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Factors Determining Social Participation in the First Year After Kidney Transplantation: A Prospective Study

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Background. This study describes changes in social participation in the first year after kidney transplantation and examines the influence of clinical factors, health status, transplantation-related symptoms, and psychological characteristics on change in social participation.

Methods. A prospective study was performed on a cohort of primary kidney transplant recipients, transplanted between March 2002 and March 2003. Data on participation in obligatory activities (i.e., employment, education, household tasks) and leisure activities (i.e., volunteer work, assisting others, sports, clubs/associations, recreation, socializing, going out) were collected by in-home interviews (n=61) at 3 months (T1) and 1 year posttransplantation (T2). Analysis of covariance was performed.

Results. Data showed an increase in participation in obligatory activities and diversity of leisure participation between T1 and T2, although pre–end-stage renal disease level was not regained and differed from the general population. On T1, the majority of employed recipients were on sick leave, but returned to work on T2. Employment rate remained stable. An increase in obligatory participation was predicted by clinical factors (i.e., peritoneal dialysis, initial hospitalization), whereas change in leisure participation was related to serum albumin and cognitive capacity. No effects were found for type of donation, comorbidity, and renal function.

Conclusions. We found that mainly clinical factors were associated with an increase in participation in society. Although health-status related factors and the psychological attribute self-efficacy may be related to recovery of social participation, their effect was outweighed by the strength of clinical predictors in multivariate analysis.

Keywords: Kidney transplantation, Social participation, Employment, Leisure activities, Rehabilitation, Health status.

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Successful kidney transplantation implies the transition from a life with the constraints imposed by dialysis to a "new" way of living. As quality of life (QoL) increases after transplantation, recipients expect that social life returns to "normalcy" again (*1*, *2*). The first weeks after transplantation sometimes are referred to as a euphoric "honeymoon" period (*3*). Disappearance of dietary restrictions, increased energy, and available time gained by the absence of dialysis creates the expectation that recipients will become more active (*4*). Nevertheless, life after transplantation also has drawbacks, such as the strict immunosuppressive regimen and its side effects, frequent medical follow-up visits, rejection episodes, infections, and uncertainty and anxiety for potential graft loss (*5–8*). The prospect of the new life and these additional negative aspects have to be integrated in daily life and appeal to the adaptability of recipients.

In contrast with increased QoL after kidney transplantation (*9–11*), results concerning resumption of social life are less satisfactory. A recent study showed that transplant recipients participated less in employment and sports compared to the general population (*12*). Worse social outcome was also found in adults treated with kidney transplantation in childhood (*13*). Factors contributing to this impaired social participation are not widely studied yet, although worse social outcome has been reported for cadaveric donation as compared to living donation, and for patients with cardiovascular disease (*14*). Posttransplantation return to work was associated with employment status pretransplantation (*15–17*). From rehabilitation perspective, it is desirable to understand the process of social participation after transplantation and the factors associated. If factors appear to be amenable to change, this would offer opportunities for interventions in the rehabilitation process.

The main purpose of the present study was to describe prospectively changes in social participation in the first year after transplantation, focusing on the period of 3 months to well over 1 year after transplantation. Hilbrands et al. (*18*) suggested that it takes at least 1 year before patients reach an optimum as far as QoL is concerned. Clinical transplantation practice learned that the immediate posttransplantation period (i.e., first 3 months) is characterized by physical recovery and further amelioration of renal function. After this initial

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phase of stabilization, outpatient visits become less frequent and social life can be regained, although this does not apply to all patients. For this reason, we examined factors potentially related to changes in social participation in the first year. Three research questions were addressed: 1) how does the level of social participation develop in the first year after kidney transplantation; 2) which clinical factors predict change in social participation in the first year; and 3) are changes in health status, symptoms and psychological characteristics in the first year associated with change in social participation.

PATIENTS AND METHODS

Patients transplanted at the University Medical Center Groningen (UMCG) who visited the outpatient clinic for follow-up after primary kidney transplantation were invited for this study. Patients 18 years of age or older with a stable renal allograft function and transplanted between March 1, 2002 and March 31, 2003 were eligible. Combined transplant (i.e., kidney/pancreas, kidney/liver) and retransplant recipients were excluded, as were patients unable to understand Dutch. The study was approved by the Medical Ethics Review Committee of the UMCG. After receiving information, recipients signed informed consent.

