Medical and psychosocial rehabilitation of young adults receiving renal replacement therapy since childhood: a single-centre experience

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Abstract. This study reviews medical and psychosocial rehabilitation of children and adolescents with end-stage renal disease (ESRD) and analyses data of young adults with ESRD from a single centre providing renal replacement therapy (RRT) for more than 20 years. Data from 30 patients, aged 25 ± 4 (18–34) years of receiving renal replacement therapy (RRT) since childhood were analysed. Medical and psychosocial rehabilitation were assessed by a medical questionnaire and by chart review. The sociological data were compared to an aged-matched control population (n = 26) with long-standing diabetes mellitus type I (DM) and to the available national demographic data. Seventeen patients were treated by dialysis (D) and 13 by transplantation (TPL). The duration of RRT was 13 (1–21) years. Growth failure was pronounced in most patients, and a significant number were suffering from hypertension, left ventricular hypertrophy, anaemia, osteodystrophy, hepatitis, and physical disabilities. Vocational training/school performance, and employment was not markedly different in patients with RRT and controls with DM. However, the type of employment was different with an overrepresentation of lower-income jobs in RRT patients. Most patients with RRT were unmarried and one-third was living with their parents. These data, largely reflecting early experience of a paediatric RRT programme, indicate that young adults receiving RRT from childhood have a multitude of medical and psychosocial problems, providing a continuing challenge for centres providing RRT.

Key words: children; renal replacement therapy; rehabilitation

Introduction

Comprehensive medical and psychosocial rehabilitation is the main goal of any treatment programme for patients with end-stage renal disease (ESRD). In children and adolescents with ESRD, medical problems with the exception of growth are in many ways similar to those encountered in adult patients. In contrast, psychosocial rehabilitation in young patients is an issue of special importance mainly because of (1) the long-term consequences of coping with the burdens of chronic illness in childhood, and (2) decisions regarding schooling, marriage, job training, and employment. Only few centres have published their experience concerning long-term rehabilitation of young adults who have received renal replacement therapy (RRT) since childhood [1–3]. The EDTA has recently published rehabilitation data obtained from 617 patients between the ages of 21 and 35 years [4,5] and the collected demographic information on over 8000 young RRT patients in Europe [6]. However, data from individual centres can provide important additional information obtained in a more homogeneous population.

We had the unique opportunity to collect data on medical and psychosocial rehabilitation from a single centre with over 20 years of experience with RRT in children. A programme for haemodialysis, peritoneal dialysis, and renal transplantation integrated with a psychosocial support team was initiated at the University Children’s Hospital of Cologne in 1972, being one of the earliest in Europe. In interpreting the data it must be remembered that these largely reflect a learning experience starting in the beginning years of paediatric RRT—and incorporating the advances in medical treatment achieved during the last two decades.

In estimating the quality of rehabilitation, the question of a meaningful comparison is bound to arise: while data concerning medical rehabilitation speaks for itself, sociological data (e.g. employment rates) seem far more complex and need to be evaluated more cautiously, especially if one considers the influence of economical (e.g. employment rates within a society) and psychological factors (e.g. coping with dwarfism). It seems appropriate to compare social rehabilitation to a control group of young individuals with chronic illness of similar duration [7]. We therefore collected information from a matched group of young adults with long-standing diabetes mellitus type I (DM) in
addition to the available national demographic statistics [8,9].

Patients

A total of 36 adult patients (minimum age 18 years at the time of survey) with ESRD could be identified retrospectively who had commenced treatment with any form of RRT at our institution before the age of 18 years. Patients were contacted by telephone and asked for written and informed consent to participate in the study. Interviews with patients were performed at home or at their dialysis centre. Data were also collected by chart review. No additional clinical investigations including blood sampling, radiological studies, or other tests were performed. Of the 36 patients identified, three had died, and three refused participation; thus 30 patients with RRT participated. Of these, 11 were still being treated in paediatric facilities and 19 in adult facilities; 17 patients were treated by dialysis (D) and 13 by transplantation (TPL). Among the patients on D, seven had had one previous TPL, three had been transplanted twice and one patient three times. Nine patients with functioning transplant had their first TPL, and four their second.

Medical rehabilitation was assessed by a catalogue of clinical parameters including the most common complications of long-term dialysis. Social rehabilitation was estimated by evaluating schooling and educational training, professional training and employment, living conditions and marital status. The sociological data was compared to the available national demographic data concerning normal adults of similar age [8,9] and to patients with DM (since childhood, with a similar duration of chronic disease) who were treated in the Düsseldorfer Diabetes Institute, located in the proximity of our institution. A total of 32 patients could be identified and 26 consented to participate (Table 1).

Methods

Height was expressed in standard deviation scores (SDS) of normal children, and height was also reported as the difference (in cm) compared to the 3rd percentile of healthy children. Data for normal German children were taken from the Zürich Longitudinal Growth Study [10] and for Turkish children (n = 5; 17%) from published percentiles [11]. Hypertension was defined as a blood pressure above 140/90 and/or treatment with antihypertensive medication.

