

**HEALTH CARE WORKERS' PERCEPTIONS ON HEALTH STATUS AFTER RENAL TRANSPLANTATION:
A COMPARISON WITH TRANSPLANTATION CANDIDATES' EXPECTATIONS**

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ABSTRACT

Objective

The aim of this study is to compare health care workers' perceptions on the quality of life (QoL) after renal transplantation (RTX) with expectations of RTX candidates and actual QoL of RTX patients.

Methods

A comparative study design was used for the comparison of health care workers' perceived and patients' expected and actual QoL after RTX. The EQ-5D self-report questionnaire was used for the measurement of health status. Seventy-eight RTX candidates were surveyed and followed longitudinally from November 1999 until May 2000. Fifteen patients were transplanted and surveyed again two weeks and four months after discharge from hospital. All health care workers (N= 123) had regular contact with dialysis or RTX patients. VAS scores were analysed as well as U.K. EQ index scores assigned to the health state descriptions of patients and health care workers. Given the non-normality of the data, non-parametric tests were used for statistical analyses.

Results

Preliminary results show that health care workers' perceptions on QoL after RTX were significantly lower than patients' expectations. After discharge, transplanted patients showed an ongoing improvement on the VAS compared to their pre-transplant VAS score for actual health. However, pre-transplant QoL expectations were not (yet?) fulfilled at four months after discharge for most patients. Finally, transplant nurses' and physicians' valuations were closer to patients' actual QoL after transplantation than nurses' on other wards.

Conclusion

The preliminary results are based on a small sample of patients. As patients will be followed-up further in the future (at 8 and 12 months after RTX) and more patients will be included, more results will be available to show how patients' actual QoL evolves after RTX and how this evolution compares to their expectations before transplantation.

INTRODUCTION

Renal failure is a progressive, irreversible destruction of both kidneys, which is life threatening if not treated appropriately. In the early stage of the disease, renal failure can be treated with medications and by means of lifestyle adjustments. If medication treatment is no longer effective in end stage renal disease (ESRD), patients must be dialysed or receive a renal graft. Unlike dialysis, renal transplantation restores all aspects of renal functioning but calls for a lifelong immunosuppressive regimen to avoid rejection of the renal graft.

The effectiveness of both treatment options can be measured in different ways and using different perspectives. Health care workers or patients may assess the outcome of the treatment modalities either in terms of objectively measurable units, for instance walking speed, or in more subjective terms, such as perceived physical capacity. It has been shown in previous research that the aspects of life beyond the physical dimension may often be of more importance to patients in quality of life assessment than physicians anticipate. For instance, in a study on perspectives on prostate cancer, Crawford et al.⁽¹⁾ found that patients' goal with therapy is in the first place to retain or regain quality of life, followed by life extension and delaying disease progression, whereas for the physicians treatment efficacy in terms of objective improvement in a patient's health status is the main goal of treatment. As a consequence, the impact of an intervention on patients' quality of life is often perceived differently by health care workers than by patients^(2,3,1,4,5,6,7,8,1,3). From an extensive literature review, Sprangers and Aaronson⁽⁶⁾ concluded that, overall, independent from disease area, health care workers' tend to underestimate patients' quality of life. Multiple variables are related to the concept of quality of life, for instance, pain, anxiety, depression, symptom distress and functional status. Physicians tend to underestimate the pain intensity of patients, whereas nurses overestimate patients' feelings of anxiety, depression and distress. The agreement between health care workers and patients is higher, however, for more visible, concrete and objective dimensions of quality of life (e.g. functional status). One of the possible explanations for the discrepancies found between patients' and health care workers' ratings of quality of life might be the difference in interests and expectations of both respondent groups^(6,4). One study in patients after total hip arthroplasty found that patients' and physicians' ratings with respect to pain and satisfaction after the operation were similar the less pain the patients had and the more satisfied they were. Although ample longitudinal studies exist on the evolution of quality of life pre- to post-intervention, no longitudinal studies could be retrieved from literature on patients' expectations for future quality of life before the intervention and patients' actual quality of life after the intervention. A comparison between health care workers' perceptions of what constitutes a "normal" outcome after an intervention and patients' expectations for that outcome, would

provide more insight into the relevance of expectations for the discordance between health care workers' and patients' valuations of quality of life after the intervention.

