Quality of life in adults with end-stage renal disease since childhood is only partially impaired

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Abstract

Background. Little is known about the quality of life of adults with end-stage renal disease (ESRD) since childhood. In a long-term follow-up study, we assessed quality of life in these patients and compared their outcomes with those in the general population and in dialysis patients with adult-onset of ESRD.

Methods. All Dutch adult patients with onset of ESRD at age 0–14 years between 1972 and 1992 were asked to complete the RAND-36 questionnaire. We obtained clinical information by reviewing all available medical charts, and by current history. Patient scores were compared with those of age-matched healthy controls and with those of patients with adult onset of dialysis, of whom data were derived from a national study on the adequacy of dialysis (NECOSAD-2).

Results. We obtained a complete RAND-36 score in 131 of 187 surviving patients. Clinical characteristics of participants and non-participants were similar. Compared with the general population, we found a higher prevalence of impaired quality of life in dialysis patients in the following domains: physical functioning, role limitations due to physical health, social functioning (SF), general health perception (GH) and physical component summary. In other domains, impaired quality of life was equally or less prevalent (mental component summary). In transplanted patients, only impaired GH and SF were more prevalent. In dialysis patients with adult ESRD onset, impaired quality of life was more prevalent than in the general population in all domains, except in emotional role limitations.

Conclusions. Dialysis patients with paediatric ESRD have an impaired physical quality of life, but in contrast to dialysis patients with adult ESRD onset, they have a normal mental quality of life.

Keywords: adult-onset ESRD; childhood-onset ESRD; epidemiology; NECOSAD-2; quality of life; RAND-36

Introduction

As renal replacement therapy in children with end-stage renal disease (ESRD) has become routine treatment, concern has arisen about its implications on adult life. In the last 10 years, self-assessment of health status has gained importance in patients with chronic renal failure. Not surprisingly, most studies in adult patients on dialysis show an impaired quality of life on items that reflect both physical and mental health [1–4]. On the other hand, reports on quality of life in renal transplanted patients show contradictory results [3,5]. For young adult patients with ESRD since childhood, no data on quality of life exist at all. Given the success of renal replacement therapy in children, knowledge of this subject has become extremely important.

We conducted a national long-term follow-up study in order to evaluate Late physical, social and psychological Effects of Renal Insufficiency in Children (LERIC) in all Dutch children who had commenced renal replacement therapy between 1972 and 1992, and who were born before 1 January 1979. The objectives of the part of the LERIC study reported here were to assess the quality of life of these patients, both transplanted as well as currently on dialysis, and to compare their quality of life with the general population. We also made a comparison between quality of life scores of the dialysis patients of our cohort, i.e. adult dialysis patients with paediatric onset of ESRD, and those of dialysis patients with adult onset of ESRD. Finally, we explored which medical determinants are associated with an impaired quality of life.
Quality of life in childhood-onset ESRD is only partially impaired

Subjects 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 ethical committees of all participating centres approved the study.

Formation of the cohort

The LERIC cohort comprises all Dutch patients who had started chronic renal replacement therapy at age 0–14 years between 1972 and 1992, and who were born before 1979. Patients in whom renal function recovered within 4 months after commencing dialysis were excluded. Pre-emptively transplanted patients were included. Patients who 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 paediatric nephrology in The Netherlands. The procedure of the cohort formation has been described previously in detail [6].

Data collection

Between November 1998 and August 2000, members of the LERIC team visited 37 hospitals in The Netherlands. They collected data on clinical characteristics and potential determinants in relation to quality of life. The predefined variables were: gender, other ethnicity, period of onset of renal replacement therapy (1972–1981 vs 1982–1992), age at onset of renal replacement therapy, total duration of renal replacement therapy and of dialysis, the occurrence of disabilities, co-morbidity, obesity, the existence of diabetes mellitus and a short stature at adult age (defined as height -2 SD). Co-morbidity was found to be present in the occurrence of one or more of the clinical diseases as defined by Davies et al. [7] (i.e. malignancy, clinically apparent ischaemic heart disease, peripheral vascular disease, clinically apparent left ventricular dysfunction, diabetes mellitus, systemic collagen vascular disease, cerebrovascular disease, chronic obstructive airway disease or other significant pathology). Disabilities were found to be present in severe deafness, blindness or being disabled by motor function disorders. All medical charts of all patients, participants as well as non-participants in the cross-sectional study, were reviewed. Patients who had emigrated were located and medical information was obtained from their current physician.

