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ORIGINAL ARTICLE

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The impact of delayed development on the quality of life of adults with end-stage renal disease since childhood

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Abstract Little is known about the impact of the course of life of children with end-stage renal disease (ESRD) on their quality of life in adulthood. We therefore assessed the course of life of adult patients with onset of ESRD at an age of <15 years between 1972 and 1992 and compared it with that of the general population. Furthermore, we explored how course of life is associated with quality of life (QoL) in young adulthood. A total of 75 young adult patients who had had ESRD since childhood, aged between 20 years and 30 years, completed the RAND-36 Health Survey and a questionnaire, which retrospectively assesses the achievement of development milestones. Patients achieved fewer milestones than peers with respect to autonomy, social, and psycho-sexual development, and displayed less risk behaviour. Patients who achieved fewer social milestones while growing up experienced more emotional problems and less vitality, and they had a lesser overall mental quality of life. Paediatric nephrologists should pay more attention to the development of social and independent functioning of children with ESRD in order to prepare them for active participation in society in adult life.

Keywords Adjustment · Growing up

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Introduction

As renal replacement therapy in children with end-stage renal disease has become routine treatment, concern has arisen about its implications on adult life. In order to establish late physical, social and psychological effects of renal insufficiency in children, we undertook a long-term follow-up study of all Dutch adult patients who had commenced renal replacement therapy (RRT) at an age of <15 years between 1972 and 1992, the so-called LERIC study. Previously, we reported on quality of life (QoL). We found that dialysis patients with paediatric ESRD had an impaired physical QoL as adults, but they had a normal mental QoL. Important medical determinants of QoL were co-morbidity for all patients and disabilities for patients that had received a transplant [1]. Rosenkranz et al. [2] found that general and health-related satisfaction with life of adult patients with ESRD was reduced compared to that of the general population.

The course of life in the transition from childhood to adulthood may also be an important mediator for later quality of life. Fulfilling developmental tasks and achieving development milestones at youth, such as search for contacts outside the family, or acquisition of independence, referred to as the 'course of life', are of great importance for adjustment in adult life [3, 4]. The burden of chronic morbidity and hospitalisation interferes with this process in children with ESRD. Suffering from ESRD, and its treatment, often increases children's dependence on their parents and other adults and decreases their motor performance [5] and the participation in peer and school-based activities of these children [6]. This could be a threat to the accomplishment of developmental tasks. Cognitive problems and non-attendance, as a result of the disease and treatment, can result in less educational achievement [7–9]. However, the developmental consequences of growing up with ESRD have scarcely been investigated. We therefore analysed the differences in the course of life between patients of the LERIC cohort and young adults from the general Dutch population. We also analysed the impact of

development milestones on the quality of life in adulthood in these patients.

Patients and methods

Study design This nationwide study was designed as a cohort study and consisted of a cross-sectional and a retrospective part. The aim of the cross-sectional study was to establish current health status. The aim of the retrospective part of the study was to evaluate the relationship of a set of predefined determinants with health outcome. The study covered the total period of renal replacement therapy for each patient. The end of the study was marked by the day of last chart review for potential non-participants in the cross-sectional study and the day of the cross-sectional examination for participants. The medical ethics committees of all participating centres approved the study. We obtained informed consent from all study participants.

Formation of the cohort The LERIC cohort comprises all Dutch patients who had started chronic renal replacement therapy at the age of 0–14 years between 1972 and 1992 and who were born before 1979. Patients in whom renal function recovered within 4 months of commencement of dialysis were excluded. Patients that had received a pre-emptive transplant (n=4) were included. Patients who had started renal replacement therapy after 1991 were excluded in order to have at least a (potential) follow-up period of 6 years. Patients were recruited from the database of The National Dutch Registry of patients on renal replacement therapy (RENINE, Rotterdam, The Netherlands) and the database of all centres for pediatric nephrology in The Netherlands. The procedure of the cohort formation has previously been described in detail [10].

Data collection Between November 1998 and August 2000 members of the LERIC team visited 37 hospitals in the Netherlands. Patients were treated previously in seven pediatric units. The team collected data on clinical characteristics and potential determinants in relation to health outcome, QoL and course of life. The predefined variables were: gender; period of onset of renal replacement therapy; age at onset of renal replacement therapy; total duration of renal replacement therapy and of dialysis; the occurrence of motor, visual and auditory disabilities ("disabilities"); co-morbidity. Co-morbidity was found to be present in cases of clinical cardiac disease (signs of cardiac failure, angina pectoris), neurological disease or other chronic diseases, not directly related to end-stage renal disease (i.e. pulmonary or gastro-enterological diseases). All medical charts of all patients, participants as well as non-participants in the cross-sectional study, were reviewed. Patients that had emigrated were located, and medical information was obtained from their current physician.