Expectations of patients and health care workers may especially be relevant for decisions concerning treatment of end stage renal disease patients. Whether or not a patient wants to be put on the renal transplant waiting list, depends on his expectations about quality of life after transplantation. These expectations are influenced by the information patients get from health care workers, their current health status, stories from previously transplanted patients, personality and other external or internal patient factors. It is, however, not clear to what extent patients are influenced by health care professionals and to what extent their decision to be put on the transplant waiting list is based on the perceptions of the very individuals on whom they rely for information and advice. Thus, it is important to determine whether health care workers' perceptions on quality of life after transplantation are similar to or differ systematically from those of dialysis patients. Furthermore, the discrepancy between actual quality of life of patients after transplantation and expectations about post-transplant quality of life may have an important impact on the long term success of the transplantation, both in clinical terms (through therapeutic compliance) and in psychological terms. Unlike the relationship between expected and actual quality of life after transplantation, the relationship between expectations and clinical outcome after transplantation will not be examined in this study.

OBJECTIVE

The aim of this study was to compare health care workers' and dialysis patients' ideas on the quality of life after renal transplantation. Moreover, patients' expectations are compared to their actual quality of life after transplantation. Finally, the impact of demographic variables and current health status on the expectations of patients is examined. It is hypothesised that own current health has an impact whereas age and sex have not.

METHODS AND MATERIALS

Design

A cross-sectional study design was used for comparisons between health care workers' and renal transplant candidates' opinions on health after transplantation. Health care workers were surveyed once to retrieve their personal opinion on health related quality of life after renal transplantation. They were asked to describe and value their personal perception of the health state of an 'average' renal transplant patient on the EuroQoL EQ-5D. A longitudinal prospective study design was used for the assessment of patients' valuations over time. Patients were

surveyed once before transplantation, to retrieve their expectations on health after transplantation and their current health state valuation and twice after transplantation, at 14 days and at 4 months after discharge from hospital, to retrieve their actual health state valuation after transplantation.

Sample

The survey was performed in health care workers from selected wards in five hospitals¹ and dialysis patients on the waiting list for renal transplantation in the same hospitals. One of the included hospitals was a university hospital. The survey in health care workers was anonymous, whereas eligible patients were approached directly by the investigator. Health care workers consisted of nurses and physicians from wards that treated either dialysis or transplant patients or both. In one hospital, three wards were contacted: the dialysis, nephrology and transplantation ward. In addition, health care workers on the outpatient clinic of internal medicine, where transplant patients are followed-up on a regular basis, were asked to fill out the questionnaire. In four non-university hospitals, only dialysis wards were contacted, in the absence of a transplantation ward. Patients from these hospitals were transplanted in the participating university hospital and followed-up in the non-university setting thereafter. In case of serious complications during follow-up, patients are referred to the university hospital.

The patient sample consisted of dialysis patients on the waiting list for renal transplantation at the University Hospitals of Leuven. Patients were eligible if they gave informed consent for participation in the study, were 18 years of age or older, literate, Dutch speaking and on dialysis for at least three months. Patients were asked to describe and value their current health state as well as their anticipated health state after transplantation. Patients were followed up longitudinally from November 1999 till May 2000. Transplanted patients were surveyed again two weeks and 4 months after discharge from hospital.

All questionnaires were filled out by the respondents themselves, after a short introduction from the investigator. Additional information on age and sex was derived from each respondent. Health care workers were moreover asked to state how long they were working as health care workers and how long they were working with renal transplant patients.

The EuroQol EQ-5D

The EuroQol EQ-5D is a standardised non-disease specific instrument for describing and valuing health states. The EuroQol (EQ) consists of a descriptive and a valuation task. The descriptive system of the EuroQol comprises five dimensions of health with three levels of severity in each

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dimension. The respondent describes health states by indicating that there are no (level 1), some (level 2) or severe (level 3) problems on the dimension of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The descriptive system theoretically allows for 243 (i.e. 3⁵) composite health state descriptions^(9,10). States are represented as 5-digit codes, in which each digit represents the level of severity on the respective dimension. A state of 11232 is a state in which the person has no problems in walking about, no problems with self-care, some problems with usual activities, severe pain or discomfort and is moderately anxious or depressed. The valuation of EQ health states occurs by rating the states on a thermometer-like Visual Analogue Scale (VAS) from 0 (worst imaginable health state) to 100 (best imaginable health state)^(11,12,13). The advantage of the VAS is that it is well accepted by the general public due to its simplicity and is easy to administer^(14,12,15).

The valuations from respondents on the VAS can be used directly to reflect a respondent's personal view of his own or someone else's health state and for the evaluation of a person's subjective quality of life over time^(16,12,17).

