

Original Article

Life situation and quality of life in young adult kidney transplant recipients

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Abstract

Background. Young adults, 18–35 years of age, may be more vulnerable to chronic diseases than other age groups. In this study we describe the life situation and lifestyle of young adult kidney transplant recipients and compare their health-related quality of life (HRQoL) with a general population sample.

Methods. Questionnaires, including items on life situation, lifestyle, and the SF-36 HRQoL questionnaire, were mailed to all 280 renal transplant recipients in Norway between 18 to 35 years of age at the time of investigation of whom 131 (47%) responded. For comparison, we used 2,360 respondents aged 18 to 35 years from a general population survey in one Norwegian county. SF-36 scores are presented with unadjusted scores and the mean difference between groups adjusted for age, sex and education using multiple linear regression analysis.

Results. The kidney transplant recipients reported high participation rates in cultural and sports activities, and the majority of them were satisfied with their work. A larger proportion of the transplant recipients had attained university education than the general population sample. However, 25% of the total group were not integrated in professional life. The transplant recipients scored lower than the general population on seven of the eight SF-36 scales and the two summary scales after adjusting for age, sex and education.

Conclusions. The majority of young adult kidney recipients aged 18–35 years were well adapted in their family and professional life and satisfied with their current life situation. However, in aggregate they reported lower HRQoL on most scales of the SF-36 than a general population sample.

Keywords: HRQoL; quality of life; renal transplantation; young adults

Introduction

In addition to mortality and morbidity, health-related quality of life (HRQoL) has become a major outcome of health interventions, including renal transplantation [1]. Kidney transplant recipients have better HRQoL than transplant candidates maintained on haemodialysis [2,3], and HRQoL improves when patients undergo renal transplantation [4]. HRQoL in patients with kidney transplants is influenced by demographic, socio-economic and disease-related variables, such as rejection episodes [5], HLA incompatibility [6], cold-ischaemia time [6], donor type [6–8], old age [9,10], gender [11] and comorbidity [12].

Only a few studies of renal transplant recipients have assessed HRQoL in different age groups. One study could not show any difference in HRQoL according to age in this patient group [13], in contrast to another study that reported better HRQoL among elderly than among younger kidney transplant recipients relative to the general population [9]. Further, adult kidney transplant recipients' participation in employment and leisure activities is associated with age, educational status and time since transplantation [14], though little information is available on the changes in lifestyle of young adults undergoing renal transplantation. In young adults, HRQoL may be influenced more by chronic diseases than in other age groups, because of the many important life events that take place at this age, such as education and family building. Therefore, young adults with kidney transplants may experience limitations in their ability to lead normal lives, including education, family building and socialization.

The aim of this study was to describe the life situation, lifestyle and common activities of daily life in young adult kidney transplant recipients aged 18–35 years. In addition, we compared their HRQoL with a general population sample, adjusting for age, sex and education.

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Subjects and methods

Sample and study design

Renal transplantations in Norway are centred in Rikshospitalet University Hospital. All renal transplant recipients are registered in the National Renal Transplant Registry; however, follow-up is decentralized to many other hospitals. In 1999, we mailed a postal questionnaire to every kidney transplant recipient between 18 and 35 years in this registry ($n = 280$). We asked the participants to return the questionnaire within 14 days. No reminders were sent, but questionnaires that were returned later were included in analysis.

After mailing the questionnaires, individual data on the non-responding renal transplant recipients were not available in the original data file. However, from a new database search for transplant recipients as of 31 December 1999 aged 18–35 in the National Renal Transplant Registry, we could reconstruct a closely matching sample ($n = 289$), of which we have identified 119 as respondents in our study.

The questionnaire included items about demographics, comorbidity, lifestyle and the Short Form 36 (SF-36) questionnaire. For some of the items, including responses to the SF-36, we also had data for comparison from a general population survey in one Norwegian county in 1998, the health survey of Akershus county [15,16]. In this survey, 2360 persons between 18 and 35 years old responded to the questionnaire and were used as a comparison group in the present study.

Comorbidity was self-reported comorbidity, which was framed as impaired functioning (yes or no) in the following dimensions: limitations in the ability to move legs or arms, physical illness, psychological illness, impaired/reduced hearing or vision. Detailed medication was not recorded. Most of the transplant recipients used standard immunosuppression with cyclosporin (or tacrolimus), azathioprine (or mycophenolate) and prednisolone. Additional medication was used by 82% of the patients (Table 2).