Left ventricular hypertrophy was diagnosed from electrocardiography or echocardiography or both. Renal anaemia was defined as a haemoglobin level of less than 10 g/dl and/or treatment with erythropoietin. The presence of renal osteodystrophy was assumed if elevated PTH-levels and/or medication with phosphate binding agents were recorded. The diagnosis of hepatitis B and C was assumed if Hbs-Ag and/or anti-HCV antibody respectively were found. Antibodies against HCV were determined by a second-generation assay.

Statistical evaluation of overall differences between the two groups (RRT and DM patients) was performed by Fisher’s exact test (two-tail).

Results

Growth failure was the most obvious problem in the RRT population: the median height achieved was −3.1 SDS of normal children, or expressed differently, averaged 6 cm less than the 3rd percentile of healthy children (Table 1). In addition, hypertension, LVH, anaemia, osteodystrophy, and hepatitis B and C were frequently encountered (Table 2). All patients had to take medications: less than five drugs were prescribed in eight dialysed and six transplanted patients and more than five drugs in seven dialysed and seven transplanted patients (missing data in two cases).

Disabilities could be identified from chart review with certainty in a total of 11 (37%) patients: five patients with RRT (16%) had ophthalmological problems (complete or partial blindness) due to steroid-induced cataract (n = 3), retinal bleeding and cystin-crystal deposits in the cornea (n = 2). Six patients (20%) had otological problems, including complete or partial deafness (n = 6) with additional tinnitus in two patients. Aseptic femoral head necrosis was recorded in two patients. Two patients had more than one disability: One had aseptic femoral head necrosis, muscular contractures and hearing loss, the other one had blindness and hearing loss.

Table 1. Patient and controls data

<table>
<thead>
<tr>
<th></th>
<th>Patients dialysis (n=17)</th>
<th>Patients transplant (n=13)</th>
<th>Controls DM (n=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>26 (20–34)</td>
<td>24 (18–31)</td>
<td>27 (16–39)</td>
</tr>
<tr>
<td>Male/Female (n)</td>
<td>7/10</td>
<td>8/5</td>
<td>13/13</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>44 (34–57)</td>
<td>54 (44–109)</td>
<td></td>
</tr>
<tr>
<td>Height (cm)</td>
<td>148 (128–169)</td>
<td>157 (149–179)</td>
<td></td>
</tr>
<tr>
<td>Age at start of RRT (years)</td>
<td>13 (7–18)</td>
<td>15 (8–20)</td>
<td></td>
</tr>
<tr>
<td>Duration of RRT/DM (y)</td>
<td>15 (4–20)</td>
<td>10 (1–21)</td>
<td>15 (6–29)</td>
</tr>
<tr>
<td>GFR (ml/min per 1.73 m²)</td>
<td>7 (8–11)</td>
<td>75 (11–109)</td>
<td></td>
</tr>
<tr>
<td>Height SDS (without Turkish patients)</td>
<td>−3.1 (−6.0 to 0.4)</td>
<td>−1.7 (−3.6 to 0.1)</td>
<td></td>
</tr>
<tr>
<td>Height, difference (cm)</td>
<td>−6 (−24 to +10)</td>
<td>−0.2 (−14 to +13)</td>
<td></td>
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</tbody>
</table>

RRT, renal replacement therapy; DM, diabetes mellitus; GFR, glomerular filtration rate; SDS, standard deviation scores. Values are given as median and range.
Table 2. Medical problems in young adults with RRT since childhood

<table>
<thead>
<tr>
<th>Problem</th>
<th>Dialysis (n) total n = 17</th>
<th>Transplantation (n) total n = 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth failure</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Underweight</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Hypertension</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>LVH</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Anaemia (Hb &lt; 10 g%)</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Treatment with Epo</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Osteodystrophy</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Disability (n = 11*)</td>
<td>5 visual</td>
<td>6 hearing</td>
</tr>
<tr>
<td></td>
<td>2 walking</td>
<td>1 movement (muscular contractures)</td>
</tr>
</tbody>
</table>

Growth failure and underweight were assumed if weight and height respectively were below the third percentile of normal. LVH, left ventricular hypertrophy; Epo, recombinant human erythropoietin.

*More than one disability in two patients (one with two, one with three disabilities).

The social rehabilitation of young adults with RRT was characterized by ‘normal’ educational achievements (compared to DM patients); school attendance (P = 0.52), job training and employment rates (P = 0.15) were similar in both groups (Tables 3, 4). However, RRT patients had different types of employment compared to DM patients (P = 0.01), with most of them belonging to low-income groups, e.g. low-ranking employees (Table 5).

Significant differences between these two groups of young adults could also be observed with respect to living conditions (P = 0.008) and marital status (P = 0.04); RRT patients were frequently unmarried and living with their parents (Table 6).