Measures

All patients who participated in the cross-sectional part of the study were asked to complete the "Course-of-life" questionnaire and the RAND-36, a QoL questionnaire, at our hospital, under the supervision of one of our team members.

The "Course-of-life" questionnaire was used to assess the achievement of development milestones retrospectively. This Dutch instrument was developed by the Psychosocial Department of the Emma Children's Hospital/Academic Medical Centre in order to be able to investigate the course of life of young adults, aged 18–30 years, who have grown up with a chronic or life-threatening disease, and to facilitate comparison with the course of life of peers without a history of disease [11]. Reference values were obtained from 508 young adults, aged 18–30 years, from the general population [11, 12].

The items, based on literature and clinical experience, concern behaviours characteristic of age stages, developmental tasks, and limitations children could have during their maturation into adult life while having a chronic disease. Most questions ask whether the respondent has achieved development milestones (yes, no) or at what age the respondent achieved the milestones. The answers are dichotomised, if needed, before being added to the scale score. The items are divided into five scales: (1) development of autonomy (autonomy at home and outside it, e.g. "age of going on holidays without parents"); (2) social development (social contacts with peers, at school and in leisure time, e.g. "belonging to a group of friends during secondary school"); (3) psycho-sexual development (love and sexual relations, e.g. "the first time of falling in love"); (4) anti-social behaviour (misbehaviour at school and outside it, e.g. "ever been refused admission to lessons?"); (5) substance use and gambling (use of alcohol, tobacco and drugs, and gambling). A higher score on the first three scales indicates the accomplishment of more developmental tasks, and is thus indicative of a more favourable course of life. A higher score on antisocial behaviour and on substance use and gambling means that the respondent displays more anti-social behaviour and more substance use and gambling. Apart from the five scales, the questionnaire measures socio-demographic outcomes, such as living situation, marital status, education, and employment.

The validity of the course-of-life-scales is good. First, the items are based on the literature and clinical experience. Second, the results among a normative population of 508 young adults from the general Dutch population proved to be in line with several datasets of the Dutch population [11, 12]. The test–retest reliability is good ($r \geq 0.86$) [13]. The internal consistency of the scales is satisfactory, except of the autonomy scale, probably because the items concern diverging aspects of autonomy [11]. The use of scales with moderate internal consistency is acceptable for group comparisons because internal consistency is an indication of random error and has nothing to do with systematic error (bias). The Cronbach's alphas in the population under

study are moderate to good: (1) development of autonomy (6 items; range 6–12): LERIC 0.48, controls 0.52; (2) social development (12 items; range 12–24): LERIC 0.83, controls 0.71; (3) psycho-sexual development (4 items, range 4–8): LERIC 0.68, controls 0.73; (4) anti-social behaviour (4 items; range 4–8): LERIC 0.75, controls 0.57; (5) substance use and gambling (12 items; range 12–24): LERIC 0.77; controls 0.77.

The RAND-36 Health Survey is almost identical to the MOS SF-36 [14]. In the Dutch versions, both questionnaires are made up of the same questions and they handle the same scoring system. The only difference lies in the slightly different formulation of some of the questions [15]. The RAND-36 is made up of 36 questions with standardised response choices, which measure eight distinguishing health concepts: physical functioning, role limitations due to physical health, social functioning, role limitations due to emotional problems, bodily pain, vitality, general health perception, and mental health. All raw scores are converted to a 0–100 scale, in which a higher score indicates a higher level of well being. Overall physical health and mental health are assessed by aggregation of all domain scores according to an algorithm described by Ware et al. [16], leading to the so-called Physical Component Summary and Mental Component Summary. In contrast to the 0–100 score of the eight RAND-36 scales, both the Physical Component Summary (PCS) and Mental Component Summary (MCS) have a mean of 50 and a standard deviation of 10 in the general population.

Statistical analysis

The course-of-life questionnaire has been developed for adults aged 18–30 years. Therefore, the scope of this paper is limited to the LERIC participants aged 20–30 years, 75 patients in total. The data from 381 young adults from the general Dutch population (control group), aged 20–30 years, were used as reference values.