All patients who participated in the cross-sectional part of the study were asked to complete the RAND-36 questionnaire at our hospital under the supervision of one of our team members. The RAND-36 Health Survey is almost identical to the MOS SF-36 [8]. In the Dutch versions, both questionnaires are made up of the same questions and they handle the same scorings system. The only difference lies in the slightly different formulation of some of the questions [9]. The RAND-36 is made up of 36 questions and standardized response choices, which measure eight distinctive 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. [10], 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 and Mental Component Summary have a mean of 50 and a standard deviation of 10 in the general population. Data of all patients were compared with data derived from the general Dutch population [9]. Data of dialysis patients of our cohort were also compared with data derived from The Netherlands Co-operative Study on the Adequacy of Dialysis, phase 2 (NECOSAD-2), in which dialysis patients who had developed ESRD at adult age participated [11]. In this study, patients were asked to complete the SF-36 questionnaire 3, 6, 12 and 24 months after onset of dialysis. We used scores of all patients aged 18–40 years that were obtained at 12 months after onset of dialysis, to compare with the LERIC patients’ scores.

Statistical analysis

A comparison of the frequency of nominal variables of participants and non-participants of the cross-sectional study was performed by the χ2-test. We hypothesized that there would be a considerable difference in quality of life outcome between patients currently on dialysis (‘LERIC dialysis patients’) and transplanted patients (‘LERIC transplanted patients’). We therefore compared these subgroups from the LERIC cohort with the general population. We also compared dialysis patients of our cohort at adult onset of ESRD from the NECOSAD-2 study (‘NECOSAD patients’) with the general population. The comparisons of mean RAND-36 scores between these patient groups and controls were analysed using Student’s t-test.

In addition, since comparison of the RAND-36 in a diseased group with the general population has been considered problematic due to the skewed distributions, we dichotomized the RAND-36 domains for comparison as proposed by Rose et al. [12]. In this analysis, a score below the 25th percentile value for the appropriate age and gender population stratum was considered to indicate an impaired quality of life. We formed two groups for each RAND-36 domain, one with values below the 25th percentile and one with values above the 25th percentile. By definition, the prevalence of impaired health in the general population is 25% for each health domain. If the lower boundary of the 95% confidence interval (CI) for the percentage of patients with an impaired health score (i.e. below the 25th percentile) on a certain domain exceeded 25, the analysed patient group was considered to have an impaired health on that particular domain [12].

To analyse the relationship between determinants and RAND-36 scores, both RAND-36 scores and the values of the determinants were dichotomized. Determinants were dichotomized according to the mean value or to clinical relevance as follows: male vs female gender, age of onset of renal replacement therapy < 6 years vs ≥ 6 years, duration of...
renal replacement therapy < 18 years vs ≥ 18 years, duration of dialysis < 4 years vs ≥ 4 years, dialysis vs functioning renal graft as renal replacement therapy-modality at time of investigation, height ≤ −2 SD vs ≥ −2 SD, and motor, severe visual, or auditory disabilities vs no disabilities, being an immigrant yes or no. Cumulative renal replacement therapy duration and dialysis duration were dichotomized according to their mean values in this cohort (18 and 4 years, respectively), and onset of renal replacement therapy according to the clinical relevance. The effect of determinants on outcome were analysed in both subgroups of transplanted and dialysis patients separately. The RAND-36 scores were divided into two groups according to the 25th percentile of the mean score in the general population. All significant determinants from a univariate analysis (entry level set at \( P < 0.4 \)) were entered into logistic regression models to assess their independent impact on impaired quality of life domains. The independent explanatory values of the characteristics were expressed as adjusted ORs, with 95% CIs. The OR can be interpreted as an estimation of the relative risk of impaired quality of life given the presence of the determinant as compared to the absence of that determinant.

We used SPSS 9.0 for Windows (SPSS Inc., Chicago, IL, USA) and MS-DOS Confidence Interval Analysis (M. J. Gardner and D. G. Altman, London, UK) for all statistical analysis.

