



Impact of Renal Replacement Therapy in Childhood on Long-Term Socioprofessional Outcomes: A 30-year Follow-Up Study

Lidwien A. Tjaden, MD^{1,2}, Heleen Maurice-Stam, PhD³, Martha A. Grootenhuys, PhD³, Kitty J. Jager, MD, PhD², and Jaap W. Groothoff, MD, PhD¹

Objective To evaluate socioprofessional outcomes after 30 years of renal replacement therapy (RRT) and explore predictors of these outcomes.

Study design The cohort comprised all Dutch patients, born before 1979, who started RRT at age <15 years in 1972-1992. Outcomes including family life, educational attainment, and professional life were obtained in 2000 and 2010 in 80 out of 152 survivors. Participants also completed the Course of Life Questionnaire in 2000, which retrospectively assessed the achievement of developmental milestones while growing up. Socioprofessional outcomes in 2010 were compared with the age-matched general population and with outcomes obtained in 2000. Logistic regression analysis was performed to identify determinants of socioprofessional outcomes.

Results Mean age and time on RRT in 2010 were 40.6 years (range 32.1-52.4) and 28.9 years (range 18.1-39.7), respectively. Patients were less likely to be employed (62.5% vs 81.0%) and have children (28.8% vs 64.8%) compared with the age-matched general population. Comorbidities, dialysis, short stature, and fewer milestones on autonomy were associated with adverse outcomes. Compared with 2000, in 2010 more patients lived with a partner (68.8% vs 43.0%), and more patients had completed a high level educational degree (22.5% vs 13.9%). However, more patients were unable to work on medical grounds in 2010 (36.3% vs 16.3%).

Conclusions Survivors of pediatric end-stage renal disease may gain social autonomy and optimal educational attainment at an older age compared with their general population counterparts. Awareness among health care professionals of the potential of these children and tailored psychosocial interventions might improve socioprofessional development. (*J Pediatr* 2016;171:189-95).

End-stage renal disease (ESRD) affects 5-10 children per million age-related population per year. It increases mortality risk by 30-fold compared with healthy children and induces important disabling comorbidities.^{1,2} Renal transplantation is the gold standard of renal replacement therapy (RRT), as it is associated with longer life expectancy, better quality of life, and lower costs compared with long-term dialysis.¹⁻⁴ However, there are several technical, social, or immunologic hurdles to transplantation that may force physicians to initiate dialysis.⁵ In addition, there is always the risk of graft failure because of rejection, drug toxicity, viral infection, or recurrence of primary disease.^{6,7} Consequently, most adult patients with childhood onset ESRD have experienced several changes of RRT modality.

Because the survival of children on RRT has substantially increased over the last decades, concern exists about the long-term impact of the disease and its treatment on adult life. Most studies focus on patient and graft survival and physical complications,⁸⁻¹⁰ but important measures of successful treatment in childhood might also include the level of achieved independency and social participation in adulthood.

Patients with adult onset of ESRD experience substantial limitations in social and recreational activities as well as in the capacity to remain employed.¹¹⁻¹⁴ Comorbidities, mode of RRT, and time spent on RRT are the most important determinants of adverse socioprofessional outcomes.^{15,16} Although previous studies conducted among adult survivors of pediatric ESRD also found high percentages of unemployment and social dependency, all of these studies only included post-transplanted children, whereas no study with a follow-up time of more than 20 years of RRT exists.¹⁷⁻²⁰

In 2000, we conducted the first comprehensive study on late effects of renal insufficiency in children (LERIC) in a cohort of all Dutch patients who started RRT at age <15 years between 1972 and 1992.²¹ As expected, we found delays in setting up family life, educational attainment, and professional outcomes compared with healthy individuals after a mean follow-up time of 18 years. In terms of psychosocial development, patients achieved fewer milestones while growing up with ESRD than their peers in the general population with respect to autonomy, social, and psycho-sexual development.²² The

ESRD	End-stage renal disease
HD	Hemodialysis
LERIC	Late effects of renal insufficiency in children
RRT	Renal replacement therapy

From the ¹Department of Pediatric Nephrology, Emma Children's Hospital, ²Department of Medical Informatics, and ³Psychosocial Department, Emma Children's Hospital, Academic Medical Center, Amsterdam, The Netherlands

Supported by the Dutch Kidney Foundation (NSNKI39). The authors declare no conflicts of interest.

0022-3476/\$ - see front matter. Copyright © 2016 Elsevier Inc. All rights reserved.