In this study, two approaches are used to compare health state valuations. First, patients' longitudinal valuations on the EQ-5D VAS are assessed in order to compare the expected gain in quality of life with the actual gain in quality of life. Because different respondents may have different ideas about what constitutes the best and the worst imaginable health state, VAS valuations cannot be reasonably aggregated into population ratings. Moreover, VAS valuations usually do not have interval properties but should be considered as ordinal data. Therefore, they cannot be regarded as measures of utility and can, as a consequence, not be used in cost-utility analysis^(20,21). For the comparison of patients' and health care workers' valuations. EQ-index scores from a British population sample⁽²²⁾ will be used. The EQ index scores represent a score for every one of the 243 health states generated by the descriptive system of the EuroQol on a scale from 0 to 100, where 0 corresponds to the value of "death" and 100 to the value of "perfect health" (= 11111) for every respondent (negative values are allowed for)⁽¹⁰⁾. The use of a common reference scale for every respondent allows comparisons across respondent groups. The index valuations from the British sample were elicited with the time-trade off technique. On the theoretical level it is often argued that time trade-off scores have, unlike VAS-scores, interval properties and are therefore useful for cost-utility analysis^(20,12,21). Moreover, the time trade-off method was found to discriminate slightly better between health states than the rating scale⁽¹³⁾. The index scores have been validated in normal populations and used in patients with chronic conditions, such as chronic fatigue syndrome⁽²³⁾, rheumatoid arthritis⁽²⁴⁾, stroke⁽²⁵⁾, end stage renal disease⁽¹⁹⁾, liver transplantation⁽²⁶⁾, obstructive pulmonary disease⁽²⁷⁾, obstructive sleep apnoea⁽²⁸⁾ and many other diseases.

Although the relevance of U.K. valuations for the Belgian population could be debated, they are useful as long as no index valuations for the EQ health states are available for the Belgian population. The EQ-Net Biomed project that is currently being performed will provide more

insight into the similarities or dissimilarities between health state valuations from different countries{57}.

Statistical analysis

Non-parametric tests were used for the analyses for two main reasons: first, the majority of the valuations given by patients and health care workers ended either with zero or five, which suggests that the scale was not used as a continuous scale by respondents. Second, valuation data were highly skewed, both for expected, perceived and actual health after transplantation (Kolmogorov-Smirnov statistic significant at 1% significance level for all valuations). The Mann-Whitney U test was used to compare the valuation data from health care workers and patients. Differences in categorical variables, such as sex, between the two respondent groups were examined by means of the χ^2 test, differences in continuous variables, such as age, by means of the t-test. Longitudinal continuous data were compared using the Wilcoxon's matched pairs signed-ranks test (2-tailed).

A Kruskal-Wallis test was used to test differences between mean values from more than 2 respondent groups. Correlations between two continuous variables were calculated by means of the Kendall's Tau. The significance level was set at 5%.

RESULTS

Response

A total of 274 questionnaires were distributed to health care workers. One-hundred and thirty-four (48,9%) questionnaires were returned, of which 6 (4,5%) were blank. Three health care workers only filled out the EQ-5D for their own current health state and not for that of a renal transplant patient. In two health care workers, either the 5-dimensional health state description or the valuation of the health state of a renal transplant patient was missing. A total of 123 (44,9%) complete responses were obtained from health care workers. Table 1 shows the overall response figures as well as the ward-specific response rates. Not surprisingly, the majority of responses comes from the dialysis wards, as this was also the largest study group. Health care workers worked on average 17 years in a health care setting (SD= 9,5) and 11,7 years (SD= 8,58) with renal transplant patients.

Ward	Total N	Response (% of total sample)	Response rate per ward
Dialysis	205	77 (62,6%)	37,6%
Nephrology	13	6 (4,9%)	46,1%
Dialysis + Nephrology	2	2 (1,6)	100%
Transplantation	27	15 (12,2%)	55,5%
Transplant outpatient clinic	27	15 (12,2%)	55,5%
Not stated		8 (6,5)	
Total	274	123	44,9%

Table 1: Response distribution over the different wards

All patients (N= 98) in the five dialysis centres who fulfilled the inclusion criteria were asked to fill out the questionnaire. Fifteen patients (15,3%) did not want to participate in the study. Two patients did not answer the question on expected health state after transplantation and two patients answered it incompletely. Another patient was excluded because he did not describe his current health state. A total of 78 complete responses were obtained from patients. This represents a response rate of 79,6%, which is comparable to studies in other fields (Myers and Wilks 1999: 66,9%; Walters et al. 1999: 86%).

Patients were significantly older than health care workers ($p < 0,0005$). Mean age of patients was 54, mean age of health care workers 39. There were significantly more women in the health care workers' group ($P < 0,0005$) (Table 2).