Before conducting the final analyses we conducted several preparatory analyses. First, scales were constructed, based on the guidelines of the questionnaires used, and the reliability of the scales was calculated. Second, we compared the study population and controls with respect to their demographic characteristics in order to detect confounders. Student's *t*-test and χ^2 tests were used. As the participants did not differ from the control group with respect to demographic characteristics such as age and gender, there was no need to correct for confounders.

After these preparatory analyses, multivariate analysis of variance (MANOVA) were conducted to test group differences on the course-of-life-scales and to assess the main effects for age and gender. We calculated effect sizes (d) by dividing the difference in mean score between patients and controls by the standard deviation of the scores in the control group. We considered effect sizes up to 0.2 to be small, effect sizes about 0.5 to be moderate, and effect sizes about 0.8 to be large [17]. To be sure about the results we also performed non-parametric Mann–Whitney U-tests because the scores of the course of life scales were not distributed quite normally.

We performed multiple linear regression analyses to investigate the impact of the developmental scales of the course-of-life-questionnaire (i.e. autonomy, psychosexual and social development) on the RAND scales, while controlling for age, gender, and medical variables. Selection of the medical variables was based on correlations with the RAND scales (entry level set at $P<0.4$). For each regression, the explained variance (R square) was determined and tested with the F test. T values and their significance level were calculated to test the hypothesis that the contribution of an entered variable, expressed by the regression coefficient, differed significantly from zero.

The Statistical Package for Social Sciences (SPSS) Windows version 11.5 was used for all analyses.

Results

The cohort

The results of the LERIC cohort formation are described in Table 1. Of all 187 patients alive, 52 (27.8%) declined to participate in the cross-sectional study, leaving 135 subjects. Of these 135, a complete score was obtained for 130 patients, of whom 75 were aged 20–30 years. At time of investigation 14 patients were on dialysis and 61 had a functioning renal graft. Of all patients currently on dialysis, the mean duration of the last uninterrupted dialysis period was 3.4 years (range 0.0–19.9 years).

Course of life in patients with ESRD compared with the general population

The multivariate analysis of variance (MANOVA) for the course-of-life scales as a function of group, age and gender showed multivariate main effects for group [F (5,444)=18.5,

Table 1 Characteristics of the patients with ESRD, aged 20–30 years (*RRT* renal replacement therapy, *SD* standard deviation)

Characteristic	Number	
Gender: male/female	75	39/36
Mean age of start RRT in years (SD)	75	10.2 (3.0)
Mean age at time of investigation in years (SD)	75	25.3 (2.7)
Mean duration of RRT in years (SD)	75	14.6 (4.1)
Mean duration of dialysis in years (SD)	75	3.4 (3.8)
Mean duration of functioning renal graft in years (SD)	75	11.2 (5.0)
On dialysis at time of investigation (*n*)	75	14 (18.7%)
Disabilities[a]	75	11 (14.5%)

[a]Motor, visual or auditory

Table 2 Mean scores, standard deviations (*SD*) and differences (effect sizes) between LERIC patients aged 20–30 years and Dutch persons aged 20–30 years ("control group") on the five scales of the course-of-life questionnaire, as a function of group. Multivariate effects were found for group ($P<0.001$), gender ($P<0.001$) and age ($P<0.01$)

Scale	Patients with ESRD ($n=71$)	Control group ($n=381$)	Effect size
Autonomy development			
Mean (SD)	8.8 (1.5) *	9.5 (1.5)	0.42
Psycho-sexual development			
Mean (SD)	5.7 (1.3) **	7.2 (1.2)	1.22
Social development			
Mean (SD)	19.9 (3.2) *	20.9 (2.4)	0.42
Anti-social development			
Mean (SD)	4.5 (1.0)	4.7 (1.0)	0.20
Substance use and gambling			
Mean (SD)	13.7 (2.2)**	15.1 (2.6)	0.52

*$P<0.01$, **$P<0.001$: differences between patients with ESRD and the control group (based on univariate F tests according to MANOVA, course-of-life scales by group, gender and age)

$P<0.001$], gender [F (5,444)=15.0, $P<0.001$] and age [F (5,444)=3.3, $P<0.01$]. The results of the univariate F tests according to MANOVA showed the achievement of fewer development milestones among LERIC patients than among the control group: social development [F (1,452)=9.8, $P<0.01$], autonomy development [F (1,452)=11.1, $P<0.01$], and psycho-sexual development [F (1,452)=86.2, $P<0.001$]. In addition, patients scored less on the scale substance use and gambling [F (1,452)=20.4, $P<0.001$] (Table 2). The differences between patients and their peers were moderate to high: effect sizes ranged from 0.20 (anti-social development) to 1.22 (psycho-sexual development). The results of the F tests according to MANOVA are confirmed by the non-parametric Mann–Whitney U-tests, for all scales of statistical significance ($P<0.001$).