Of the cohort of transplant recipients (n=98), three recipients (3%) were back on dialysis and one (1%) visited an outpatient clinic elsewhere at the time of inclusion. Of the remaining 94 recipients, 12 were found ineligible because of mental retardation (n=1), inadequate mastery of Dutch (n=9), and blindness (n=2). Furthermore, four recipients were not included due to asynchronous scheduling of outpatient clinic visits and informed consent procedure. Of the 78 recipients approached for participation in this study, 62 agreed to participate (response rate 79%). However, 61 were finally enrolled, as one recipient died due to infection shortly before the first interview.

Data Collection Procedures

Data on clinical characteristics were collected by review of medical charts and the Groningen Renal Transplant Database. Data on demographic and anthropometric characteristics, and the outcome social participation, were measured twice by interview at patient's homes, at 3 months (T1; mean 3.3 [SD 0.5] months) and 1 year (T2; mean 13.6 [SD 0.5] months) posttransplantation. Both interviews were performed by the same interviewer. To prevent distortion of data collection the second interview was scheduled a few weeks after the first transplantation anniversary, often experienced as an emotionally charged period. Data on health status, transplantation-related symptoms and psychological characteristics were collected by standardized self-report questionnaires, sent to participants preceding the interview. Methodology of data collection is described in detail elsewhere (*12*, *14*).

Definitions

Outcome Measure

Social participation was defined as patient's actual involvement in society and divided in two types of participation: 1) participation in activities with *obligatory* characteristics, including paid work, education and household tasks. Number of hours per week spent on these activities were added, yielding a continuous score (range 4–70); 2) participation in *leisure* activities, including volunteer work, assisting others, sports (walking/cycling as means of getting about excluded) and involvement in clubs/associations were dichotomously (yes/no) assessed. Participation in recreation and socializing with relatives and friends respectively (both scored as yes if >1 time/week), and going out to public and cultural places (yes if ≥1 time/2 weeks) were assessed as well. Scores on these seven dichotomous leisure activities were summed, to obtain a total score (range 0–7) representing diversity, or width of leisure participation.

Furthermore, subjective experience of recipients regarding restrictions in social participation was assessed. Five questions on interference of health with participation in relevant social domains (i.e., employment, household tasks, sports/exercise, recreation, social relations) were scored as 1 (not at all) to 4 (very much).

In addition, recipients were requested to make a graphic representation of overall participation in daily life, including both obligatory and leisure activities, which was rated on a scale from no participation to full participation (range 0–8). To minimize recall bias, distinctive time points in the history of renal disease were chosen. At T1, participation at pre–end-stage renal disease (ESRD), at diagnosis of ESRD, at start of dialysis, and at transplantation were retrospectively assessed, besides present level of participation. Likewise, at T2, participation at 6 and 9 months posttransplantation were retrospectively assessed, besides present participation and future expectations.

Clinical Characteristics

Primary renal disease was classified according to the ERA-EDTA (*19*). Comorbidity was defined as diabetes mellitus (insulin or oral antidiabetic drugs dependent), and presence of cardiovascular disease evidenced by a history of cardiovascular events (*14*). Additional clinical characteristics: type of transplantation (cadaveric vs. living); type (peritoneal vs. hemodialysis) and duration (years) of dialysis prior to transplantation; allograft rejection (biopsy proven); duration of initial hospitalization (days); follow-up hospitalization at the UMCG; renal allograft function (24-hour urinary creatinine clearance); type of triple immunosuppressive therapy (Table 1); body mass index (BMI).

Health Status

Health status was assessed by the Short-Form (SF)-36, version 1 (*20*), a questionnaire consisting of eight multi-item scales: physical functioning, role limitations due to physical health problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and general mental health. Higher scores indicate higher levels of health and functioning, and freedom of pain (range 0–100). The SF-36 is a reliable and valid instrument for use in chronic disease populations, including kidney transplant recipients (*21–24*).

Transplantation-Related Symptoms

The End-Stage Renal Disease Symptom Checklist-Transplantation Module (ESRD-SCL) (*25*) measures self-reported physical and psychological distress (43 items)

TABLE 1. Demographic and clinical characteristics at 3 months posttransplantation (n=61)