	Health care workers N= 123		Patients N= 78	
	%	Mean age (SD)	%	Mean age (SD)
Male	22,1	39,3 (9,4)	67,7	55,5 (11,4)
Female	77,9	38,7 (9,2)	32,3	53,7 (11)
Total sample	100	38,9 (9,2)	100	54,5 (11,5)

Table 2: Characteristics of respondents

Table 3: Reported problems on the EQ-5D gives the percentages of health care workers and patients reporting moderate (level 2) or severe (level 3) problems on each of the 5 dimensions of the EQ-5D for own current health state. Patients reported more problems in current health on all dimensions of the EuroQol than health care workers, which illustrates that the EuroQol is indeed able to distinguish the health of end stage renal disease patients from that of, in principle, more healthy respondents.

EuroQol dimension	Health care workers	Patients
- Mobility	3,2%	32,9%
- self-care	0%	10,5%
- usual activities	4,8%	47,4% ¹
- pain/discomfort	21,9%	45,3% ²

- anxiety/depression	7,8%	27,6% ³
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The problems reported by health care workers did never exceed level 2 on either dimension.

¹ six patients (7,8%) had a level 3 on this dimension, all others had level 2

² three patients (4%) had a level 3 on this dimension, all others had level 2

³ two patients (2,6%) had a level 3 on this dimension, all others had level 2

Table 3: Reported problems on the EQ-5D

Patients' expected and health care workers' perceived health status after renal transplantation

Table 4 reflects the percentages of health care workers and renal transplant candidates that think there are/will be problems after transplantation on the respective EuroQol dimensions, i.e. reporting a level 2 or 3 on the respective dimensions. The percentage of patients expecting problems after transplantation is clearly lower than the percentage of health care workers for four EuroQol dimensions (mobility, usual activities, pain/discomfort and anxiety/depression). This means that patients expect to have a better quality of life after transplantation than health care workers think they will have. This is also reflected by the fact that only 8% of the health care workers report a health state of 11111 after transplantation, compared to 45% of the patients.

EuroQol dimension	Health care workers' perceptions	Patients' expectations
- mobility	24,4%	16,2%
- self-care	9,8%	10,8%
- usual activities	78,9%	35,1%
- pain/discomfort	71,7%	37,8%
- anxiety/depression	65,9%	22,9%
state 11111	8%	44,6%

Table 4: Percentage of health care workers and patients that perceive/expect problems on each EuroQol dimension after transplantation.

The EQ index score given to the expected or perceived health state is significantly higher in patients than in health care workers (Table 5). The median EQ index score reported by health care workers is 69 (Inter Quartile Range (IQR) 69-81), patients report a median EQ index score of 88 (IQR 76-100). These results confirm the observation from table 4 that health care workers have worse perceptions about health after transplantation than patients.

	Health care workers	Patients	Significance*
EQ index score, median (IQR)	69 (69-81)	88 (76-100)	P < 0,0005

* Mann-Withney U test

Table 5: VAS-scores of perceived and expected health states after transplantation

A graphical representation of the distribution of the VAS and index scores is given in Figure 1. The VAS scores are clearly more strongly skewed to right than the EQ index scores (i.e. the left tail is longer). This is due to the fact that on the EQ "health thermometer" rating scale, the

respondents are reluctant to use the entire scale and this effect is most articulate in patients with current experience of illness ⁽²⁹⁾. Moreover, the contextual factors between the VAS and the time trade-off are different. For instance, a value of 100 on the VAS represents the “best imaginable health state”, whereas in the time trade-off technique, 100 corresponds with “absence of disease” ⁽³⁰⁾. In general, the VAS generates lower values than the time trade-off technique by which the index-scores are derived ^(31,32,33,14). Our results confirm this conclusion.

