „pain”). With regards to kidney disease related dimensions, differences in the studied dialysed population were smaller, significant differences were found in four dimensions („symptoms”, „burden of kidney disease”, „work” and „sleep”).

Further examination of the association between albumin levels and quality of life showed a weak but positive correlation between serum albumin levels and quality of life scores for three of the examined subscales („energy”, „emotional wellbeing” and „vitality”). Higher albumin level patients had better quality of life regarding the mentioned subscales.

In case of illness related subscales, two subscales („symptoms” and „sleep”) showed better quality of life for higher albumin level patients. Our sample did not show significant correlation between quality of life and serum albumin levels for the „effect of kidney disease”, and the „burden of kidney disease” scales.

The assessment correlation of comorbidity and quality of life showed strong significant correlation with all examined domains of quality of life, including general and illness specific domains. Thus it can be declared, that according to our expectations,

comorbidity showed a tight correlation with the health related quality of life of dialysed patients.

Contradictory to our expectations however, Kt/V, measuring dialysis dose, did not show correlation with any of the examined quality of life domains. Similarly, patients' serum haemoglobin levels only showed significant correlation with „energy”.

#### Multivariate analysis

Independent association of primary examined factors in connection with certain domains of quality of life were analysed using a multivariate linear regression model. These primary factors constituted of gender, age, serum albumin, serum haemoglobin and comorbidities. General subscales „energy” and „emotional wellbeing” and illness specific subscales „symptoms”, „burden of kidney disease” and „effect of kidney disease” were examined as outcome variables.

The „energy” subscale scores showed significant correlation with age, gender and number of comorbidities. In case of the „burden of kidney disease” subscale patient age and number of comorbidities proved to be a significant, independent predictor of quality of life scores. With regards to the „effect of kidney disease” subscale, adjustment for covariables revealed significant correlation only for number of comorbidities. The subscale „emotional wellbeing” failed to show significant association with any of the examined variables in our study. The number of comorbidities showed association with all examined quality of life dimensions, also after adjustment for other variables.

## *2. The association between non-medical factors and attitude towards renal transplantation in patients on maintenance hemodialysis*

### Attitudes for renal transplantation

Of the 459 patients included in this analysis, 325 (71%) reported yes for the question if 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 analyze answers for this latter question to avoid redundancy. Two hundred 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 analyzing this question, since further analyses would have had low explanatory power.

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

### 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 vs. 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 ( $P < 0.001$ ).

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 one year later if they stayed on dialysis and their expected health status one year later if they received a renal transplant. 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). By 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). The proportion of patients who expected their health to improve, remained stable or deteriorate is shown on Figure 1. 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 were seen in patients who recommended Tx to others versus the ones who did not (not shown).

To further explore potential factors associated with attitudes to transplantation we analyzed 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 which wanted Tx, whereas it was almost twice as much (72% and 68%, respectively) in the group who 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 .

#### Information about transplantation

A series of questions was asked of 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 them. Although the overwhelming majority of the patients (more than 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 answers 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 unfavorable outcomes (32%) and 71% of them saw favorable examples regarding Tx. Seventy-seven percent vs 55% of the patients who wanted vs. did not want Tx, respectively, said that they had seen many successful transplant cases and 25% vs. 50%, respectively admitted that they had seen many sad and unsuccessful cases ( $P<0.001$  for both).

Importantly, 56% of the participants suggested that they received insufficient information about the transplant, with no difference between the groups. Patients with a

positive attitude to Tx, however, had more accurate knowledge of transplantation. Seventy-five percent vs. 43% of the patients who wanted vs. did not want Tx disagreed with the statement that the transplanted kidney would be rejected within one year ( $P < 0.001$ ), and 51% vs. 38% disagreed with the statement that transplantation is more successful in men vs. 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 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. 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 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 eight years or less education was also a near significant negative predictor of willingness to consider renal transplantation.

## **SUMMARY**

- Most scales of the Hungarian version of the modular Kidney Disease Quality of Life questionnaire (KDQOL-SF36) are reliable, valid tools for measuring quality of life in chronic kidney disease patients receiving renal replacement therapy
- older and female patients reported worse quality of life than their younger and male counterparts
- worse quality of life with increasing age was most pregnant along physical dimensions and the association was weaker concerning emotional/mental dimensions

- serum albumin showed significant correlation with scores measuring the physical aspects of quality of life, showing association with certain questions addressing emotional well being
- the number of comorbidities showed tight correlation with all examined domains of quality of life, remaining significant along subscales in a multivariate linear regression model
- serum Hb showed significant correlation with health status only
- Kt/V did not show correlation with any of the quality of life domains
- increasing age showed significant correlation with the rejection of transplantation as a treatment modality, remaining significant after adjustment for various covariates
- lower education showed only marginal association, while female gender and lower financial status did not show any correlation with the intention to undergo transplantation, after adjustment for several covariates
- patients' negative transplantation perceptions, fears show an association between the rejection of transplantation as a treatment modality
- patients reporting unsuccessful cases amongst their peers were less likely to desire a transplantation, even after adjustment for several covariates
- patient groups desiring and rejecting transplantation were not different in their opinions about having received enough information about transplantation
- positive perceptions towards transplantation and negative perceptions towards dialysis showed correlation with desire for transplantation



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### *Publications related to thesis:*

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