Characteristic	Data
Age, mean years ± SD (range)	44.2±13.6 (19–72)
Gender, male	32 (52.5)
Living arrangement, with others	52 (85.2)
Educational status	
Primary	9 (14.8)
Lower secondary	24 (39.3)
Upper secondary	17 (27.9)
Tertiary	11 (18.0)
Primary renal disease	
Glomerulonephritis	41 (67.2)
Renal vascular disease	5 (8.2)
Polycystic renal disease	8 (13.1)
Other/unknown cause	7 (11.5)
Type of comorbidity	
Diabetes mellitus	2 (3.3)
Cardiovascular events	7 (11.5)
Type of transplantation	
Cadaveric	39 (63.9)
Living	22 (36.1)
Pre-transplant dialysis	
None	3 (4.9)
Hemodialysis	21 (31.4)
Peritoneal	37 (60.7)
Duration of dialysis, median years (range)	3.6 (0.4–8.8)
Duration initial hospitalization, median days (range)	22 (14–78)
Acute allograft rejection	26 (42.6)
Rehospitalization	14 (23.0)
Immunosuppressive protocol	
CsA+MMF+Pred	42 (68.9)
Tac+MMF+Pred	12 (19.7)
Srl+Tac+Pred	7 (11.5)

Data are n (%) unless noted.
CsA, cyclosporine; MMF, mycophenolate mofetil; Pred, prednisone; Tac, tacrolimus; Srl, sirolimus.

with a focus on side effects of immunosuppressive medication. This questionnaire has six subscales: limited physical capacity, limited cognitive capacity, cardiac and renal dysfunction, side effects of corticosteroids, increased growth of gum and hirsutism, and transplantation-associated psychological distress. Higher scores reflect more transplantation-related symptoms (range 0–4). The ESRD-SCL showed adequate validity and reliability (*25*).

Psychological Characteristics

Mastery, the extent to which one regards one's life chances as being under one's own control, in contrast to being controlled by fate, was assessed with a seven-item questionnaire (range 7–35) (*26*). Self-efficacy, the belief of a person in one's ability to organize and execute certain behaviors that are necessary in order to produce given attainments, was assessed with a 16-item questionnaire (range 16–80) (*27*). Dispositional optimism, the generalized outcome expectancy that good things rather than bad things will happen, was assessed with the revised Life Orientation Test (LOT-R) (range 6–30) (*28*). Neuroticism (emotional instability) and extraversion (sociability) were assessed by subscales of the Eysenck Personality Questionnaire-Revised (EPQ-R), each consisting of 12 items (range 0–12) (*29*). Higher scores indicate higher levels of the psychological characteristic under study. Psychometric properties of these scales were previously described as satisfactory (*28–30*).

Statistical Analysis

Nonresponse analysis was performed with the independent sample *t* test, Mann-Whitney test, and chi-squared test. In accordance with the research questions the data were analyzed in three steps.

First, descriptive statistics (mean ± standard deviation [SD]; median; proportion) represent the outcome measures and explanatory factors at T1 and T2. Continuous data were tested with the paired sample *t* test, or the Wilcoxon paired test (nonnormal distribution). Proportions were tested with the McNemar test. Health status at T2, measured with the SF-36, was compared with the general population (n=1742; mean age 47.6±18.0; 56% male; [*20*]) and tested with the independent sample *t* test.

Secondly, we applied analysis of covariance (ANCOVA) to examine influencing factors on change in social participation. ANCOVA is a linear regression analysis in which the follow-up measurement (T2) is used as the outcome variable, and the baseline measurement of this variable (T1) is used as a covariate (*31*). Accordingly, we used T2 *obligatory* participation as outcome variable, and T1 obligatory participation as covariate, and thus expressed change in obligatory participation in the first year after transplantation. In addition, univariate associations of clinical factors were examined and adjusted for age, gender and educational status. Next, multivariate regression analysis was performed. Factors with univariate adjusted associations of $P<0.10$ were entered into the multivariate model and sequentially deleted, starting with the variable having the weakest association. This procedure of ANCOVA was also applied to analyze diversity of *leisure* participation.

To address the third research question, ANCOVA was applied as described above. Besides adjustment for age, gender and educational status, significant clinical factors from the second step were included as well. In addition, effect of change in explanatory factors (i.e., health status, symptoms, psychological characteristics) was assessed by including both T1 and T2 measures of each explanatory factor in the analysis. Besides this univariate analysis, also multivariate analysis, as described in the second step, was applied.

RESULTS

Study Population

Descriptive data on 61 kidney transplant recipients interviewed at T1 are outlined in Table 1. Three recipients (5%) withdrew at 1-year follow-up. One recipient had diabetes mellitus (DM, no diabetic nephropathy) at admission for

transplantation. One third of the recipients (36%) received a kidney from a living donor (64% related donors). Two recipients had developed posttransplant lymphoproliferative disease (PTLD) at T1 and were treated accordingly.