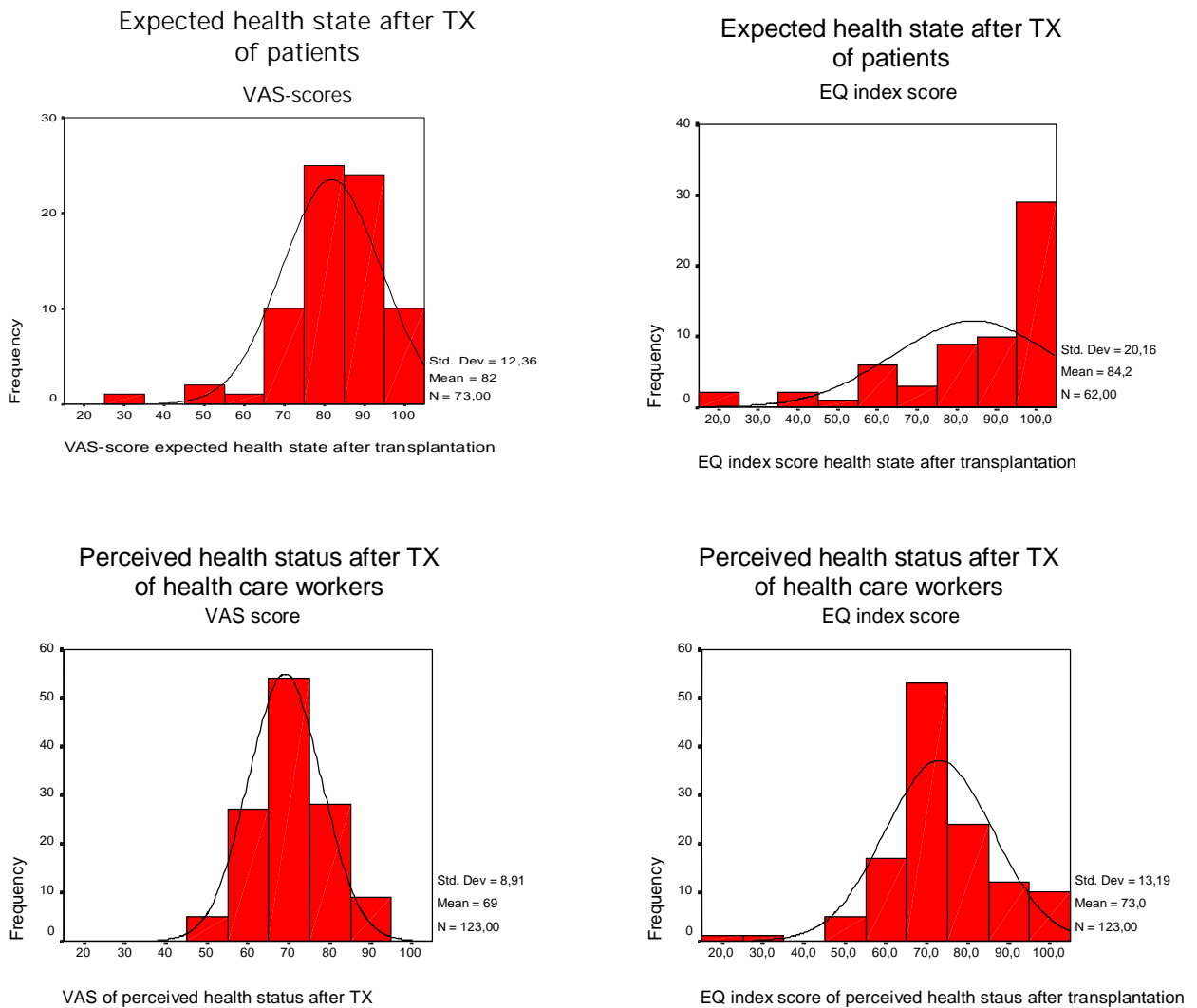


Figure 1: Patients’ expected versus health care workers’ perceived health after transplantation: a comparison of VAS and EQ-index-scores

Change in quality of life pre- to post transplantation

Fifteen patients were transplanted during the study period and were surveyed again two weeks after discharge from hospital. Eight patients could be followed up to 4 months after discharge from hospital. The remaining seven were transplanted less than 4 months ago.

In total, 12 (80%) patients showed health improvement on the VAS two weeks after discharge relative to dialysis whilst 3 (20%) patients showed a deterioration in quality of life. Remarkably, the EQ index scores show an improvement at 14 days after discharge in only 4 patients, a deterioration in 5 patients and no change in 5 patients. The difference between pre- and post-transplant index scores was, however, not significant (Table 6).

At four months after discharge, 6 patients had a VAS score for actual health that was higher than their VAS score before transplantation. Only one patient had a lower VAS score and 1 patient an equal score. In terms of index scores, 3 patients showed an improvement at 4 months after discharge relative to pre-transplantation, 4 no change and 0 a deterioration.

The percentage of patients reporting perfect health after transplantation (state 11111), increases with time after transplantation, although the absolute number remains the same.

