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The quality of life in end stage renal disease care

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Abstract The improved prognosis and survival statistics of both renal transplantation and dialysis have focused attention on the quality of life offered by these treatments. Using a standardized questionnaire, we assessed the quality of life of 612 patients undergoing renal replacement therapy at our center. Of these patients, 359 had been transplanted and 253 patients were on dialysis. Concerning the sociodemographic data, only the time on specific treatment was longer in dialysis patients than in transplanted patients (49.2 versus 55.6 months, $P < 0.05$). Most complaints were more common in dialysis patients than in transplanted patients. Only the side effects of medication were seen more in transplanted patients ($P < 0.005$). Life satisfaction was higher in transplanted patients than in dialysis patients. Dialysis patients were more anxious ($P < 0.05$) and more depressed ($P < 0.001$) than transplanted patients. Transplanted patients also felt that they had more social support than did dialysis patients. Overall life quality was almost equal between patients on hemodialysis and patients on peritoneal dialysis, and between patients on the waiting list for transplantation and those not on the waiting list. Despite a significantly better quality of life after renal transplantation, the percentage of patients working remained unchanged. (57.5 % versus 57.8 %, P = n.s.). We conclude that despite an improved quality of life after renal transplantation, these patients are economically not more productive than patients on dialysis.

Key words End-stage renal disease · Hemodialysis · Kidney transplantation · Peritoneal dialysis · Quality of life

Introduction

During recent decades, the number of patients with end-stage renal disease on long-term renal replacement therapy has continuously increased. Renal transplantation has become a routine therapy option worldwide besides hemodialysis (HD) and peritoneal dialysis (PD). According to data from the United Network for Organ Sharing (UNOS) registry, annual registrations on the kidney waiting list in the USA grew from 13943 in 1988 to 24973 in 1993 (79.1 %) [11]. During the same period the total number of cadaver-donor renal transplants increased from 7200 to 8100 (12.5 %). Data from the Eurotransplant-registry [4] confirm this development.

Some recent investigations indicate that elderly patients who receive a kidney transplant might experience a greater survival probability than those who remain on dialysis [19]. However, in general, patient survival seems to be independent of the kind of renal replacement therapy [2, 3]. Therefore, the quality of life offered by these therapy options is increasingly important. While most studies in this field have focused on single aspects of quality of life, we tried to get an impression of the overall life satisfaction including the employment situation

Table 1 Sociodemographic data

	TX	Dialysis
Patients (*n*)	359	253
Age (years)	47.6 ± 0.6	49.9 ± 0.9
Male (%)	61.6	64.8
German nationality (%)	94	95
Time on treatment (months)	$49.2 \pm 2.0^{*}$	55.6 ± 3.0
Married (%)	70.2	64.8
No children (%)	33.4	34.4
Secondary school and better (%)	64.9	68.7
Annual income ≥ 40000 DM (%)	18.4	13.5

* $P < 0.05$

of the patients. Using a standardized and validated questionnaire, we compared the quality of life of renal allograft recipients with that of patients on center HD and on PD in a large population.

Materials and methods

All patients (n = 1079) undergoing renal replacement therapy at the University of Erlangen-Nürnberg received a standardized questionnaire. Completed questionnaires from 612 patients (56.7%) were evaluable. Of these patients, 359 (58.7%) were transplanted (TX), 235 (38.4%) were on HD, and 18 (2.9%) on PD. Of all patients on dialysis (253, 41.3%), 164 (26.8%) were on the waiting list (WL) for renal transplantation, while 89 (14.5%) were not (NWL).

The somatic complaints were evaluated according to the 'Freiburg Somatic complaint List' [8]. Life satisfaction was investigated using the 'Freiburg Life Satisfaction Questionnaire' [9]. For the evaluation of psychological status, a shortened form of the 'Brief Symptom Inventory' was used [5]. Social support was analyzed according to the 'SOZU-K-22 questionnaire' [10]. All these questionnaires were answered by using a semiquantitative scale ranging from 1 to 5. In addition, sociodemographic data and questions concerning the employment situation were evaluated. The results of the questionnaire were finally supplemented by data from the medical files. Using these tools, we compared the quality of life of renal allograft recipients and patients on dialysis (HD plus CAPD). In addition, we compared patients on HD with those on PD, and WL patients with NWL patients.

Statistical analysis was done using SPSS software. Group comparison was done using the Mann-Whitney *U*-test and the Chi-Squared-test. Variance analysis was done by ANOVA. All values are given as means ± standard deviation. *P*-values ≤ 0.05 were considered as statistically significant.