Impact of course of life on QoL in young adulthood

The results of the multiple regression analyses are presented in Table 3 and include the total variance explained (R^2) for all RAND scales.

Age and gender did not predict any of the RAND scales significantly. The most important medical predictor of QoL was having co-morbidity. Social development appeared to be the most important additional predictor of QoL. Participants who had achieved fewer milestones in the social development domain during childhood experienced more limitations due to physical problems (role physical) as well as more limitations due to emotional problems (role emotional), and reported less vitality and a worse Mental Component Summary (MCS) later in life.

Table 3 Standardised regression coefficients β for the relationship between the scores on the RAND subscale and the scores on the course-of-life scales, while controlling for age, gender, and medical determinants (*RRT* renal replacement therapy)

Parameter	Physical functioning β	Social functioning β	Role physical β	Role emotional β	Mental health β	Vitality β	Bodily pain β	General health β	Physical component summary	Mental component summary
Age	–0.11	0.03	–0.12	0.07	0.03	–0.04	–0.13	0.07	–0.16	0.10
Gender (female)	0.03	–0.08	–0.16	0.00	–0.17	–0.10	–0.05	–0.03	–0.08	–0.06
RRT at investigation (dialysis versus renal graft)	–0.08	–0.19	–0.12	–	–	–0.10	–	–0.32**	–0.15	–
Duration of dialysis (years)	–0.07	0.19	0.04	–	–0.04	–	0.12	0.17	0.16	–
Co-morbidity (yes versus no)	–0.47***	–0.46***	–0.30*	–0.09	–0.40**	–0.43***	–0.44***	–0.49***	–0.48***	–0.27*
Disabilities (yes versus no)	–0.12	–0.10	–	–0.18	–0.15	–	–0.29*	–0.10	–0.14	–0.10
Autonomy	0.19	–0.01	–0.04	–0.23	0.18	0.05	0.07	0.13	0.20	–0.12
Psycho–sexual development	–0.02	–0.05	–0.14	–0.06	–0.14	–0.06	–0.05	0.06	–0.07	–0.05
Social development	0.01	0.24	0.28*	0.34**	0.08	0.33**	0.03	0.07	0.04	0.30*
DF	9,62	9,62	8,63	7,64	8,63	7,63	8,62	9,62	9,60	7,62
R^2	0.32**	0.33**	0.27**	0.17	0.24*	0.36***	0.29**	0.37***	0.33**	0.20*

*$P<0.05$, **$P<0.01$, ***$P<0.001$

Discussion

We found that adults with ESRD since childhood achieved development milestones later in life. On average, patients achieved fewer milestones than their peers with respect to autonomy development, social development, and psycho-sexual behaviour. Also, they displayed less risk behaviour, in terms of trying out, than age-matched controls from the general Dutch population. Patients who achieved fewer social milestones while growing up experienced more emotional problems and less vitality and had a less overall mental quality of life. These findings show that development milestones during childhood and the quality of life during adulthood are associated.

The differences in mean score on the course-of-life scales between participants and their age-matched and gender-matched peers were moderate to large, especially for psycho-sexual development. From previous assessments, we know that, compared with young adults who have grown up with another disease, such as anorectal malformations, Hirschsprung's disease, or oesophageal atresia, the course of life of patients with ESRD, just as that of survivors of childhood cancer, was hampered most [18].

What is the meaning of achieving development milestones later in life? From a developmental, psychological, point of view, the fulfilling of age-specific developmental tasks in childhood is of great importance for adjustment in adult life [3, 4]. Knowledge about possible gaps in the course of life could be useful in clinical practice, because it enables health care providers to aim at a most favourable course of life for children with ESRD, during and after treatment. Health care workers should be aware of, and pay attention to, the continuation of peer-related activities, parental overprotection, reflection on school-performance, and alertness for body image-related problems. Moreover, this study has also shown that fulfilling developmental tasks while growing up indeed has a predictive value for the quality of adult life. Those patients who were not able to continue peer-related activities during childhood reported a lower mental quality of life later in adulthood. The time spent on dialysis and hospital visits and admissions may cause considerable disruption to normal social activity and school attendance, and appears to be associated with lower mental quality of life later in adulthood. Therefore, it is important for parents and clinicians to stimulate children with ESRD to perform peer-related activities as much as possible, and to maintain the social contacts they had before they became ill. One way of creating autonomy and social independence during childhood is putting effort into having haemodialysis at home. This has been put into practice in the Netherlands and has been shown to be very effective for children and young adults.