### Results

#### The cohort

The results of the LERIC cohort formation are described in Table 1. Of all 249 patients, 62 were deceased at time of investigation. No patients were lost to follow-up. 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 in 131 patients. No significant differences were found in age, gender, age of onset of renal replacement therapy, and clinical characteristics between participants and non-participants of the cross-sectional study (Table 2).

At the time of investigation, 28 patients were on dialysis and 107 had a functioning renal graft. Of all patients currently on dialysis, the mean duration of the last uninterrupted dialysis period was 4.9 years (range 0.13–20.6).

#### RAND-36 scores: mean values

Table 3 presents the means scores of all quality of life domains of LERIC dialysis patients, LERIC transplanted patients and NECOSAD patients, in comparison with scores of the general Dutch population. We indicated the statistically significant differences between these three populations and the general Dutch population. We also indicated the significant differences between mean scores of LERIC dialysis patients and NECOSAD patients.

Mean scores of Physical Functioning, Social Functioning, Role limitations due to Physical health, General Health perceptions, and Physical Component Summary were lower in LERIC dialysis patients, compared to those found in the general population.
(Table 3). However, these patients had scores within the normal range on Role limitations to Emotional problems, Mental Health, Vitality, Bodily Pain and Mental Component Summary.

Compared to the general population, LERIC transplanted patients only had significantly lower scores on Physical Functioning and General Health perceptions, and a borderline significantly lower score on Role limitations due to physical impairment (Δ6.6; \( P = 0.05 \)) (Table 3). Age-matched NECOSAD dialysis patients had significantly lower scores on all items, compared with the general population, except for Mental Health (Table 3).

**RAND-36 scores: percentage of scores below the 25th percentile**

In Table 4, the percentages of patients with a RAND-36 score below the 25th percentile are given for LERIC dialysis patients, LERIC transplanted patients and NECOSAD patients. In LERIC dialysis patients, the prevalence of an impaired quality of life was higher than in the general population concerning Social Functioning, Physical Functioning, Role Limitations due to Physical Health, General Health Perceptions and Physical Component Summary (Table 4). The prevalence of a value below the 25th percentile in these domains varied from 54% (95% CI 32–76) to 68% (95% CI 46–82) in the LERIC dialysis patients. On the other hand, an impaired Mental Component Summary was less prevalent in dialysis patients than in the general population. On all other domains, the prevalence of impaired scores was comparable with that of the general population (Table 4).

In LERIC transplanted patients, Social Functioning (prevalence 36%, 95% CI 27–45) and General Health Perceptions (prevalence 41%, 95% CI 32–150) were more often impaired, and Role Limitations due to Emotional Problems (prevalence 17%, 95% CI 10–24) were less often impaired than in the general population. In all other domains, the prevalence of impaired scores in transplanted patients was comparable with the general population (Table 4).

In NECOSAD patients, the prevalence of impaired quality of life was higher than in the general population for all domains, except Role limitations due to Emotional problems. The prevalence of a value below the 25th percentile varied from 78% (95% CI 70–86) to 34% (95% CI 25–43) in these patients (Table 4).

**Differences in scores between the paediatric onset (LERIC) and the adult onset (NECOSAD) of ESRD.**

Compared to NECOSAD dialysis patients, LERIC dialysis patients had a higher mean score on the Mental Summary Component [50.3 (10.4) vs 45.2(10.6); \( P < 0.05 \); Table 3]. Significantly more NECOSAD patients than LERIC dialysis patients had low scores of the following domains: Role Limitations

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**Table 3. Mean RAND-36 scale scores (SD) of all LERIC dialysis and transplanted patients, healthy age-matched Dutch controls, and age-matched dialysis patients with adult onset of ESRD (NECOSAD-2)***