Table 2 Complaints (1 = no complaints, 5 = very strong complaints)

	TX (n = 359)	Dialysis (n = 253)
Sickness, inappetence	$1.6 \pm 0.9^{***}$	2.1 ± 1.2
Blood pressure	$2.7 \pm 1.2^{*}$	3.0 ± 1.2
Tiredness, exhaustion	2.5 ± 1.1	3.0 ± 1.0
Cardiovascular	$2.0 \pm 1.0^{*}$	2.4 ± 1.2
Dermatological, pruritus	$1.9 \pm 1.2^{***}$	2.7 ± 1.3
Gastrointestinal	$1.7 \pm 1.0^{***}$	2.1 ± 1.2
Arthralgia	$2.2 \pm 1.2^{**}$	2.5 ± 1.3
Muscle cramps	$1.9 \pm 1.0^{***}$	2.6 ± 1.2
Headaches	$1.9 \pm 1.0^{*}$	2.1 ± 1.1
Sleep disturbance	$2.1 \pm 1.0^{***}$	2.8 ± 1.3
Restrictions	$2.0 \pm 1.0^{***}$	2.6 ± 1.1
Feeling of thirst	$2.3 \pm 1.3^{***}$	3.2 ± 1.3
Restlessness	$2.3 \pm 1.0^{*}$	2.5 ± 1.0
Nervousness	$2.3 \pm 1.0^{*}$	2.5 ± 1.1
Dreams	1.6 ± 0.9	1.5 ± 0.8
Dysmnesia	$2.3 \pm 1.0^{*}$	2.1 ± 1.0
Fear of medical complications	2.5 ± 1.2	2.4 ± 1.2
Side effects of medication	2.7 ± 1.1	$2.3 \pm 1.1^{**}$
Fear of the future	2.4 ± 1.2	2.4 ± 1.2
Low spirits	$2.1 \pm 1.0^{*}$	2.3 ± 1.0
Lack of interests	$1.7 \pm 0.9^{***}$	2.1 ± 1.1
Physical appearance	2.3 ± 1.2	$2.0 \pm 1.2^{**}$

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.005$

Table 3 Life satisfaction (1 = very dissatisfied, 5 = very satisfied)

	TX (*n* = 359)	Dialysis (*n* = 253)
Physical performance	$3.3 \pm 1.2^{***}$	2.7 ± 1.1
Intellectual performance	3.5 ± 1.0	3.4 ± 1.0
Personal contentment	$3.6 \pm 1.0^{***}$	3.2 ± 1.0
Employment situation	$3.3 \pm 1.1^{***}$	2.9 ± 1.1
Financial situation	$3.5 \pm 1.2^{***}$	3.1 ± 1.2
Interpersonal relationships	$4.0 \pm 1.1^{***}$	3.8 ± 1.0
Relationship with spouse/partner	4.0 ± 1.1	3.8 ± 1.2
Family life	$4.2 \pm 1.0^{*}$	4.0 ± 1.0
Role in the family	$4.2 \pm 0.9^{***}$	3.9 ± 1.0
Sexual performance	$3.1 \pm 1.2^{**}$	2.9 ± 1.2
Leisure time	$3.5 \pm 1.1^{***}$	3.1 ± 1.2
Overall life satisfaction	$4.0 \pm 0.9^{***}$	3.4 ± 0.9

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.005$

Results

The demographic data are shown in Table 1. Significant differences between renal allograft recipients and patients on dialysis were found only in time on specific treatment. TX patients had significantly lower levels of complaint than dialysis patients for most parameters (Table 2). Only the side effects of medication were seen more in TX patients. Similarly, TX patients proved to have a higher grade of life satisfaction than dialysis patients (Table 3). Assessment of the psychological status revealed that TX patients had significantly lower levels of depression (1.5 ± 0.7 versus 1.8 ± 0.7, $P < 0.001$) and anxiety (1.8 ± 0.7 versus 1.9 ± 0.8, $P < 0.05$) than dialysis patients. TX patients felt that they had a higher grade of social integration (4.0 ± 0.8 versus 3.7 ± 0.8, $P < 0.001$). In all other parameters, namely emotional support, practical support, confidence and overall satisfaction with social support, significant differences between the groups were not detected.

Employment status changed dramatically with the onset of renal replacement therapy. While only 24.8% of all patients were not working before the onset of dialysis, 57.5% of these patients were not working during their time on dialysis ($P < 0.001$). Successful renal transplantation did not change this situation, as 57.8% of patients remained without work (P = n.s.). Among those working during dialysis, the number of patients working more than 30 h per week increased from 23.1% to 28.9% ($P < 0.05$), while the number of patients working part-time (≤ 30 h per week) decreased from 19.4% to 13.3% ($P < 0.05$).

