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## Social participation after kidney transplantation

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## Summary

Research on medical treatment of chronic diseases focused initially on outcome parameters such as survival and morbidity. In the 1980s it was realized that not only the 'quantity', but also the 'quality' of life after treatment was an important outcome measure. This awareness resulted in a growth of (health-related) quality of life studies and literature. In 2001, the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization introduced a new concept, suitable to assess the impact of diseases and medical treatment: participation. This concept is the central theme of this thesis in a study on social participation of kidney transplant recipients.

The number of patients affected by end-stage renal disease (ESRD) has not only increased in recent years, but is expected to continue to rise, and consequently has a major impact on public health. Kidney transplantation, as one of the treatment modalities for chronic renal failure, is nowadays regarded as the treatment of choice and even has become a routine procedure. Literature shows that transplantation, compared to dialysis, is associated with favourable quality of life outcomes, and offers the potential for restoring a 'productive' and independent life. A 'new' kidney evokes the image of restored health, and creates expectations regarding corresponding performance of recipients. However, clinical transplantation practice shows that kidney transplant recipients are also confronted with difficulties in re-entering 'normal' life. The inconsistency between results of previous studies and practice constitutes the background for this thesis.

The introductory chapter, *Chapter 1*, describes the incidence and prevalence of ESRD, and gives an overview of renal replacement therapies from a historical perspective. Furthermore, it addresses the question if it can be expected that life returns to 'normal' after successful kidney transplantation. The concept of participation in society as defined by the ICF is introduced, and participation instruments are referenced. In addition, the definition of social participation is stated and operationalized as obligatory participation (i.e. employment, education, household tasks), and leisure participation (i.e. volunteer work, assisting others, recreation, sports, clubs/associations, socializing, going out). This thesis aims to assess social participation after successful kidney transplantation, and to examine influencing factors.

The research questions are:

1. To what extent do kidney transplant recipients participate in society, i.e. participate in obligatory and leisure activities?
2. Do kidney transplant recipients deviate in their level of social participation compared to a matched control group of the general population?
3. Which socio-demographic, clinical and psychological factors are associated with social participation after kidney transplantation?
3. How does social participation develop in the first year after kidney transplantation, when the initial convalescence period of three months has passed?
5. Which socio-demographic, clinical, health status related, and psychological factors are associated with social participation in the first year after kidney transplantation?

*Chapter 2* presents a systematic review on social participation of kidney transplant recipients. The benefits of kidney transplantation on survival and quality of life are well studied, however less is known on actual performance of social activities after transplantation. Therefore, we systematically searched and selected literature in Medline (1980-2003) and five other databases, on topics related to social participation. The contents of 17 selected studies is described, as well as the methodological quality, which was rated by two reviewers.

The selected studies that addressed actual social participation mainly focused on employment status, whereas two studies briefly reported on vacation and recreation. Employment rate ranged from 18% to 82%. Comparison of employment rates between studies was hampered by a lack of definition, or the use of different defining categories of employment. Moreover, study populations were heterogeneous with regard to demographic and clinical characteristics. Three studies identified pretransplant employment status as a predictor of post-transplant employment. Other potential risk factors were not consistent across studies. Quality assessment revealed shortcomings in data presentation and internal validity. These results indicate that the focus of research regarding actual participation in society after kidney transplantation is limited, and that in general studies have insufficient methodological quality.

The results of *Chapter 3* are based on a cross-sectional study, which assessed patients transplanted between January, 1996, and December, 2001 (n=239). This study aims to explore and describe the degree of social participation after kidney transplantation. In addition, a comparison with the general population was

made, by means of an age and gender matched control group from the Time Use Survey database of the Social and Cultural Planning office. Factors associated with social participation were examined as well. Cross-sectional data were collected by in-home interviews on participation in obligatory activities (i.e. employment, education, household tasks), and leisure activities (volunteer work, assisting others, recreation, sports, clubs/associations, socializing, going out).

In general, transplant recipients were active in obligatory participation, although 36% showed a low degree of participation. Fifty-two per cent of recipients of working age had a paid job. Of those employed, 48% received additional social security benefits (WAO). Transplant recipients were actively involved in a variety of leisure activities. Participation in sports represented the lowest participation rate (26%). Results indicated a connection between obligatory and leisure participation. Recipients with extreme levels of obligatory participation (i.e. low or high) had a more diverse leisure pattern compared to recipients with a mediate level. However, comparison of the study group with the matched control group demonstrated that kidney transplant recipients had a lower educational level, spent less time on obligatory participation, had part-time jobs more often, and participated less in sports. No differences were found for participation in socializing, church attendance, volunteer work and going out.

Multivariate regression analysis showed an association between advanced age and a lower level of obligatory participation. Recipients with an advanced educational level and prolonged time since transplantation showed a higher level of obligatory participation. Logistic regression analysis demonstrated that advanced educational level and prolonged time since transplantation were also associated with participation in volunteer work. Transplant recipients of young age and with advanced educational level, participated more often in sports and going out.

This study demonstrates that although kidney transplant recipients participate less in employment and sports, and are less well educated, they do participate in meaningful activities, such as household tasks, volunteer work, socializing, and other leisure activities.

*Chapter 4* focuses on the association between transplantation-related clinical factors and social participation. Besides the interview data on social participation of the cross-sectional study group (n=239), results are based on data extracted from medical charts and the Groningen Renal Transplant Database.