Discussion

This single-centre experience indicates that young adults with a history of ESRD dating from childhood have a multitude of medical problems, with growth failure being the most obvious. About half of our patients also had a weight below the 3rd percentile, but no further data on anthropometric measurements like skinfold thickness etc. were obtained which would have been helpful for better assessment of nutritional status. However, one of the requirements of the present study was to avoid any additional clinical investigation. This decision was made on principal grounds but was also facilitated by the frank refusal of some of the patients to cooperate with any additional medical procedures.

Morbidity was high, which is also reflected by the amount of medication prescribed. The presence of hypertension and LVH are ominous findings in young RRT patients, indicating the need for more aggressive antihypertensive therapy.

Hepatitis C-virus mRNA was not measured and serum transaminase levels were not determined regularly in most of the patients; thus we have no information regarding chronic disease activity. However, at

Table 3. Schooling achievements*

<table>
<thead>
<tr>
<th>Degree of schooling completed or attending at time of study</th>
<th>RRT n = 30 (%)</th>
<th>DM n = 26 (%)</th>
<th>% National population**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary school</td>
<td>10 (33)</td>
<td>7 (27)</td>
<td>56</td>
</tr>
<tr>
<td>Secondary school</td>
<td>10 (33)</td>
<td>12 (46)</td>
<td>14</td>
</tr>
<tr>
<td>Gymnasium</td>
<td>4 (13)</td>
<td>1 (4)</td>
<td>26</td>
</tr>
<tr>
<td>University</td>
<td>2 (7)</td>
<td>4 (15)</td>
<td></td>
</tr>
<tr>
<td>No data</td>
<td>4 (13)</td>
<td>2 (8)</td>
<td></td>
</tr>
</tbody>
</table>

*According to [9]. **According to national demographic data 1991 [8].
higher than in others and that one frequently cited in view of the small sample size in the subgroups. The statistical comparison should be viewed with caution.

15–35 years, according to [11]. That young adults receiving RRT in childhood have a calculated median percentages of males (m) and females (f) aged. In summary, our single-centre experience indicates that young adults starting RRT in childhood seem to be affected. However, it appears that at the ‘child–adult interface’ of medical and psychosocial problems. Interpretation of the data is limited by the fact that different time periods with respect to the development of medical treatment are covered by this report. However, it is difficult to evaluate the psychological burdens of chronic illness it is remarkable that a better than expected psychiatric adjustment has been reported in studies of patients with RRT [12] and in adults grown up with chronic illness [13,14].

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As for social rehabilitation, the data indicate that more favourable results. Besides being the background achievement was comparable in patients with RRT and in patients with DM. However, the employment data for future comparisons, the present data indicate the type of schooling as well as the educational level and the present state of knowledge it can be assumed that seropositivity for HCV antibody indicates chronic active disease. Patients frequently underestimated the degree of disability in interviews and in the the medical questionnaire. For instance, one patient could hardly walk and refused to admit so in the questionnaire. In the EDTA report [4], 20% of young adults had one disability and another 11% had more than one. In a study involving five paediatric centres, 71% had no disabilities [1]. Therefore about 20–30% of young adults starting RRT in childhood seem to be affected by disabilities. The fact that self-reporting and assessment of disabilities by physicians are at variance has been similarly observed in other studies [3].

As for social rehabilitation, the data indicate that the type of schooling as well as the educational level achieved was comparable in patients with RRT and in patients with DM. However, the employment data show that at least six patients with RRT (results of 4 were missing) and only one with DM were without a job at the time of investigation; therefore the unemployment rate in RRT patients is at least 20% compared to only 4% in the group with diabetes. The statistical comparison should be viewed with caution in view of the small sample size in the subgroups. The comparison with the EDTA data shows that unemployment rates in some European countries are much higher than in others and that one frequently cited reason for unemployment is ‘lack of training’ [4]; however, lack of training seems to be hardly a causative factor in the patients included in the present study.

Of even greater interest is the type of employment. It is apparent that most of the RRT patients were in lower-ranking employment status and that employment was much more diversified in diabetic patients. Therefore, while almost half of the RRT patients were employed on a regular basis, most of them worked in lower-income jobs, thus differing from DM patients in spite of similar schooling achievements.

There were striking differences in marital status and living conditions of these patients. Thus, one third of the RRT patients (but only about one fifth of the DM patients) were living with their parents and only 23% of patients with RRT (compared to 65% with DM) were living with a partner. The EDTA data shows similar results, with only 35% of patients being married and 61% living at home [5]. Similar experience in transplanted patients has been reported in another single-centre study [2] and in a study including five paediatric centres [1]. It is thus obvious that chronic disease takes a heavy toll on the afflicted patients both in terms of medical complications and psychosocial consequences. Although it is difficult to evaluate the psychological burdens of chronic illness it is remarkable that a better than expected psychiatric adjustment has been reported in studies of patients with RRT [12] and in adults grown up with chronic illness [13,14].

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