	Dialysis <i>N</i> = 15	14 days post TX <i>N</i> = 15	4 months post-TX <i>N</i> = 8
Most frequently reported health state (%)	11111 (33,3%)	11111 (40%)	11111 (75%)
EQ index score, median (P ₂₅ -P ₇₅)	86,5 (77,7-100)	81 (75-100)*	100 (78,25-100)**

* *P* = 0,441 (Wilcoxon's matched pairs signed-ranks test (2-tailed))

** *P* = 0,102 (Wilcoxon's matched pairs signed-ranks test (2-tailed))

Table 6: health status in dialysis versus after transplantation

Patients' expected versus actual gain in quality of life after transplantation

The expected gain was significantly higher than the actual gain in VAS-scores at 14 days after discharge (*P* < 0,005). Four months after discharge, the difference between expected and actual gain in VAS scores was no longer significant (Table 7). The expected gain in index scores at 4 months after transplantation was significantly higher than the expected loss (*P* < 0,005).

In terms of patient numbers, 10 transplant patients showed a lower score on the VAS than the expected one at 14 days after discharge, three patients felt better off and two patients equally well off. According to the EQ index scores, 5 patients were in better health 14 days after transplantation than expected.

The disparity in the results between VAS and index scores may be a consequence of inconsistencies in patients' VAS valuations of expected and actual health state after transplantation. Seven patients gave inconsistent valuations for expected and actual quality of life after transplantation. This means that they rated a state that was logically better or worse than another, respectively lower or higher than the other. For instance, state 11111 is logically

better than state 11112 and should hence get a higher value. In three patients, consistency could not be established due to the fact that there was no logical ranking between the two states. The remaining four gave consistent valuations.

	Expected health gain/loss	Actual health gain/loss 14 days post-TX	Actual health gain 4 months post-TX
VAS scores, mean (s.d.)	21 (16,9)	12,5 (16)	13,5 (12,7)
EQ index scores (s.d.)	-1,3 (5,8)	-4,7 (18)	5,8 (9,2)

Table 7: Comparison of patients' expected versus actual health gain after transplantation

Figure 2 graphically represents the extent to which patients' expectations are fulfilled after transplantation, both at 14 days and at 4 months after discharge from hospital. All points on the diagonal represent situations in which the patient's expectation is exactly fulfilled. Each dot is one patient. Both at 14 days and at 4 months after discharge, the proportion of patients whose actual gain is less than their expected gain is larger than the proportion of patients whose expectations are at least fulfilled.

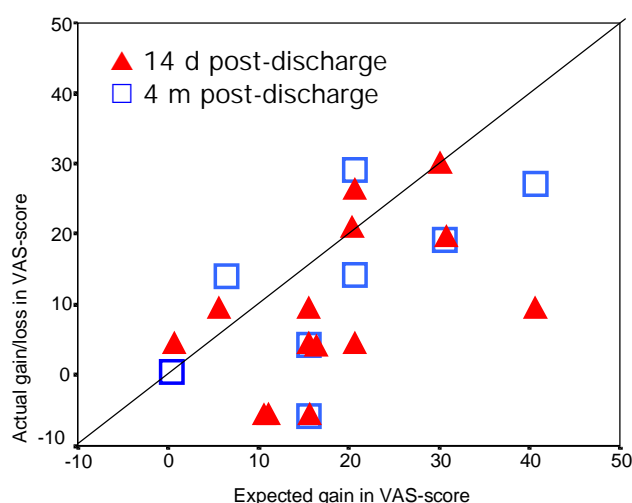


Figure 2: Expected VAS scores pre-transplant versus actual VAS score post-transplant

Health care workers' perceptions on health after transplantation and patients' actual health state post-transplantation.

The comparison between health care workers' perceptions of transplanted patients' quality of life and renal transplant patients' actual quality of life 14 days after discharge showed that health care workers more often describe the health state of a renal transplant patient as worse than experienced by patients. (Table 8). The index scores are hence significantly different.

	Health care workers' perceptions (N = 123)	Patients' actual health state (N = 15)	Significance*
EQ index score, median	69 (69-81)	94 (76,5-100)	P = 0,001

(IQR)			
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* *Mann-Withney U-test*

Table 8: Patients' actual health state valuations post-transplantation versus health care workers' perceptions

If a closer look is taken at the valuations from health care workers at different wards, significant differences were found between transplant candidates' expectations and renal transplant patients' actual quality of life on the one hand and index valuations of health care workers on the dialysis wards, the outpatient clinic for internal medicine and the nephrology ward on the other hand (Table 9). In general, health care workers from wards other than the transplantation ward underestimate the health state of a renal transplant patient. No significant differences were found between physicians' perceptions and patients' expectations nor between transplant nurses' valuations and patients' expected or actual quality of life after transplantation.