<table>
<thead>
<tr>
<th></th>
<th>Gen. populationa</th>
<th>TX (LERIC)</th>
<th>Dx (LERIC)</th>
<th>Gen. populationb</th>
<th>TX (NECOSAD)</th>
<th>Dx (NECOSAD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>90.2 (15.7)</td>
<td>88.5 (19.0)</td>
<td>85.5 (26.2)</td>
<td>92.5 (18.0)</td>
<td>87.0 (17.0)</td>
<td>84.5 (19.9)</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>85.8 (17.0)</td>
<td>84.2 (19.9)</td>
<td>81.9 (34.0)</td>
<td>86.7 (19.8)</td>
<td>79.6 (18.0)</td>
<td>81.9 (34.0)</td>
</tr>
<tr>
<td>Role Limitations Em.</td>
<td>74.9 (25.1)</td>
<td>71.9 (25.1)</td>
<td>75.4 (38.1)</td>
<td>74.9 (25.1)</td>
<td>72.0 (16.7)</td>
<td>75.3 (38.1)</td>
</tr>
<tr>
<td>General Health Perceptions</td>
<td>68.4 (14.9)</td>
<td>67.9 (16.2)</td>
<td>75.9 (16.2)</td>
<td>68.4 (14.9)</td>
<td>67.0 (16.2)</td>
<td>75.9 (16.2)</td>
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<tr>
<td>Physical Component Summary</td>
<td>44.0 (20.8)</td>
<td>47.4 (22.0)</td>
<td>47.0 (22.0)</td>
<td>44.0 (20.8)</td>
<td>53.4 (20.8)</td>
<td>49.1 (20.8)</td>
</tr>
<tr>
<td>Mental Component Summary</td>
<td>50.0 (10.0)</td>
<td>49.8 (10.1)</td>
<td>47.5 (10.1)</td>
<td>50.0 (10.1)</td>
<td>49.8 (10.1)</td>
<td>47.5 (10.1)</td>
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</table>

aHealthy Dutch control group age 18–44 years (van der Zee et al. [9]); bDifference between mean score patient groups and general population \( P < 0.05 \); cDifference between mean score patient groups and general population \( P < 0.01 \); dPatients on dialysis aged 18–40 years with onset of renal replacement therapy \( > 18 \) years (NECOSAD-2 study: data from Korevaar et al. [11]); eDifference between mean score NECOSAD dialysis group and LERIC dialysis group \( P < 0.05 \).

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due to Physical Health (78 vs 54%, $P<0.05$), Mental Health 43 vs 21%, $P<0.05$), Vitality (71 vs 39%, $P<0.01$), Bodily Pain (59 vs 26%, $P<0.01$) and Mental Component Summary (45 vs 12%, $P=0.001$; Table 4).

### Determinants of low RAND-36 scores

Table 5 and 6 show the association of clinical determinants with low quality of life for LERIC dialysis patients and LERIC transplanted patients, respectively, as analysed by logistic regression with stepwise forwards strategy. No patients with diabetes mellitus or apparent obesity were part of the cohort. Since the group of immigrants was too small (i.e. 6.7%), ethnicity as a determinant was excluded from analysis. Co-morbidity was present in 60 (46.9%) of all patients and in 18 (67%) of all dialysis patients. Disabilities were present in 21 (15.9%) of all patients and in four (16%) of all dialysis patients.

In the LERIC dialysis patient group, a duration of renal replacement therapy of longer than 18 years was associated with an increased risk of impaired health on Physical Functioning (OR 5.9, 95% CI 1.1; 32), having disabilities with an increased risk of impaired Mental Health (OR 20, 95% CI 1.5; 230), and a duration of dialysis longer than 4 years with an increased risk of an impaired Vitality (Table 5).

In LERIC transplanted patients, having co-morbidity was associated with an increased risk of impaired health on all domains, except Role Limitations due to Emotional Problems and on Mental Component Summary (Table 6). A duration of renal replacement therapy of >18 years was associated with an increased risk of impaired Physical Functioning (OR 5.2, 95% CI 1.6; 16), Limitations due to Emotional Problems (4.1; 95% CI 1.4; 12) and impaired Mental Health (OR 5.1, 95% CI 1.6; 16) (Table 6).

### Discussion

As far as we know, this is the first report on quality of life in a cohort of young adults with ESRD since childhood. In this study, we measured the quality of life in adult patients who have been treated with renal replacement therapy since childhood, with a special focus on the impact of early treatment on long-term health outcomes.
interest in subdomains of the quality of life component score. We also compared the quality of life found in a subgroup of patients who were on dialysis at the time of investigation with dialysis patients who started renal replacement therapy at an adult age, and analysed potential medical determinants for impaired quality of life.