Transplant recipients included in this study were younger than nonresponders (n=12; mean 55.3 yr; mean difference 10.7 yr; 95% CI: 3.4 to 18.1). No differences were found for gender (52.6% male; $P=0.74$), type of transplantation (88% cadaveric; $P=0.08$), duration of initial hospitalization (median 24.5 days; $P=0.64$), and allograft rejection (31%; $P=0.22$).

At T2, 5% (n=3) of the recipients declined further participation in the study. These dropouts appeared to be younger (mean age 36.0 yr), were longer hospitalized (median 28 days), all received prior peritoneal dialysis (PD), and all experienced allograft rejection. They had average levels of social participation at T1 (median obligatory time 15 hr/week; mean diversity of leisure 3.0). Differences were not tested due to small sample size.

Social Participation

Three months posttransplantation (T1), total time spent weekly on employment, education and household tasks showed that 60% of the recipients scored ≤16 hr, indicating a low degree of participation in obligatory activities (Table 2). In contrast, at 1 year after transplantation (T2) only 33% participated ≤16 hr, whereas 36% had a high degree of participation (>32 hr/week). This median increase of 9.3 hr/week was statistically significant ($P<0.001$).

With respect to employment, 54% (n=29) of working-age recipients (in the Netherlands legal retirement starts at the age of 65 years) had a paid job at T1, including those with minor jobs (1–11 hr/week). Of those employed recipients, 52% (n=15) were on full sick leave at T1, whereas 31% (n=9) had resumed work therapeutically or returned to work partially. Only 17% (n=5) were fully recovered at T1 and worked the number of hours as before transplantation. As a result, median actually worked hours at T1 was zero. At T2, 56% (n=30) was employed of which one recipient still worked therapeutically.

Table 2 shows an increase in mean diversity of leisure participation at T2 ($P<0.05$). The rise in proportion of participation in separate leisure activities between T1 and T2 was not statistically significant.

Perceived restrictions (Table 2) in separate domains of social participation showed that at T1 recipients felt mostly restricted in sports/exercise and in employment, whereas socializing was the least affected domain. At T2, recipients experienced fewer restrictions in employment ($P<0.001$). Decrease in other domains of participation was not statis-

TABLE 2. Social participation 3 months and 1 year after kidney transplantation (n=58)

Social participation	3 months (T1)	1 year (T2)	*P* value
Obligatory activities			
Total time, median hrs	15.0	24.3	<0.001
Total obligatory time			
≤16 hr/wk	35 (60.3)	19 (32.8)	
17–32 hr/wk	16 (27.6)	18 (31.0)	
>32 hr/wk	7 (12.1)	21 (36.2)	
Employed participants, median hrs	0	20.0	<0.001
Household tasks, median hrs	9.5	9.5	0.49
Students, median hrs	15.0	32.5	NT
Leisure activities			
Volunteer work	12 (20.7)	19 (32.8)	0.09
Assisting others	7 (12.1)	13 (22.4)	0.15
Sporting activity	15 (25.9)	23 (39.7)	0.08
Involvement in clubs/associations	36 (62.1)	38 (65.5)	0.80
Recreational activity[a]	26 (44.8)	33 (56.9)	0.21
Socializing (relatives/friends)[a]	30 (51.7)	32 (55.2)	0.83
Going out (public, cultural)[b]	26 (44.8)	24 (41.4)	0.79
Diversity (mean±SD)	2.6±1.4	3.1±1.6	0.02
Perceived restrictions (mean±SD)			
Employment[c]	2.3±0.9	1.4±0.7	<0.001
Household tasks	1.9±0.9	1.7±0.8	0.05
Sports/exercise	2.3±1.0	2.1±1.0	0.28
Recreation	1.7±0.8	1.6±0.8	0.51
Socializing	1.4±0.8	1.3±0.7	0.34

Data are n (%) unless noted.
[a] >1 time/week.
[b] ≥1 time/2 weeks.
[c] Only data of participants employed at both time points (n=23) were included in the analysis (n=2 missing value at 3 months).
NT, Not tested due to small sample (n = 7 full-time or part-time students at 3 months; n = 6 at 1 year).