Assessment of HRQoL

The SF-36 questionnaire is a non-disease-specific questionnaire that assesses HRQoL during the past 4 weeks. It is self-administered and has been extensively validated in many patient groups [17]. It contains eight scales: physical functioning, role functioning—physical, bodily pain, general health, vitality, social functioning, role functioning—emotional and mental health. Scores are transformed to a 0 (minimal level of health)-to-100 (maximal level of health) scale. Scores on the eight scales are aggregated to two summary scores, the physical component summary (PCS) and the mental component summary (MCS) [17,18]. The PCS and MCS are reported on a standardized scale for comparison with a general American population (with mean score 50 and SD 10) [18]. We used the Norwegian standard SF-36 version 1.0 [19,20]. The SF-36 is probably the most widely used HRQoL measure and has previously been used to assess the impact of renal transplantation [4,7].

Statistical analysis

Results are presented with the mean (SD), median (25th–75th percentile), or number and percent. We compared groups using a two-sample t -test or Fisher's exact test, or the Mann–Whitney U -test.

Comparison of SF-36 scores between the renal transplant recipients and the general population is presented with unadjusted scores in the two groups and the mean difference between the groups after adjusting for age, education and sex using multiple linear regression analysis. The adjusted difference scores represent the predicted difference in the score for a patient with the average age, education and sex in the pooled study population. We chose a 5% significance level, using two-sided tests. The SPSS (SPSS Inc., Chicago, IL, USA) version 12.0 and Stata (Stata Inc., College Station, TX, USA) version 8.2 were used for all analyses. The study was approved by the Regional Committee for Medical Research Ethics.

Results

Sample characteristics and comparison with the general population

Of the 280 renal transplant recipients, 131 (47%) responded to the questionnaire. They had a mean age of 29.8 (4.0) years (Table 1). According to analysis on the reconstructed data set, respondents were slightly older than non-respondents with a mean age of 30.1 (SD 4.1) and 28.8 (SD 4.7) years, respectively ($P = 0.02$). At the time of transplantation, respondents had a mean age of 24.4 years (SD 5.9) and non-respondents 22.8 years (SD 6.3), ($P = 0.04$). Time since transplantation was similar for respondents and non-respondents with median (25th–75th percentile) 4.6 (1.9–8.0) and 4.8 (2.3–8.4) years, respectively ($P = 0.52$),

Table 1. Descriptive statistics for transplant recipients and a comparison group from the general population

	Transplant recipients ($n = 131$)	General population ($n = 2360$)	P
Age, mean (SD)	29.8 (4.0)	27.4 (5.3)	< 0.001
Male sex	57 (44)	1031 (44)	0.52
Married/cohabiting	70 (53)	1364 (59)	0.24
Education > 12 years	53 (42)	644 (28)	0.001
Disability pension	15 (15)	12 (< 1)	<0.001
Physical activity, times per week			<0.001
<1	52 (42)	810 (35)	
1–2	46 (37)	1244 (53)	
≥3	27 (23)	292 (12)	
Smoking status		0.70	
Daily	37 (30)	645 (32)	
Previous	19 (16)	266 (13)	
Never	66 (54)	1127 (55)	
Smoking >20 cigarettes per day	1 (2)	57 (8)	0.05
Alcohol abstainer	14 (11)	279 (12)	0.34

Number (%), unless otherwise stated.

Table 2. Self-reported characteristics among young kidney transplant recipients, $n = 131$

Age at transplantation	
Median (25th–75th percentile)	24 (20–29)
Range (years)	8–34
Time since transplantation	
Median (25th–75th percentile)	4.9 (2.1–10.0)
Range (years)	0.1–26.2
Living donor	79 (66%)
Pretransplant dialysis	79 (66%)
> 1 year dialysis	54 (19%)
Comorbidity	59 (45%)
First kidney transplant	114 (87)
Kidney disease	
Glomerulonephritis	16 (12)
Pyelo-/interstitial nephritis	14 (11)
Polycystic kidney disease	10 (8)
Diabetes mellitus	3 (2)
Other	34 (26)
Unknown	54 (41)
Medication	
No antihypertensive medications	52 (40)
≥3 antihypertensive medications	3 (2)
Analgetics/week	13 (10)
Tranquilizer/hypnotics (> 1/week)	7 (6)

Number (%), unless otherwise stated.

whereas the respondents consisted of a higher proportion of women (56%) than non-respondents (38%) ($P = 0.002$).