Quality of life of LERIC transplanted patients

We found that the quality of life was only marginally impaired in our transplanted patients compared with the general population. Actually, they only showed mild impairment of Social Functioning and a lower General Health Perception. Moreover, most mean scores, especially those related to the mental quality of life, were higher than found by Fujisawa et al. [3] in renal transplanted patients of the same age. In this study, nearly all scores of haemodialysis patients awaiting transplantation appeared to be similar to those of transplanted patients. In contrast, dialysis patients not awaiting transplantation (i.e. not on a transplantation waiting list for medical or personal reason) had much lower scores. Most available studies emphasize the improvement of the quality of life after renal transplantation [5,13–15], but these have all been conducted on older patients. Rebollo et al. [13] demonstrated that elderly patients with ESRD had relatively better quality of life scores than younger patients. This difference appeared to be even clearer in transplanted patients than in dialysis patients [13]. Therefore, it seems that transplanted patients with ESRD since childhood overall have a relatively good mental health, compared with age-related transplanted patients with an adult onset of ESRD.

Quality of life of LERIC dialysis patients

As one could expect, low scores in the LERIC dialysis patients were seen on all domains that reflect discomfort by physical impairment. These scores were similar to those found in age-matched dialysis patients with adult onset of renal replacement in the NECOSAD study. Both the means scores and prevalences of an impaired quality of life in these domains were equal in both groups. However, in the LERIC dialysis patient group we found normal mean values and normal prevalences of an impaired quality of life in these domains were equal in both groups. However, in the LERIC dialysis patient group we found normal mean values and normal prevalences of an impaired quality of life in domains, which reflect mental quality of life. Impaired Mental Component Summary tended to be even less prevalent in this group than in the general population. Like in the transplanted group, Impaired Role Limitations due to Emotional Problems and impaired Mental Component Summary had the lowest prevalence in LERIC dialysis patient group.

Our results contrast on several counts with data derived from dialysis patients with onset of ESRD in adulthood [1–3,13,16]. These patients appear to have a substantially poorer quality of life, particularly with respect to Role functioning Physical and General Health perceptions, but also to domains related to the mental quality of life. We derived data from the NECOSAD-2 study of patients in the same age group as our patients, who were measured 1 year after onset of dialysis. In all domains except one, the mean scores were lower and the prevalence of scores below the 25th percentile was higher than those found in the general population. The low scores on physical domains, overcompensating the mental scores, could influence the relatively high score on the Mental Component Summary in the LERIC dialysis patients. Nevertheless, it is remarkable that the prevalence of low scores in domains related to mental quality of life was within the

### Table 6. Determinants with respect to low RAND-36 scores (≤0.67 SD) of all transplanted LERIC patients by stepwise forward logistic regression: adjusted ORs with 95% CI

<table>
<thead>
<tr>
<th>Duration of dialysis</th>
<th>Physical Functioning</th>
<th>Social Functioning</th>
<th>Role Limitations Physical</th>
<th>Vitality</th>
<th>Role Limitations Emotional</th>
<th>Mental Health</th>
<th>General Health Perception</th>
<th>Bodily Pain</th>
<th>Physical Component Summary</th>
<th>Mental Component Summary</th>
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<tr>
<td>&gt;4 years</td>
<td>9.2</td>
<td>7.1</td>
<td>8.0</td>
<td>3.7</td>
<td>5.9</td>
<td>4.0</td>
<td>3.2</td>
<td>11</td>
<td>3.6</td>
<td>3.2</td>
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<td>&gt;18 years</td>
<td>(2.7;38)</td>
<td>(2.9;17)</td>
<td>(2.8;23)</td>
<td>(1.6;8.9)</td>
<td>(2.1;17)</td>
<td>(1.7;9.2)</td>
<td>(1.2;8.5)</td>
<td>(4.0;30)</td>
<td>(1.2;8.7)</td>
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<td>1972–1981</td>
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<td>Co-morbidity</td>
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<td>Disabilities</td>
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| RRT, renal replacement therapy; SD, standard deviation; *P<0.05; **P<0.01; ***P<0.001. Note: only significant characteristics are shown.
normal range in our dialysis patients, in contrast with dialysis patients with adult onset of ESRD.