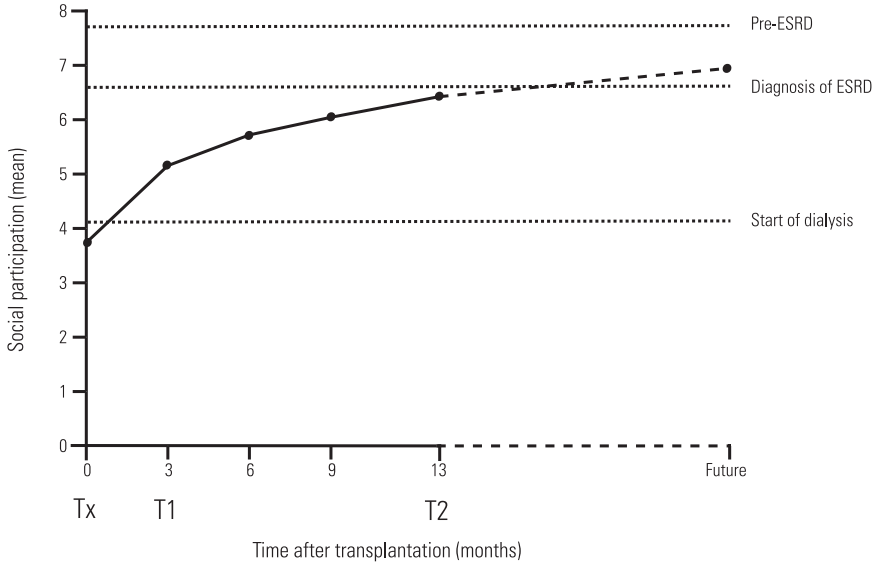

FIGURE 1. Level of social participation by ESRD trajectory (n=55). Tx, transplantation; ESRD, end-stage renal disease.

tically significant, although household tasks was borderline ($P=0.05$).

Figure 1, showing the pattern of overall social participation (i.e., obligatory and leisure) in time, indicates an improvement in social participation after kidney transplantation. Social participation remained steadily improving throughout the first year. Although at T2, the level of participation was higher compared with the level of participation at start of dialysis (mean difference 2.3; 95% CI: 1.6 to 2.9), it was still below the level of participation preceding diagnosis of ESRD (mean difference of −1.3; 95% CI: −1.7 to −0.9). At T2, recipients expressed expectations of a further improvement in future.

Clinical Characteristics and Health Status

Table 3 shows that creatinine clearance increased during the first year ($P<0.01$), as did level of hemoglobin ($P<0.001$), hematocrit ($P<0.001$), and serum albumin ($P<0.01$). Mean BMI increased as well ($P<0.001$). Three months posttransplantation, 9% were obese (BMI ≥30), and 1 year posttransplantation 17% were obese.

The SF-36 (Table 3) demonstrated a statistically significant increase in physical functioning ($P<0.01$) between T1 and T2, an increase in role physical functioning (i.e., less role limitations due to physical health problems; $P<0.01$), as well as an increase in social functioning ($P<0.01$). Improvement in other scale scores was not statistically significant. Comparison of health status of recipients at T2—a time period after transplantation when recovery may be expected—with the general population (*20*) showed that transplant recipients were more limited in role physical functioning (mean difference −12.4; 95% CI: −23.3 to −1.4; $P<0.05$). In addition, their general health perception was lower compared to the general population (mean difference −7.9; 95% CI: −13.0 to −2.7; $P<0.01$). Differences in other scales were not statistically significant (data not shown).

Transplantation-Related Symptoms

Higher scores on the subscales of the ESRD-SCL at T2 suggested an increase in burden of transplantation-related symptoms (Table 3). Perceived cardiac and renal dysfunction (e.g., increased blood pressure, swollen legs and feet or paresthesia, proneness to bruises) increased ($P<0.05$), as well as burden of growth of gum and signs of hirsutism ($P<0.05$).

Psychological Characteristics

Psychological characteristics (Table 3) appeared to be stable in time. Disease specific psychological distress (e.g., worrying about kidney donor, uncertainty about transplant functioning) measured with the ESRD-SCL increased, but was not statistically significant. SF-36 mental health subscale was stable in time. Transplant recipients reported a level of mental health that equaled mental health of the general population (mean difference 2.7; 95% CI: −1.5 to 6.9; $P=0.21$) (*20*). Even so, 26% of recipients received professional psychosocial support (i.e., social worker, psychologist) during the first year.