The majority of recipients (78%) reported that their overall participation in daily life had increased in comparison with pretransplantation level of partici-

pation. Multivariate regression analysis with obligatory participation as outcome measure, and adjusted for age, gender and education, showed associations for three clinical factors. Comorbidity and postmortal transplantation were associated with lower levels of obligatory participation; time since transplantation showed a positive association, indicating higher levels of obligatory participation as time passes. Besides these effects, advanced age was related to lower levels of obligatory participation, whereas the effect of education was not statistically significant anymore. This multivariate model explained 36% of the variance in obligatory participation. Results of regression analysis with diversity of leisure participation and perceived change in participation as outcome measures, were less distinct. Although univariate analysis showed associations for some clinical characteristics, adjustment for age, gender and education nullified these effects. It is concluded that transplantation-related clinical factors had a distinct effect on obligatory participation.

*Chapter 5* is based on the cross-sectional study as presented in Chapter 3 and 4, and elaborates on the results considering explanatory factors of social participation. The aim of the study presented in Chapter 5, is to examine the effects of psychological characteristics on social participation of kidney transplant recipients, adjusted for the effects of other factors (covariates), such as demographic and clinical characteristics, physical functioning, and transplantation-related symptoms (i.e. side-effects of immunosuppressive medication). Data on psychological characteristics and covariates were collected by use of standardized self-report questionnaires.

Multivariate regression analysis with adjustment for covariates showed that perceived control (i.e. mastery) was related to a higher level of obligatory participation. This effect was modified by age, as the association was stronger for younger transplant recipients. Besides the known effects of covariates as presented in Chapter 4, the transplantation-related symptom of 'increased growth of gum and hair', induced by the use of immunosuppressive medication, was associated with a lower level of obligatory participation. The analysis of leisure participation demonstrated more diverse participation for extraverted personality. In addition, physical functioning was related to leisure participation as well. Other psychological characteristics (i.e. self-efficacy, dispositional optimism, neuroticism) were not associated with the outcome measures of social participation. These results suggest a small additional effect of psychological characteristics on social participation after kidney transplantation, beyond the effect of other explanatory factors.

The results of *Chapter 6* are based on a prospective study, which assessed patients transplanted between March, 2002, and March, 2003 (n=61). Data on obligatory and leisure participation were collected by in-home interviews at three months (T1), and 1 year posttransplantation (T2). This prospective study aims to describe changes in social participation in the first year after kidney transplantation, and to examine the influence of clinical factors, health status, transplantation-related symptoms, and psychological characteristics on change in social participation.

Results showed an increase in obligatory and leisure participation during the first year after transplantation, although 33% showed a low degree of obligatory participation at 1 year posttransplantation. At T1, the majority of employed recipients was still on sick leave, but returned to work on T2. The employment rate remained stable during the first year, and 56% of the working age recipients was employed at T2. However, 47% of those who were employed also received social security benefits due to work disability. The overall level of participation in daily life at 1 year posttransplantation did not equal the pre-ESRD level of participation. In addition, transplant recipients reported more limitations in fulfilling social roles due to physical health problems, compared with normative data of the general population.

Analysis of covariance showed that an increase in obligatory participation was related to clinical factors (i.e. peritoneal dialysis, prolonged initial hospitalization), whereas the increase in leisure participation was related to increased serum albumin and improved cognitive capacity. Although no effects were found for type of donation, comorbidity and renal function, the findings indicate that mainly clinical factors are associated with an increase in social participation during the first year after transplantation. Nevertheless, health status related factors and self-efficacy as a psychological attribute, may be related to recovery of social participation, but their effect was outweighed by the strength of clinical factors in multivariate analysis.

*Chapter 7* discusses the main findings, addresses methodological issues regarding study design, considers the contribution of this thesis to the current body of knowledge on social participation after kidney transplantation, and ends with recommendations for further research, transplantation practice and health policy.

The definition and measurement of participation according to the ICF are still under debate. As such, the objective approach in measuring social participation as actual social behaviour, and the operationalization as obligatory and leisure participation, can be questioned. The choice for this approach however

enabled us to compare transplant recipients' level of social participation to a population standard.

One of the objectives of this thesis was to assess social participation of kidney transplant recipients. Our study showed that kidney transplant recipients have a disadvantaged position in Dutch society, as they are lower educated and participate less in employment compared to the age and gender matched control group from the general population. Furthermore, transplant recipients need additional social security benefits due to work disability, and have a less active lifestyle. On the other hand, they equally participate in volunteer work, socializing and going out. However, transplant recipients do not return to their pre-ESRD level of participation in daily life.

A second objective was to examine influencing factors of social participation. Results indicated that social participation of transplant recipients is mainly explained by transplantation- and health-related factors, and less by psychological characteristics. Participation in leisure activities is only to a small extent explained by factors included in our study. The finding of the cross-sectional study that recipients after living donation participate more in obligatory activities, needs further investigation. This also applies to the finding of the prospective study, which indicates that recipients previously treated with peritoneal dialysis have a greater improvement in obligatory participation during the first year after transplantation. Future research should focus on the underlying cause of these effects. The association between body appearance-related side-effects of immunosuppressive medication and obligatory participation, underlines the importance of adequate treatment of gingival hyperplasia and hirsutism.

In conclusion, as a result of developments in kidney transplantation technology the number of transplant recipients will continue to grow. The disadvantaged position of transplant recipients in society brings into question to what extent health care in the Netherlands promotes posttransplant social participation. Furthermore, it can be questioned if these efforts are sufficient in maximizing rehabilitation of transplant recipients. Therefore, this study should be viewed as a first step to fill in the gap of knowledge considering social participation after kidney transplantation. Future research on social participation of end-stage renal disease patients should be more structured and should be embedded in an integrated and multidisciplinary research programme. Moreover, the concept of participation, as introduced by the ICF, should be a topic in research on chronic diseases.