Long-Term Quality of Life and Social Outcome of Childhood End-Stage Renal Disease

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Objective To assess quality of life (QoL) and social status after 30 years of renal-replacement therapy (RRT) and to explore determinants of this QoL.

Study design The cohort comprised all Dutch patients, born before 1979, who started RRT at age <15 years in 1972-1992. All patients still alive in 2010 were asked to complete questionnaires on QoL (RAND-36) and sociodemographic outcomes. Scores were compared with those in the age-matched general population and with previous patient scores obtained in 2000. We performed logistic regression analysis for prediction of QoL outcomes.

Results A total of 89 of 152 patients still alive in 2010 participated. Compared with the general population, QoL more often was impaired in patients receiving dialysis for most physical domains, in transplanted patients only on general health perception. Both transplanted and dialysis patients had normal or high scores on mental health. Scores in most physical domains were lower than in 2000. Patients were employed less often (61.8% vs 81.0%), had fewer offspring (31.5 vs 64.8%), and were less likely to have an income equal to or above average (34.8% vs 55.7%) compared with the general population. Disabilities, comorbidity, and unemployment were associated with impaired QoL.

Conclusions After 30 years of RRT, adult survivors of pediatric end-stage renal disease have an impaired physical but a good mental QoL. The decrease of general health perception and physical functioning over time is worrying and may further hamper employment status and social functioning of these relatively young patients. *(J Pediatr 2014;165:336-42)*.

As renal replacement therapy (RRT) in children with end-stage renal disease (ESRD) has become routine, concern has arisen about its implications for adult life. Outcomes measured in clinical trials typically include biochemical values, infections, cancer, and patient survival. However, quality of life (QoL) is an important marker of disease burden and also can be used to assess treatment effectiveness and risk for adverse outcomes.[1]

Investigators report that ESRD in adults negatively affects social, financial, and psychological well-being.[2-4] Low QoL scores are associated with hospitalization, graft failure, and long-term mortality.[5-7] QoL also has been associated with mortality in other populations, such as individuals with chronic obstructive pulmonary disease,[8] diabetes,[9] and with cardiovascular disease.[10,11] Determinants found to be associated with an impaired QoL in the ESRD population include both medical (ie, disabilities, comorbidities, RRT modality, and prolonged time on dialysis) and sociodemographic factors (ie, older age, female sex, low level of educational attainment, unemployment status, and low income).[12-17] However, few data exist on the effect of intensive, chronic therapy since childhood on physical and social development in adulthood.

In 2000, we performed a comprehensive study on the late effects of renal insufficiency in children (LERIC) in a cohort of all Dutch patients who had started chronic RRT in childhood. In contrast to reports of adult onset of ESRD, we found close-to-normal QoL in patients who underwent transplantation, and significantly impaired physical but normal mental QoL in patients receiving dialysis.[18] We hypothesized that an even longer period on RRT would affect their physical condition and that aging would negatively influence their QoL and social status. We therefore conducted a 10-year follow-up of this study with the aim to assess QoL and social status after 30 years of RRT and to explore determinants (both medical and socio-demographic) associated with an impaired QoL.

BP	Bodily pain	QoL	Quality of life
ESRD	End-stage renal disease	RE	Role limitation due to emotional problems
GH	General health perception		
LERIC	Late effects of renal insufficiency in children	RP	Role limitation due to physical problems
MCS	Mental Component Summary	RRT	Renal replacement therapy
MH	Mental health	SF	Social functioning
PCS	Physical Component Summary	VT	Vitality
PF	Physical functioning		

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Methods

This study is part of a further 10-year follow-up of a comprehensive long-term follow-up study into the long-term effect of renal insufficiency in children in patients on RRT since childhood in the Netherlands. The LERIC cohort comprised all Dutch patients who had started chronic RRT at <15 years of age between 1972 and 1992 and who were born before 1979. In 2000, the first follow-up study, 152 of 187 surviving patients of childhood RRT participated in this part of the study on QoL.[18] In the current study, patients still alive in 2010 were invited to participate again. Patients who declined to participate in the QoL study in 2000 were excluded. The end of the study was marked by the day of the examination of the last participant. After informed consent was obtained, a survey was sent to the home addresses of the participants. To assure anonymity, the returned questionnaires contained only a study number. Nonrespondents were sent a reminder letter and a questionnaire after 3 and 6 months. The medical ethical committees of all participating centers approved the study.