Clinical Predictors of Change in Social Participation

Analysis of covariance (ANCOVA) showed that peritoneal dialysis (regression coefficient (B)=8.41; $P<0.05$), prolonged duration of initial hospitalization ($B=0.32$; $P<0.01$), rehospitalization ($B=9.16$; $P<0.05$), allograft rejection ($B=8.41$; $P<0.05$), and serum albumin ($B=1.25$; $P<0.05$) predicted an increase in *obligatory* participation. Presence of comorbidity, type of transplantation, duration of dialysis and type of immunosuppressive protocol showed no statistically significant effects. After adjustment for age, gender, and educational status, the effect of initial hospitalization ($B=0.31$; $P<0.05$) remained, whereas the effects of peritoneal dialysis ($B=6.44$; $P=0.087$), rehospitalization ($B=8.14$; $P=0.061$), and allograft rejection ($B=6.33$; $P=0.094$) weakened.

Multivariate analysis of change in obligatory participation, including adjustment for age, gender, and educational status, resulted in a model ($R^2=0.55$; $F=7.04$; $P<0.001$) with significant effects of prolonged initial hospitalization and peritoneal dialysis (Table 4). The T1 measure of obligatory participation, which was used as a covariate, contributed substantially ($R^2=0.24$) to the variance in T2 obligatory participation.

TABLE 3. Clinical characteristics, health status, transplantation-related symptoms, and psychological characteristics of the study group (n=58)

	N	3 months (T1)	1 year (T2)	ΔT2 – T1
Clinical characteristics				
24-hr creatinine clearance (mL/min)	56	61.0±19.5	69.6±22.3	8.6±21.1[d]
Hemoglobin (mmol/L)	58	7.8±1.1	8.5±1.1	0.7±1.0[e]
Hematocrit (%)	58	37.6±5.2	41.5±5.7	3.9±4.8[e]
Serum albumin (g/L)	58	40.0±2.9	41.3±3.6	1.4±3.7[d]
BMI (kg/m^2)	58	24.3±4.0	25.8±4.6	1.6±1.7[e]
Health status (SF-36)[a]				
Physical functioning	57	70.7±20.6	79.5±19.1	8.8±20.1[d]
Role-physical	57	38.7±39.2	64.0±41.2	25.3±51.7[d]
Bodily pain	57	73.0±23.0	76.5±20.5	3.5±24.1
General health	57	60.5±16.6	62.8±19.4	2.3±21.0
Vitality	57	65.1±15.6	67.9±16.7	2.8±15.6
Social functioning	57	76.3±20.0	82.4±17.8	6.1±17.2[d]
Role-emotional	56	81.0±30.4	87.5±25.9	6.5±37.8
Mental health	57	81.2±14.6	79.5±16.0	−1.7±15.1
Transplantation-related symptoms[b]				
Physical capacity limitation	57	0.55±0.41	0.57±0.46	0.03±0.43
Cognitive capacity limitation	57	0.31±0.34	0.38±0.39	0.07±0.27
Cardiac/renal dysfunction symptoms	57	0.42±0.36	0.56±0.44	0.14±0.42[f]
Side-effects corticosteroids	57	0.57±0.58	0.67±0.45	0.10±0.62
Increased growth gum/hair	57	0.53±0.49	0.67±0.55	0.14±0.53[f]
Psychological distress	57	0.39±0.38	0.47±0.41	0.08±0.38
Psychological characteristics[c]				
Mastery	57	26.1±4.7	25.8±4.3	−0.3±4.0
Self-efficacy	57	62.4±9.4	62.1±10.9	−0.2±7.0
Optimism	57	21.3±4.2	21.4±3.2	0.1±2.8
Neuroticism	56	2.7±2.8	2.9±3.3	0.3±1.9
Extraversion	57	7.3±3.1	7.6±3.3	0.3±2.1

Data are means±SD.
[a] Higher scores indicate higher levels of health status.
[b] Higher scores indicate more transplantation-related symptoms.
[c] Higher scores indicate higher levels of psychological characteristics.
[d] $P<0.01$
[e] $P<0.001$
[f] $P<0.05$

TABLE 4. Multivariate regression analysis of change in obligatory participation on predictors present at 3 months posttransplantation (n=55)

	β	*B*	95% CI		*P* value
T1 obligatory participation	0.57	0.71	0.41	1.00	<0.001
Age	−0.10	−0.12	−0.39	0.16	0.40
Sex (reference: male)					
Female	−0.18	−5.47	−11.93	0.99	0.10
Educational status (reference: primary)					
Lower secondary	−0.13	−3.92	−13.75	5.92	0.43
Upper secondary	0.14	4.83	−5.68	15.33	0.36
Tertiary	0.14	5.57	−5.68	16.83	0.32
Type of dialysis (reference: hemodialysis)					
Peritoneal dialysis	0.24	7.56	0.73	14.39	0.03
Duration initial hospitalization	0.34	0.35	0.13	0.57	0.003

β, standardized regression coefficient; *B*, regression coefficient; CI, confidence interval (95%).