The young renal transplant recipients were on average slightly older than the comparison group from the general population, but the groups had a similar sex composition (Table 1). Self-reported transplantation-related characteristics in the study group are reported in Table 2.

Life situation and lifestyle

A majority (70%) of the young kidney transplant recipients reported that their education had been delayed as a result of their kidney disease and transplantation; however, 42% had completed higher education (> 12 years) compared with 28% in the general population sample (Table 1). Some of the transplant recipients reported considerable health problems, which was reflected by 15% (of the total group) receiving disability pension, and 25% (of the total group) were neither working nor studying. A larger proportion of the young renal transplant recipients received disability pension than the general population (Table 1). There was no difference in marital status between the transplant recipients and the general population sample.

The renal transplant recipients claimed to be more often involved in physical activity than the comparison group, but there was no difference between the young renal transplant recipients and the comparison group in other lifestyle variables such as smoking status or proportion abstaining from alcohol; however, a smaller proportion of transplant recipients were heavy smokers (>20 cigarettes per day) than the general population (Table 1).

Among the transplant recipients, 46% were satisfied with their work/occupation, although 25% were neither working nor studying (Table 3). Participation in some leisure time activities ranged from 22% for having been to an art exhibition to 98% for having been to a restaurant/café.

Table 3. Description of lifestyle factors, young kidney transplant recipients, number (%) ($n = 120$ –131)

Professional life	
Satisfied with work/occupation	51 (46)
Working/studying full day	58 (46)
Not working or studying	32 (25)
Often/always tired after work	46 (41)
Family and friends	
No special treatment from family, friends or colleagues	80 (65)
Leisure time and hobbies	
Activities during the last 4 weeks	
Been to cinema	89 (68)
Restaurant/café	129 (98)
Theatre/opera	47 (36)
Spectator at a sports event	48 (37)
Art exhibition	29 (22)
Museum	36 (27)
Religious meeting	50 (38)
Hobbies	
Reading	70 (53)
Handcraft	40 (31)
Member of a political party	11 (8)
Member of a sports club	34 (26)
Member of a music or theatre group	20 (15)
Same hobbies as before transplantation	58 (44)
Bodily image	
Dissatisfied with appearance	64 (49)
Satisfied with appearance	8 (6)
Change from before transplantation	
Change in bodily looks	94 (77)
Change in general mood	68 (54)

Only 6% of the young kidney transplant recipients were satisfied with their appearance, and 77% reported changes in bodily looks from before transplantation. Most of these changes, such as weight gain, moon face, skin problems or increased hair growth, could be attributed to side effects from corticosteroids or other immunosuppressive medication. Finally, 65% reported feeling that they received no special treatment from family, friends or colleagues. In total, 7% of the kidney transplant recipients reported that 'life as a kidney transplanted person is difficult'.

Health related quality of life

Young adult kidney transplant recipients scored markedly lower than the comparison group on seven of the eight SF-36 scales and the two summary scales, PCS and MCS, after adjusting for age, sex and education (Table 4). The largest differences were on the general health, role limitations due to physical problem and role limitations due to emotional problem scales of the SF-36. On the bodily pain scale, there was a tendency towards higher scores in the general population than among transplant recipients, though this difference was statistically not significant.

Discussion

In this national cohort of kidney transplant recipients between 18 and 35 years of age, the recipients seemed to be well adapted to their family situation and their professional life, almost at the level of a similarly aged population sample. Despite the young kidney transplant recipients having experienced delays in their education, a larger proportion

Table 4. Health-related quality of life in young renal transplant recipients and comparison with the general population, mean (SEM)

	Transplant recipients	General population ^a	Adjusted difference ^b	P
SF-36 scales (range 0–100)				
Physical functioning	86.6 (1.5)	94.1 (0.2)	7.9 (1.1)	<0.001
Role limitations—physical	74.2 (3.0)	89.7 (0.5)	15.5 (2.4)	<0.001
Bodily pain	76.4 (2.3)	80.1 (0.5)	3.5 (2.2)	0.11
General health	60.2 (1.4)	80.8 (0.4)	21.7 (1.7)	<0.001
Vitality	55.8 (1.9)	60.7 (0.4)	5.2 (1.8)	0.002
Social functioning	80.0 (2.2)	89.4 (0.4)	10.8 (1.7)	<0.001
Role limitations—emotional	75.5 (3.1)	90.0 (0.5)	16.2 (2.3)	<0.001
Mental health	76.7 (1.5)	80.1 (0.3)	4.0 (1.3)	0.002
SF-36 summary scales ^c				
Physical component summary	48.5 (0.8)	53.2 (0.2)	4.7 (0.7)	<0.001
Mental component summary	49.0 (1.0)	51.8 (0.2)	3.3 (0.8)	<0.001

SF-36, Short Form 36.