In relation to autonomy development, overprotection by parents with a chronically ill child comes into focus. Parents sometimes develop a "dominant pattern" of interacting with the child, and overprotection is an attempt to make up to the child for all he/she has suffered. The parents are reluctant to discipline or have expectations for the child. This attitude inhibits the child from developing the personal skills needed to cope with the extra challenge of the disease. Our results show the potential negative impact of this attitude on perspectives for adult life of these children.

We found a delayed sexual development for adults with ESRD since childhood. Sexuality is closely related to a person's self-concept and self-esteem. Peer relationships are important for social development and self-esteem, especially in adolescents. Adolescents with chronic illnesses may become marginalised by peers, rejected for being different at a time when body image and identity so largely depend on conformity [19]. Chronic illness may complicate the transition to adulthood, characterised by transition from family life to independent living and transition from education to employment and closely related to positive social and emotional development earlier.

The impact of reduced risk behaviour that we found in our patients remains speculative. From a developmental, psychological, point of view, risk behaviour is relevant, because, displaying risk behaviour—in terms of trying out—is, to a certain extent, part of the development of being a teenager to becoming an adult. On the one hand, we could expect more risk behaviour in ESRD children in order to compensate for the limitations in their youth caused by the disease. Non-compliant behaviour in children with ESRD and adults has been described extensively [6]. On the other hand, it is imaginable that adults with ESRD since childhood display less risk behaviour than peers because they are aware of the vulnerability of their health. Besides, increased parental involvement as a result of the disease may limit the child's opportunities for unsupervised meetings with peers, which may decrease the child's opportunities to engage in risk-taking activities [20]. Our findings are in line with the latter theories. Although indicative of a deviant course of life, reduced risk behaviour is in itself not unfavourable. In contrast, it could be indicative of protective health behaviour, which is of utmost importance for young adults with ESRD since childhood [21].

Previously, we reported [22] that growing up with ESRD during childhood has consequences for social–demographic outcome. Participants in our study were more often still living at home, or were living alone. We found associations between developmental tasks and these outcomes (data not shown). As can be expected, those who have a slower psycho-sexual development are less often married, and those who stay behind in autonomy development often are still living at home. Although this may be in the expected direction, it does again show the importance of accomplishing developmental tasks in relation to socio-demographic outcomes later in life.

Limitations of the study: in this paper the results of the first study about the impact of course of life on the QoL of young adult with ESRD since childhood in the Netherlands have been described. As far as is known, the course-of-life questionnaire is the first (Dutch) questionnaire concerning this issue. Although this study gained several useful insights, the questionnaire and the study encountered the same limitations. First, the concept of 'course of life' is more comprehensive than the milestones covered by the course-of-life questionnaire. The fact that the course of life is measured retrospectively limits the range of topics. In order to prevent bias caused by inadequate memory, the questions are factual and do not go further back than primary school. The test–retest reliability has proved to be satisfactory, so that we can conclude that the retrospective reporting about milestones is rather reliable [13]. Second, although most items of the course-of-life-questionnaire preceded (in time) the QoL in young adulthood, this cannot be considered solid evidence of causality. This means that longitudinal research is needed to confirm the causality between the achievement of development milestones and adjustment in young adulthood. Third, we do not know the differences between patients who were on peritoneal dialysis (PD) versus those patients who were on haemodialysis during life. If the advantages of PD are to be studied, as it does enable children to dialyse at home overnight and maintain more social and educational contacts, changes in the course of life domains can be expected. Finally, the question arises whether our findings are applicable to the current generation of ESRD children. As a result of the Dutch policy followed before 1990 not to accept all children for renal replacement therapy, only three patients in our cohort were developmentally disabled. This implies, however, that in the current western paediatric dialysis population with a higher proportion of mentally disabled patients, the problems signalled by this study might be even of greater importance. Whether our findings, indeed, can be generalised to other countries needs to be proved by further studies.

In conclusion, we believe that paediatric nephrologists should pay more attention to the development of social and independent functioning of children with ESRD in order to optimise their adaptation to society at the time of transition to adulthood, and, consequently, to create conditions for an optimal quality of life. In addition, nephrologists should take notice of the psychosocial course during childhood at the time of transition to adulthood in order to provide the optimal care. Paediatric nephrologists and members of the multi-professional team need to pay more attention to the development of social and independent function of children with ESRD.

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