ANCOVA of change in *leisure* participation showed no significant predictors and consequently did not result in an explanatory model. The T1 measure of diversity of leisure participation, which was used as a covariate, explained 22% (R^2=0.22) of the variance in T2 diversity.

Effect of Changes in Health Status, Symptoms, and Psychological Characteristics on Change in Social Participation

The following results address the third research question (see Statistical Analysis section, third step). Results of ANCOVA showed a univariate association of improved vitality (B=0.34; P<0.01) and increased serum albumin (B=1.23; P<0.05), with an increase in *obligatory* participation. Increased limitations in physical capacity (ESRD-SCL) were associated with decreased obligatory participation (B=−9.74; P<0.05). Adjustment for age, gender, and education resulted in an association of three variables: improved vitality (B=0.31; P<0.05), limitations in physical capacity (B=−9.36; P<0.05), and increased self-efficacy (B=0.54; P<0.05). However, multivariate analysis of change in obligatory participation, including significant clinical predictors (i.e., initial hospitalization, type of dialysis) did not result in a model, although the effect of increased self-efficacy was borderline (P=0.072).

ANCOVA of diversity of *leisure* participation showed an association for increased serum albumin (B=0.13; P<0.05). Increased limitations in cognitive capacity were associated with decreased leisure participation (B=−1.59; P<0.05). After adjustment for age, gender, and education, the effect of limitations in cognitive capacity (B=−1.50; P<0.05) was still present, and the effect of increased serum albumin (B=0.13; P=0.055) had weakened. Multivariate analysis of change in diversity of leisure participation resulted in a model (R^2=0.44; F=3.63; P<0.01) with serum albumin and cognitive capacity as predictors (Table 5).

DISCUSSION

The present study described the development of social participation in the first year after kidney transplantation. Although recipients at 3 months posttransplantation felt restricted in physical exercise and employment, there was a marked recovery at 1 year follow-up. However, the level of social participation did not parallel the pre-ESRD level, which shows that "normal" life is not completely restored, also reported by Crowley-Matoka (*2*). Furthermore, transplant recipients reported more limitations in role physical functioning (SF-36) compared with the general population. Luk (*8*) described an improvement in participation and resumption of recreational activities after transplantation, but also reported that physical activity remained quite low.

Results on employment showed that most employed recipients were still on sick leave at 3 months posttransplantation, although a few recipients had returned to work already. Clearly, longer convalescence time is needed. Despite the increase in time spent on active employment, the number of recipients with a paid job hardly changed (T1, 54%; T2, 56%), and is comparable to the employment rate (52%) we found in Dutch kidney transplant recipients with a mean follow-up of 3.8 years (*14*). The fact that in our study 47% (n=14) of employed recipients received additional social security benefits due to work disability, suggests that it is unrealistic to expect a further increase in employment rate. The stable rate indicates the importance of pretransplantation employment on return to work posttransplantation (*15*). However, maintaining employment when treated with dialysis proves to be difficult, and loss of work is already an issue during predialysis stage (*32*).

We found no increase in time spent on household tasks. A potential explanation is that recovery in this domain already took place before the first interview, as perhaps is expected in the family circle. Domestic activities can be performed at one's own pace and can be planned accordingly, and consequently may be more easily and earlier resumed compared to work outside the house.

The physical recovery at 1 year posttransplantation was also found by Hilbrands et al. (*18*). Nevertheless, transplant recipients reported worse general health compared to the general population, as earlier described by Khan et al. (*33*). This worse general health mainly concerns physical health, as we found no difference in mental health, which is in line with previous studies (*34*, *35*). Role limitations due to physical health problems may be related to insufficient physical exertion and stamina. Recently, it was recommended to promote exercise in kidney transplant recipients (*36*, *37*).