^a18–35 years old in Akershus county, Norway.^bAdjusted for age, sex and education using multiple linear regression.^cRelative to an American general reference population with mean 50, SD 10.

of them had completed higher education than the general population sample. The young kidney transplant recipients reported high participation in cultural activities, though we had no general population data for comparison here. The kidney transplant recipients seemed more concerned with their health, as judged by indications of a more healthy lifestyle with a smaller proportion of heavy smokers and a larger proportion that exercised regularly, than the general population sample. However, 25% of the young kidney transplant recipients were not integrated in professional life. Finally, the kidney transplant recipients between 18 and 35 years of age reported lower HRQoL than the general population sample after adjusting for age, sex and education.

The finding that a larger proportion of kidney transplant recipients had finished university education than the general population sample is notable. In contrast, another cross-sectional study, matching for age and sex, reported a lower proportion with higher education among kidney transplant recipients than the general population [14]. The finding in the present study may possibly be explained by differences in age between the transplant recipients and the general population sample, bias caused by the selective response of successful transplant recipients, in that patients with kidney diseases and kidney transplants feel that they need more education in order to get employed, or they are unable to perform heavy physical work. Alternatively, this finding may be related to the social security system in Norway that provides economical and practical assistance to educate young adults with chronic diseases. Finally, the comparison group may consist of a larger proportion of respondents from rural areas, with less tradition of getting higher education, than the more urban young kidney transplant recipients.

Kidney transplant recipients participated in social activities and contributed in the society, reflected in this study by, for example, membership in sports clubs and political parties. In a similar study, 26% of adult kidney transplant recipients took part in sporting activities and 64% were involved in clubs/associations [14]. Further, among adult kidney transplant recipients, comorbidity is associated with em-

ployment, education and participation in leisure activities [21]. No comparable Norwegian data on different leisure activities are available, but according to official statistics 7% of Norwegian adults were members of a political party (versus 8% among the kidney transplant recipients in our study), and 36% and 32% in the age groups 16–24 and 24–44, respectively, were members of sports clubs (versus 26% among the kidney transplant recipients) [22]. The participation in cultural activities, such as cinema and theatre, of the recipients in the present study is comparable with that of Norwegian doctors and other university graduates [23] though differences in the respondents' age and the time perspective of the questions hamper a direct comparison.

In the present study, kidney transplant recipients reported lower HRQoL scores than the general population sample. This reduction in HRQoL might have been caused by several factors related to their kidney disease, transplantation or medication. In addition, transplant recipients constitute a heterogeneous group that includes patients with complications and comorbidities. Their reported active participation in society and their higher education than the comparison group do not seem to fully compensate their HRQoL, but may be important for their social adjustment.

Some limitations of this study should be pointed out. The study was a postal survey of all kidney transplant recipients between 18 and 35 years of age in a National Cohort. The response rate in the study was only 47%, with a considerably higher response rate among females than among males. Further, we only had self-reported clinical information, and data on kidney function were not available. These limitations of the study may limit generalization of the findings.

The study was a cross-sectional survey, hence respondents were surveyed at different times following their transplantation procedure. In this age group, many individuals will still be students, and differential delays in education between the groups in the study might have influenced the results. It is also possible that the transplant recipients may have a more urban lifestyle, than the similarly aged comparison group from Akershus county, which overall is more rural. To overcome some of these difficulties, we adjusted the comparisons of HRQoL for age, sex and education.

In conclusion, this study has shown that the majority of young adult kidney recipients aged 18–35 years were well educated and well adapted to their family and professional life, and they expressed satisfaction with their current life situation, though 25% were not able to earn their own living. In aggregate, the young adult kidney transplant recipients reported lower HRQoL on most scales of the SF-36 than the general population sample after adjusting for age, sex and education.

Conflict of interest Statement. None declared.