Ward	Median VAS score (IQR)	Median EQ-index score (IQR)
Patients' expected QoL post-TX	85 (80-90)	85 (80-100)
Patients' actual QoL 14 days post-TX	75 (70-80)	81 (75-100)
Patients' actual QoL 4 months post-TX	79 (62-87)	100 (78-100)
Physicians (N= 7)	70 (60-75)	70 (63-86)
Dialysis (N= 80)	70,0 (60-75)	69,0 (69-78)
Transplantation (N= 15)	78,0 (70-90)	85,0 (76-100)
Outpatient clinic (N= 15)	70 (60-70)	69,0 (62-69)
Nephrology (N= 6)	70 (65-70)	71,0 (61,25-82,75)

Kruskal-Wallis test was used to test differences between the groups

Mann-Withney U test was used for 2x2 comparisons between wards and patients

Table 9: Comparison between health care workers' perceptions on different wards

Impact of background variables on valuations

The influence of patients' current health status on the expectations about quality of life after transplantation was tested. A significant positive correlation was found between health during dialysis and VAS scores for expected health after transplantation (Kendall's Tau= 0,502, P< 0,005). This correlation is also significant at the 0,5% level with EQ index values for both actual and expected health state (Kendall's Tau= 0,460, P< 0,005). This means that the better the health during dialysis, the more optimistic the expectations for health after transplantation. On average, female patients appeared to be in worse health condition during dialysis than male patients; the EQ index scores were significantly different (P= 0,005). EQ index scores for expected health after transplantation and actual health after transplantation were also significantly different for male or female patients.

Valuations did not appear to be significantly different between male and female health care workers. Only VAS-scores for actual health in female health care workers were significantly

higher than the scores of male health care workers ($P = 0,005$). Perceptions on health after transplantation were not gender-dependent.

Age correlated negatively with index values for current health in both health care workers and patients (Spearman's $Rho = -0,302$ ($P = 0,001$) and Spearman's $Rho = -0,261$ ($P < 0,05$) respectively). This finding is consistent with findings from general population studies ^(34,22). Age was also negatively correlated with perceived health state after transplantation for health care workers (Spearman's $\rho = -0,257$, $P = 0,005$), but not for patients.

Discussion

In this study, perceptions of health care workers with respect to quality of life after transplantation and transplant candidates' expectations about post-transplant quality of life were compared. The EQ-5D instrument was used to derive health state descriptions as well as VAS scores for both respondent groups. From the health state descriptions, it can be concluded that patients expect a better health status after transplantation than health care workers think they will have. This is also reflected in the significantly higher EQ index scores from patients.

Compared to actual health in dialysis, most patients experience an improvement in health after transplantation, at least if VAS scores are looked at. There was an improvement for a much smaller number of patients in the EQ index scores. A similar phenomenon is shown in the comparison of expected and actual health gain after transplantation. Whereas the VAS scores show an actual health gain after transplantation, the EQ-index scores show a health loss. The expected gain on the VAS was not obtained after transplantation but a positive trend was shown in VAS scores with time after transplantation. The positive balance at 4 months after discharge was most pronounced by the higher than expected gain in EQ index scores. The expected gain on the VAS, however, was still not reached at 4 months after discharge. Further follow-up of the patients will provide data to test the hypothesis of improving health with time after transplantation.

The differences in results with the VAS and the index valuations may be due to the very small sample size of transplanted patients ($N = 15$ and $N = 8$ at 14 days and 4 months after discharge respectively), inconsistencies in patients' VAS valuations, the existence of a ceiling effect in health state descriptions (the majority of the respondents report no problems on either one of the dimensions of the EQ-5D) and the generic nature of the EQ-5D (respondents take other considerations than the five dimensions into account when valuing health states).

Due to the small sample size of transplanted patients and the limited follow-up of transplant patients, results may not be generalizable to long-term outcomes and the renal transplant

population. However, the longitudinal follow-up from pre- to post-transplantation should be considered as better than cross-sectional comparisons of expected and actual health pre- as well as post-transplantation. Further longitudinal research in the same patient sample will provide more insight into the relative improvement of patients' quality of life pre- to post-transplantation. The follow-up period will be extended to one year after transplantation and more patients will be followed. Moreover, more background variables such as personality disorder, depressive state, symptom distress from immunosuppressive drugs, clinical status and co-morbidities will be measured in patients and form the basis for the establishment of more relationships between these determinants and expected and/or actual quality of life after transplantation.