<http://dx.doi.org/10.1016/j.jpeds.2015.12.017>

achievement of such developmental milestones, especially social development, was found to be positively associated with quality of life in adulthood.^{22,23}

To assess the impact of an even longer period on RRT on psychosocial functioning, we extended follow-up of the LERIC study to 2010. In a recent article focusing on quality of life, we found suboptimal socioprofessional outcomes.³ The present article provides more extensive information on socioprofessional functioning after approximately 30 years of RRT. Second, it aims to identify psychosocial and medical determinants of these outcomes. Finally, we focus on the changes in socioprofessional outcomes over time (2000-2010).

Methods

The LERIC cohort comprises all Dutch patients who started chronic RRT at <15 years of age between 1972 and 1992, and who were born before 1979. The first study with respect to socioprofessional outcomes and the achievement of psychosocial developmental milestones was conducted in 2000. Patients still alive in 2010 were invited to participate in the present study. After informed consent had been obtained, a survey was sent to the home addresses. Nonresponders were sent a reminder letter and survey after 3 and 6 months. The medical ethical committees of all 43 participating centers approved the study.

Data on clinical characteristics were collected from medical records between June 2010 and February 2011. The predefined variables were sex, age at start of RRT, age at time of investigation, short stature at adult age (height 2 SDs below national average), mode of RRT, total duration of RRT, disabilities, and comorbidities. Comorbidity was defined according to Davies et al²⁴: malignancies, clinically apparent ischemic heart diseases, peripheral vascular diseases, left ventricular dysfunction, diabetes mellitus, systemic collagen vascular diseases, cerebrovascular diseases, chronic obstructive airway diseases, or other significant pathologies. Disabilities were defined as severe deafness, blindness, or being disabled by motor function disorders.

Socioprofessional outcomes were collected by means of a questionnaire in both 2000 and 2010, including questions on family life (marital status, living alone, with parents or with a partner, and having children), educational attainment, and professional outcomes (percentage of employment, current income, unpaid work, and receiving social benefits). We categorized educational attainment according to the highest successfully completed level of education: low (primary school or low level vocational training), intermediate (intermediate level vocational training), or high (high level vocational training or a university level education). Age-matched socioprofessional data from the Dutch general population in 2010 were obtained from the Central Dutch Bureau of Statistics.²⁵ According to the Central Dutch Bureau of Statistics, employment was defined as 30% or more of full-time equivalent spent on paid work. Monthly income

of employed patients included both salary and social benefits and was compared with the Dutch national average (ie €2500 [about US\$3200] gross per month).²⁵ In depth questions were included regarding potential barriers to preferred socioprofessional outcomes (eg, "What impact did the disease have in study and career choices?").

The "course-of-life" questionnaire was administered in 2000 to assess the achievement of psychosocial developmental milestones while growing-up.²⁶ This instrument assesses retrospectively the course of life of young adults. The items are divided into 5 scales: (1) development of autonomy (eg, "age of their first holiday without parents"); (2) social development (eg, "belonging to a group of friends during secondary school"); (3) psychosexual development (eg, "the age at which they fell in love for the first time"); (4) anti-social behavior (eg, "ever been refused admission to lesson?"); and (5) substance use and gambling (eg, use of alcohol, tobacco and drugs, and gambling). Regarding socio-professional outcomes only the first 3 scales were assumed relevant. The questionnaire has been previously validated.²⁷

Statistical Analyses

Differences between participants and nonparticipants were examined by χ^2 tests for categorical variables and independent *t* tests or Mann-Whitney U tests for numeric variables.

Socioprofessional outcomes were examined in several ways. First, we compared the outcomes on family life, educational attainment, and professional outcomes in 2010 with outcomes in the age-matched general population using 95% CIs belonging to the patient outcomes. If the proportion of the general population was not included in the 95% CI of the estimate in the patient group (all patients, dialysis, transplantation), the patients were considered to differ from the general population. Second, backward logistic regression was performed to examine potential determinants of employment status ($\geq 30\%$ employed vs $< 30\%$ or unemployment), level of educational attainment (low vs intermediate and high), having a partner (yes/no), and having children (yes/no). Based on the results of univariate analyses a preselection of potential determinants was made for each outcome separately (entry level set at $P < .3$). Age and sex were included in all logistic regression models. The determinant "on dialysis at time of investigation" and "having received dialysis for a longer period of time than having a functioning transplant" could not be tested as a determinant of "having children" because none of the patients on dialysis at time of investigation and none of the patients who had received dialysis longer than they had lived with a functioning transplant, had children. The independent impact of the included determinants was expressed as ORs, with 95% CIs.

Finally, to assess socioprofessional outcomes over time, we compared the outcomes in 2010 with those in 2000 using the McNemar test. A significance level of .05 was used for all analyses. We used SPSS 21.0 for Windows (SPSS Inc, Chicago, Illinois) for all statistical analysis.

Download English Version:

<https://daneshyari.com/en/article/4164555>

Download Persian Version:

<https://daneshyari.com/article/4164555>

[Daneshyari.com](https://daneshyari.com)