References

1. Fiebigler W, Mitterbauer C, Oberbauer R. Health-related quality of life outcomes after kidney transplantation. *Health Qual Life Outcomes* 2004; 2: 2
2. Cameron JJ, Whiteside C, Katz J *et al.* Differences in quality of life across renal replacement therapies: a meta-analytic comparison. *Am J Kidney Dis* 2000; 35: 628
3. Lee AJ, Morgan CL, Conway P *et al.* Characterisation and comparison of health-related quality of life for patients with renal failure. *Curr Med Res Opin* 2005; 21: 1777
4. Joffe R, Lopez-Gomez JM, Moreno F *et al.* Changes in quality of life after renal transplantation. *Am J Kidney Dis* 1998; 32: 93
5. Shield CF, McGrath MM, Goss TF. Assessment of health related quality of life in kidney transplant patients receiving tacrolimus. FK506-based versus cyclosporine-based immunosuppression. FK 506 Kidney Transplant Study groups. *Transplantation* 1997; 16: 113
6. Aasebø W, Midtvedt K, Hartmann A *et al.* Predictors of health-related quality of life in hypertensive recipients following renal transplantation. *Clin Transpl* 2005; 19: 756
7. Kizilisik AT, Feurer ID, VanBuren DH *et al.* Effects of diabetes and cadaveric organs on functional performance and health-related quality of life after kidney transplantation. *Am J Surg* 2003; 186: 535
8. Gieva K, Ziegelmann JP, Thompson D *et al.* Quality of life and emotional responses in cadaver and living related renal transplant recipients. *Nephrol Dial Transplant* 2002; 17: 2204
9. Rebollo P, Ortega F, Baltar JM *et al.* Is the loss of health-related quality of life during renal replacement therapy lower in elderly patients than in younger patients? *Nephrol Dial Transplant* 2001; 16:1675
10. Humar A, Denny R, Matas AJ *et al.* Graft and quality of life outcomes in older recipients of a kidney transplant. *Exp Clin Transplant* 2006; 1: 69–72
11. Rebollo P, Ortega F, Baltar M *et al.* Health related quality of life (HRQoL) of kidney transplanted patients: variables that influence it. *Clin Transplant* 2000; 14: 199
12. Karam VH, Gasquet I, Delvart V *et al.* Quality of life in adult survivors beyond 10 years after liver, kidney, and heart transplantation. *Transplantation* 2003; 76: 1699
13. Cetingok M, Winsett RP, Hathaway DK. A comparative study of quality of life among the age groups of kidney transplant recipients. *Prog Transplant* 2004; 14: 33
14. Van der Mei SF, Van Sonderen ELP, Van Som WJ *et al.* Social participation after successful kidney transplantation. *Disabil Rehabil* 2007; 29: 473–483
15. Grøtvedt L, Stavem K. Association between age, gender and reasons for smoking cessation. *Scand J Public Health* 2005; 33: 72–76
16. Grøtvedt L. Helseprofil i Akershus. *Heltef Rapport 4 /99*. Lørenskog, Norway: HELTEF, Akershus University Hospital, 1999 (ISBN:82-91492-12-4)
17. Ware JE Jr, Snow KK, Gandek B. SF-36 health survey. *Manual and Interpretation Guide*. Boston, MA, USA: The Health Institute, New England Medical Center, 1993
18. Ware J, Kosinski M, Keller SD. *SF-36 Physical and Mental Health Summary Scales: a Users Manual*. Boston, MA, USA: The Health Institute, New England Medical Center, 1994
19. Aaronson NK, Acquadro C, Alonso J *et al.* International Quality of Life Assessment (IQOLA) Project. *Qual Life Res* 1992; 1: 349
20. Loge JH, Kaasa S. Short form 36 (SF-36) health survey: normative data from the general Norwegian population. *Scand J Soc Med* 1998; 26: 250
21. Van Der Mei SF, Van Sonderen ELP, Van Den Heuvel WJA *et al.* Clinical factors influencing participation in society after successful kidney transplantation. *Transplantation* 2006; 82: 80–85
22. Vaage OF. *Kultur og fritidsaktiviteter*. Norway: Statistics Norway (ISBN 82-537-4841-8, ISSN 0804-3221)
23. Nylenna M, Aasland OG, Falkum E. Survey of Norwegian doctors' cultural activities. *Lancet* 1996; 348: 1692–1694

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