Between HD patients and CAPD patients the only sociodemographic parameter that was significantly different was the time on specific treatment (58.2 ± 3.2 months vs 21.4 ± 2.2 months, $P < 0.001$). Among complaints, life satisfaction, psychological status and social support, significant differences between HD patients and CAPD patients were found only in sleep disturbance (2.8 ± 1.2 versus 2.1 ± 1.0, $P < 0.05$), restrictions (2.6 ± 1.1 versus 1.9 ± 0.8, $P < 0.01$), and feeling of thirst (3.3 ± 1.3 versus 2.4 ± 1.1, $P < 0.01$). In all other parameters investigated, significant differences were not detected.

Between WL patients and NWL patients there were significant differences in age (44.9 ± 1.0 years vs 59.0 ± 1.5 years, $P < 0.001$) and time on specific treatment (53.6 ± 3.8 months vs 59.2 ± 5.0 months, $P < 0.01$). Whereas cardiovascular complaints were less frequent in WL patients (2.2 ± 1.0 versus 2.7 ± 1.2, $P < 0.005$), muscle cramps (2.3 ± 1.1 versus 2.7 ± 1.2, $P < 0.05$), restlessness (2.3 ± 1.0 versus 2.6 ± 1.1, $P < 0.05$) and nervousness (2.3 ± 1.1 versus 2.6 ± 1.2, $P < 0.05$) were less frequent in NWL patients. In all other parameters no significant differences were detected.

Discussion

The results of our study clearly indicate that the overall quality of life of renal allograft recipients is significantly better than patients on dialysis. In summary, renal allograft recipients had fewer complaints, a higher life satisfaction, and less depression and anxiety and felt themselves to have more social support. Only the side effects of medication occurred more in renal allograft recipients. Taken together, our results confirm those of previous studies [7, 13, 18, 21]. Laupacis et al. found that the quality of life of patients with end-stage renal disease improved in almost all dimensions within 6 months of successful renal transplantation [14]. On the other hand, a diminished quality of life is more pronounced in dialysis patients, who experience failed transplants [1, 16, 21]. Within the group of renal allograft recipients, the quality of life is dependent on the immunosuppressive regimen. Patients who receive cyclosporine have a better quality of life than patients who receive conventional therapy including azathioprine [20, 22].

Several studies have found that patients on center HD have the lowest quality of life [1, 7, 15], whereas patients on home HD have significantly better quality of life [7, 15]. According to Bremer et al. the quality of life of the latter patients is similar even to successfully transplanted patients [1]. Owing to the very small number of patients on home HD in our population, we could not address this question.

In this investigation, only small differences between patients on PD and on HD were detected. Patients on HD complained more about sleep disturbance, restrictions and a feeling of thirst. Therefore, our results confirm those of Evans et al. [7] and Bremer et al. [1], who observed that the quality of life of PD patients is as low as that of center HD patients. In contrast, Morris and Jones found that the quality of life of PD patients is comparable to that of home HD patients and better than that of center HD patients [15]. It might be that the advantage of PD over HD is time-dependent and only seen in patients who stay on therapy for more than 3 years, as reported by Simmons and Abress [21].

In most parameters no significant differences were found between WL patients and NWL patients. The finding of a higher frequency of cardiovascular complaints in NWL patients seems to reflect the fact that a significant proportion of these patients are not accepted for renal transplantation because of cardiovascular disease. On the other hand, the higher frequency of muscle cramps, irritability and restlessness/nervousness in WL patients might reflect the dissatisfaction with their current situation and their yearning for transplantation.

Despite highly significant advantages to the overall quality of life, the percentage of patients not working remained unchanged after successful renal transplantation. Only within the group of patients who worked part-time during their time on dialysis, did the weekly working time slightly increase. It is remarkable that the improved quality of life after renal transplantation did not make these patients economically more productive. Therefore, the pretransplant employment status is a major predictor of the posttransplant employment status, as observed by Jones at al. [12]. Ehrich et al. [6] reported that the major factors influencing patients' rehabilitation potential are the presence of disabilities, the method of treatment, geographical factors, the duration of renal replacement therapy, and the underlying primary renal disease.

In summary, our results indicate that the quality of life of renal allograft recipients is better than that of dialysis patients. Few significant differences were found between HD patients and PD patients or between WL patients and NWL patients. Despite the advantage of having a significantly higher quality of life after successful renal transplantation, the percentage of renal allograft recipients working did not increase. As the patient's own motivation is crucial to the success of rehabilitation, it is essential to educate the kidney patients about the importance and benefits of rehabilitation before the onset of dialysis. The entire medical team should develop the patient's rehabilitation objectives by establishing goals within the context of the patient's capabilities [17].

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