TABLE 5. Multivariate regression analysis of change in diversity of leisure activities on change in clinical factors, health status and symptoms between T1 (3 months) and T2 (1 year) (n=57)

	β	B	95% CI		P value
T1 diversity leisure participation	0.46	0.52	0.22	0.82	0.001
Age	−0.02	−0.002	−0.04	0.04	0.91
Sex (reference: male)					
Female	−0.02	−0.06	−0.86	0.74	0.88
Educational status (reference: primary)					
Lower secondary	−0.17	−0.54	−1.73	0.65	0.37
Upper secondary	−0.15	−0.51	−1.74	0.72	0.41
Tertiary	−0.06	−0.24	−1.56	1.08	0.71
Serum albumin	0.38	0.17	0.04	0.30	0.011
Cognitive capacity	−0.50	−2.05	−3.41	−0.61	0.006

β, standardized regression coefficient; B, regression coefficient; CI, confidence interval (95%).

In contrast with the general physical recovery, there was a trend towards increase of transplantation-related symptoms (ESRD-SCL). Likely, recipients experience more distress due to side effects of immunosuppressive medication in time. In addition, at 1 year posttransplantation, 17% of the study group was obese (BMI ≥30). Obesity and its associated risks is a major problem after kidney transplantation (*38*, *39*) and may also have a negative impact on participation in society (*40*).

ANCOVA, aimed to explain *change* in obligatory participation, demonstrated an effect of clinical factors that signed delayed recovery, such as prolonged initial hospitalization, rehospitalization, and allograft rejection. Recipients experiencing rejection or other complications had a prolonged initial hospitalization, or were rehospitalized. Consequently, they were unable to resume employment and household tasks at the first interview, which resulted in a lower level of obligatory participation. However, their recovery in time resulted in T2 obligatory participation that equaled the average level of the study group. Therefore, recipients experiencing prolonged hospitalization showed greater increase in obligatory participation. These results show that although early participation may be low due to complications, these recipients resume participation in obligatory activities in time.

To understand the favorable effect of peritoneal dialysis (PD), we examined differences in characteristics of transplant recipients treated with PD and hemodialysis. Results indicated better cognitive capacity (mean difference 0.2; $P<0.05$), more self-efficacy (mean difference 6.48; $P<0.05$), and more optimism (mean difference 3.67; $P<0.01$) for recipients formerly treated with PD. A tentative explanation is that these characteristics enabled recipients to restore participation in obligatory activities. However, recipients treated with PD were more often employed (62% vs. hemodialysis 29%). To correct for potential confounding, employment status was added to the multivariate analysis, which resulted in a borderline change in effect of type of dialysis ($B=7.22$; $P=0.051$), whereas the effect of hospitalization remained ($B=0.34$; $P<0.01$). Employment status in itself was unrelated to obligatory participation ($B=1.14$; $P=0.76$).

Type of donation did not affect obligatory participation, in contrast to results of our cross-sectional study (*14*). Recipients after living donation (LD) in this study were younger, higher educated, and had less comorbidity. The present prospective study only found a difference in education (living 64% vs. cadaveric 36%, upper secondary/tertiary). The prospective study group was more recently transplanted and consists of a larger proportion of LD (36% vs. 21%) (*14*), due to shortage of donors and broadening criteria for living donor transplantation. This alteration in selection for living donation may affect outcome in social participation.

The effects of change in health status, symptoms, and psychological characteristics on obligatory participation were outweighed by the effect of clinical factors in multivariate analysis. However, factors expressing improved health (i.e., more vitality, improved physical capacity) and increased self-efficacy were related with obligatory participation. Self-efficacy focuses on the belief of one's ability to accomplish certain behaviors or achieve certain outcomes, and can be seen as a resilience factor that potentially may improve participation (*41*).

Besides the strengths of the study (i.e., high response rate in kidney transplant recipient cohort; low dropout rate in prospective study), this study also has some limitations. We had no baseline (i.e., pretransplantation) measurement of obligatory and leisure participation. Furthermore, the graphic representation of overall participation, which in part was assessed retrospectively, may have led to some recall bias.

To conclude, kidney transplantation enhances social participation of recipients in the first year posttransplantation, not only in obligatory activities but in leisure activities as well. Employed recipients returned to work after initial sick leave. However, overall employment rate hardly increased and 47% of employed recipients were also work disabled. Additionally, pre-ESRD level of participation could not be regained and recipients experienced more limitations in fulfilling social roles due to physical health problems, compared with the general population. Although physical functioning improved, distress due to transplantation-related symptoms increased. Change in social participation in the first year is mainly associated with clinical factors that express delayed recovery (e.g., complications), although a tendency for health status–related factors and self-efficacy was also shown. Social participation is a complex outcome measure and has multiple determinants (*42*). It is likely that individual preferences also play a role and may be unrelated to having ESRD.

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