Data on clinical characteristics and potential determinants in relation to QoL were collected from medical charts from June 2010 to February 2011. The predefined variables were age at time of investigation, age at start of RRT, sex, RRT at time of investigation, total duration of RRT and of dialysis, the occurrence of disabilities, and comorbidity. Comorbidity was defined as the presence of one or more of the clinical diseases as defined by Davies et al[19] (ie, malignancy, clinically apparent ischemic heart disease, peripheral vascular disease, clinically apparent left ventricular dysfunction, diabetes mellitus, systemic collagen vascular disease, cerebrovascular disease, chronic obstructive airway disease, other significant disorders). Disabilities were defined as being present in case of severe deafness, blindness, or having motor function disorders.

Data on sociodemographic outcomes, including employment status, current income (below vs national average or greater), educational attainment (high level vs intermediate or low level), marital status (married or living together with partner vs no partner or divorced), and having offspring were collected by a questionnaire. We categorized the educational attainment according to the highest successfully completed level of schooling: low (low vocational training, "Lager Beroeps Onderwijs"), intermediate (intermediate vocational training, "Middelbare Beroeps Onderwijs" or "Hoger Algemeen Vormend Onderwijs/Voorbereidend Wetenschappelijk Onderwijs"), and high (high level vocational training, "Hoger Beroeps Onderwijs" or university). According to the definition of the National Dutch Bureau of Statistics,[20] unemployment was defined as less than 30% of full-time equivalent spent on paid work. Age-matched data from the general Dutch population were available on employment, current income, educational attainment, and having offspring.[20]

As in 2000, we used the RAND-36 questionnaire, a reliable and valid instrument, to assess QoL.[21] It has been used previously to assess QoL in former pediatric patients with ESRD[18] and also is used widely in the evaluation of patients with other medical conditions, including rheumatoid arthritis[22] and cancer.[23] The questionnaire is almost identical to the Medical Outcomes Study Short-Form 36[24]. The difference lies in the slightly different formulation of some questions as well as a slightly different scoring system in the domains of bodily pain (BP) and general health (GH).[24,25]

The RAND-36 is made up of 36 questions and standardized response choices, which measure 8 distinct aspects of QoL: physical functioning (PF; eg, "Does your health now limit you in climbing several flights of stairs?"); social functioning (SF) (eg, "To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?"); role limitation due to physical problems (RP; eg, "Have you had any problems with your work or other regular activities as a result of your physical health?"); role limitation due to emotional problems (RE; eg, "Have you had any problems with your work or other regular activities, as a result of any emotional problems [such as feeling depressed or anxious]?"); mental health (MH; eg, "How much of the time have you felt calm and peaceful?"); vitality (VT; eg, "How much of the time did you have a lot of energy?"); BP (eg, "How much did pain interfere with your normal work, including both work outside the home and housework?"); and GH perception (eg, "In general, would you say your health is …") All crude scores are converted to a 0-100 scale, in which a greater score indicates a greater level of functioning or wellbeing. Overall physical health and emotional well-being are assessed by aggregation of all domain scores according to an algorithm described by Ware et al[26] leading to the so-called Physical Component Summary (PCS) and Mental Component Summary (MCS) scores. In contrast to the 0-100 scale of the 8 RAND-36 scales, both the PCS and MCS have a mean of 50 and an SD of 10 in the general population.

Because the age-range of the available Short-Form 36 normative sample matched the patients better than the available RAND-36 normative sample, we used the Short-Form 36 data from the general Dutch population[27] for comparison with patients.

Statistical Analyses

Data are presented as means, medians, and percentages. Differences between participants and nonparticipants were examined by χ^2 test or independent t test. QoL of the patients was examined in several ways. First, independent t tests were performed to compare the mean QoL scores of the patients (total sample, dialysis, transplanted) with the mean scores in the general population. Second, using the 95% CI, we compared the percentage of patients with impaired QoL (total sample, dialysis, transplanted) with the percentage impaired QoL in the general population. Following Rose at al,[28] we considered impaired QoL as a score less than the 25th percentile value in the general population. In other words, patients