Patients with good health during dialysis generally expect good health after transplantation. The reverse holds as well: patients with worse health usually do not expect spectacular improvements after transplantation. The reason may be that patients with worse health states during dialysis have more comorbidities, such as cardiovascular disease, that cannot be remedied by the transplantation. Therefore, they expect to remain at a less than optimal health state after transplantation.

From the comparison between health care workers' perceptions and patients' actual quality of life after transplantation, it is revealed that health care workers are in general quite good in estimating the impact of renal transplantation on quality of life. Specifically health care workers on the transplantation ward rate health after transplantation very similar to patients' actual state of health. Nurses and physicians on the transplantation ward are confronted with the good as well as the bad aspects of transplantation. Renal transplant patients with serious complications of all kinds come back to the ward. From the moment they are recovered, they are discharged. Therefore, it would rather be expected that transplant nurses and physicians underestimate the quality of life of renal transplant patients, which is not the case.

A number of remarks should be made with respect to the impact of demographic variables and current health on the data. First of all, the two respondent groups are not comparable in terms of age, sex and experience of illness. It might be argued that differences in VAS-scores for expected and perceived health may be due to the differences in actual health. In earlier population studies, it was found that older persons are in worse health than younger persons and hence are likely to report more problems on the EQ-5D dimensions^(13,34). This finding was confirmed in this study: the patient group, who was on average older than the group of health care workers, reported more problems on all dimensions of the EQ-5D. Additionally, in previous research it was found that respondents with current experience of illness give higher health state valuations⁽²⁹⁾. Studies in which health state valuations from health care workers were compared with those of patients, however, did not find an impact of age or sex of patients on the level of

agreement between both respondent groups' valuations ⁽⁶⁾. The fact that renal transplant patients had relatively high health status valuations, may have influenced the level of concordance between health care workers' perceptions and patients' actual quality of life after transplantation. Earlier research has shown that the level of agreement between patients and health care workers with respect to quality of life tends to diminish with decreasing health status in patients ⁽⁶⁾.

There might be a significant ceiling effect in the EQ-5D in that dialysis patients already score near the top of the VAS such that small improvements in quality of life are potentially missed ^(16,13). The reasons for this lack of sensitivity to small changes may be that respondents take other factors than those included in the descriptive system of the EuroQol into account when valuing their perceived, expected and/or current health state. This is illustrated by the fact that the valuation of state 11111 differs across measurement moments or even at one moment on different places in the questionnaire. Of the 78 patients and 123 health care workers, respectively 23 and 10 gave the same description to current and expected or perceived health after transplantation. Of the 23 patients who described their expected health as identical to their current health, only 6 (26%) gave the same VAS-score to both states. Of the health care workers, only one (10%) did so. Differences between thermometer scores and index scores were also found in other studies ⁽¹⁸⁾. The EuroQol questionnaire is mainly designed for use in economic evaluation studies and is, therefore, not designed to detect small changes in quality of life. Therefore, it is always recommended to use a disease specific quality of life questionnaire alongside the EuroQol if more details on which aspects of life are influenced by an illness are required. As there was no valid disease specific quality of life questionnaire available at the time of the study, no such instrument was used here.

Conclusion

Dialysis patients that consider being put on the renal transplant waiting list are influenced in their expectations about post-transplant quality of life by many different factors. The information from health care workers is one of these influences. Earlier studies showed that health care workers have different ideas about the outcome of an intervention than patients, especially with respect to quality of life. Studies on the relationship between patients' expectations on the outcome of an intervention and health care workers' perceptions of outcome could not be retrieved from the literature. This paper reports on a survey in health care workers and renal transplant candidates on perceptions about quality of life after transplantation and their actual quality of life post-transplant. It is found that health care workers' perceptions on quality of life after transplantation are close to the actual quality of life patients report after transplantation but are lower than patients' expectations. Patients' expectations on their health state post-transplantation are usually higher than their actual health state after transplantation, although this result should be considered with caution as the number of transplant patients followed is very small. Patients will be followed further in the future (at 4, 8 and 12 months after RTX) and more patients will be included to get more insight into how patients' actual QoL evolves after RTX and how this evolution compares to their expectations before transplantation. However, it is important that health care workers are aware that patients often have high expectations about their potential quality of life after transplantation in order to provide appropriate information to the patient.

The clinical importance of high expectations pre-transplant has yet to be examined. Patients may change behaviour if it turns out that their expectations are not fulfilled, e.g. fail to comply with their therapeutic regimen because they did not expect to have distressing side-effects from the immunosuppressive medication. This may have important clinical and economic consequences for the health care sector. Further research by our research group will examine these issues.

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