**Determinants of an impaired quality of life**

Not surprisingly, we found that low quality of life scores in the transplanted group were associated with the existence of co-morbidity and, to a lesser extent, with the presence of disabilities. In dialysis patients, we did not find any relationship between co-morbidity and quality of life. However, one has to consider that the overall incidence of co-morbidity in this group was high and that we could only study a small group of patients currently on dialysis. LERIC dialysis patients with a long cumulative dialysis duration had a lower risk of having impaired Vitality. One could speculate that more adaptation to the dialysis state enhances Vitality. We also found that in patients currently on dialysis, a long period of renal replacement therapy was associated with an increased risk of impaired Physical functioning. We found no other relationships between total duration of renal replacement therapy or total duration of dialysis and quality of life.

**Hypotheses on the differences found between paediatric and adult onset of ESRD**

Mental quality of life was better preserved in dialysis patients with paediatric onset than in dialysis patients with adult onset of ESRD. An explanation for this difference could lie in the different expectations of life of both groups and in the use of different coping strategies by children and adults. In their review on measuring quality of life, Carr et al. [17] conclude that health-related quality of life is based on the difference between health expectations and health experiences. Patients with a chronic disease since childhood may have grown up with a lower perception of a life without disease than those who acquired a chronic disease at an adult age. Consequently, their lives would probably meet their expectations more, despite their physical disabilities. The results of Fujisawa et al. [3] also indicate that mental health is related to expectations in life. To further explore this phenomenon, empirical research should be aimed at finding out how children cope with their chronic disease and to what extent different coping strategies in childhood may influence the quality of life in adulthood.

It is likely that the relatively strong mental health of patients with juvenile ESRD compensates for their physical impairment to some extent. Public awareness of this fact could enhance the chances of these patients finding a place in society.

**Limitations of the study**

Both the RAND-36 and the MOS SF-36 are widely used and validated measurements for quality of life assessment [18]. However, one of the problems reported in using these tools is the difficulty in comparing data of a diseased group with a general population, due to the left-skewed and unusual distribution. We tried to cope with this problem by dichotomizing all scores, and comparing the prevalence of scores below the 25th percentile, as proposed by Rose et al. [12]. By comparing this dichotomous method and the differences in means, it becomes clear that, for instance, the low mean values of Physical Functioning and Role Limitations due to Physical Health in all patients is determined by only a small percentage of patients with obviously very low values on these items. In the same way, one may conclude that Social Functioning is mildly impaired in transplanted patients. However, both methods indicate that mental health is generally intact in patients with ESRD from childhood.

We did not investigate the effect of dialysis adequacy on quality of life in the group of patients currently on dialysis, because this was beyond the scope of the study and since the group was too small. On the other hand, well-known risk factors of an impaired quality of life such as diabetes mellitus and obesity were absent [19], or counted only for a very small number of patients (other ethnicity) [20].

We could not obtain data for 52 of 187 living patients in our cohort. Therefore, our results may have been biased by the fact that a relatively healthy selection of the cohort had participated in the study. However, we did obtain data on these patients concerning the age of onset of ESRD, the primary disease, physical health and course of the disease, but we could not find differences in these items between non-participants and participants.

Inevitably, the dialysis patients of our cohort were more ‘experienced’ than the dialysis patients of the control group with adult onset of ESRD who were measured 1 year after onset of dialysis. One could argue that a prolonged duration of dialysis induces more adaptation to a new situation, and that the difference in quality of life that we found is no more than a logical result of this adaptation. However, Merkus et al. [4] showed that those adult dialysis patients in their study who were not transplanted did not adapt at all. On the contrary, the authors saw a decrease in quality of life over time in these patients. Therefore, we think that our results show that, compared with adults, children have a different way of coping with a chronic disease and that living with disabilities does not necessarily affect their mental quality of life in adulthood.

**Conclusions**

Except for mild impairments of social functioning and general health perceptions, transplanted patients with ESRD from childhood have a normal quality of life. In contrast to dialysis patients with adult onset of ESRD, adult dialysis patients with ESRD since childhood have a normal mental quality of life. Public knowledge of this fact might enhance their social careers.
Quality of life in childhood-onset ESRD is only partially impaired

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