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Registry Report

Rehabilitation of young adults during renal replacement therapy in Europe

1. The presence of disabilities

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Abstract. The aim of this study was to analyse rehabilitation during RRT in 617 young adults from different European countries who started dialysis or transplantation before the age of 15 years. The data were derived from the EDTA Registry patient data files and a special questionnaire that was sent to centres reporting to the EDTA Registry. The duration of RRT was more than 10 years in 63% of patients. Fifty-four percent were living with a functioning graft and 46% were on dialysis. The prevalence and severity of motor, hearing, sight, and mental disabilities were analysed retrospectively. They were found to vary according to primary renal disease and method of treatment. One-third of patients had one or more disabilities at the start of RRT. Although disability status had changed in many patients by 31 December 1986, some disability remained in one-third of the patients available for study. Disabilities were recorded as mild in the majority of patients. Both improvement and worsening of motor and mental disability occurred more often than changes of hearing capacity and sight. It is concluded that prevention and treatment of disabilities need special attention in children and young adults on RRT in order to improve rehabilitation.

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Key words: dialysis; transplantation; rehabilitation; disabilities

Introduction

Results of renal replacement therapy have been improving continuously, and are demonstrated readily by survival on maintenance dialysis and after renal transplantation [1]. However, data on the degree of rehabilitation achieved and on 'quality of life' are scarce and much more difficult to obtain [2]. Physical disabilities and psychosocial problems are of particular importance for those patients who reach end-stage renal failure (ESRF) whilst still at a paediatric age when schooling, social integration, and personality development are at a critical stage. With this in mind, the EDTA Registration Committee undertook a study of rehabilitation in patients from different European countries who were aged over 21 on 31 December 1986 and had started RRT before the age of 15.

Information on disabilities, schooling, employment, and social situation was requested and preliminary results have been reported at the EDTA Congresses in Berlin, Madrid and Gothenburg [3,4]. This first of two reports describes the study group of 617 patients and summarizes the presence of disabilities associated with the various primary renal diseases or which were acquired during renal replacement therapy.

Subjects and methods

A special questionnaire was designed to record data on individual patients who had been reported to the EDTA Registry. The patients to be studied were selected from the EDTA Registry's data file on the basis that they had started RRT before the age of 15 years and were aged over 20 and alive on 31 December 1985. The methods used for the continuing updating of the Registry database have been reported elsewhere [5]. In summary, individual patient questionnaires are collected on a yearly basis from all the centres taking care of the patients with ESRF known to the Registry. The data requested include information on primary renal disease, methods of treatment as a coded and dated sequence, date and cause of death, etc. The special questionnaire was designed to record, retrospectively, the presence or absence of motor, hearing, sight, and mental disabilities, both at the start of RRT and on 31 December 1986. Disabilities had to be graded as minor, moderate, or severe. In addition, information on schooling, employment and the social situation was requested, the results of which will be described in the following paper.

Early in 1987 these special questionnaires were mailed for 948 patients residing in different European countries. By June 1988, 701 (74%) were returned by the centres, and of these 617 (65%) were suitable for analysis. Reasons for excluding questionnaires from analysis were death of the patient and transfers to other centres or countries. The data of the special questionnaire for the study population of 617 patients were linked to the Registry's main patient file for analysis.

Results

Patient population

The age and sex distribution is shown in Figure 1. There were 293 males and an identical number of females, whilst the sex was not recorded for 31 patients. The majority (64%) were aged 21 to less than 25 years. The duration of RRT (Figure 2) varied between 6 and over 20 years, with 63% of patients having spent more than 10 years on RRT. Age at start of RRT was 11–15 years in over 80% of the patients reported from most countries, and the majority (65%) lived in France, the Federal Republic of Germany, the UK, and Italy (Figure 3). The distribution of primary renal diseases in the study population is shown in Figure 4. The proportion of patients with glomerulonephritis and of those with pyelonephritis/-interstitial nephritis was slightly higher than in the paediatric population starting renal replacement therapy between 1981 and 1985 [6].

Method of treatment

The method of treatment at the time of the survey (end of 1986) was a functioning transplant in 54%,

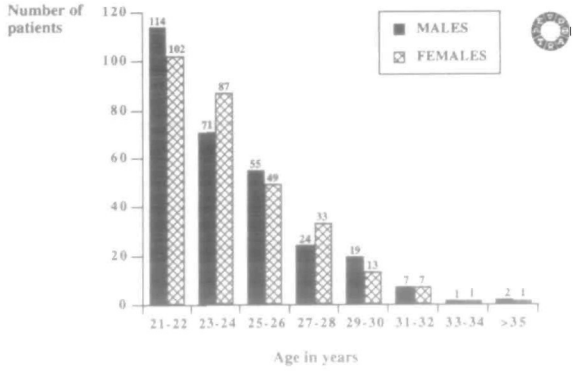

Fig. 1. Age and sex distribution.

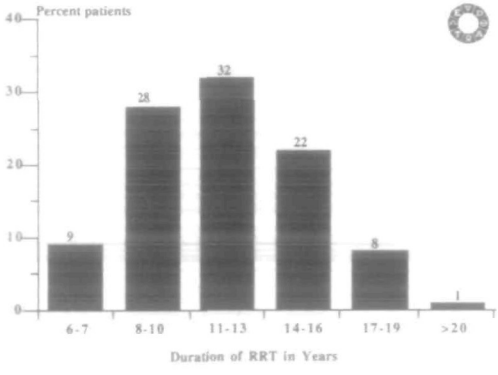

Fig. 2. Duration of RRT.

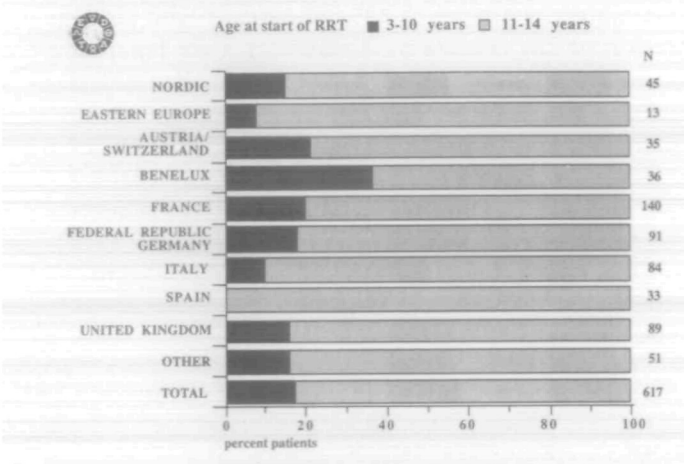

Fig. 3. Geographical distribution of patients and age at first RRT.

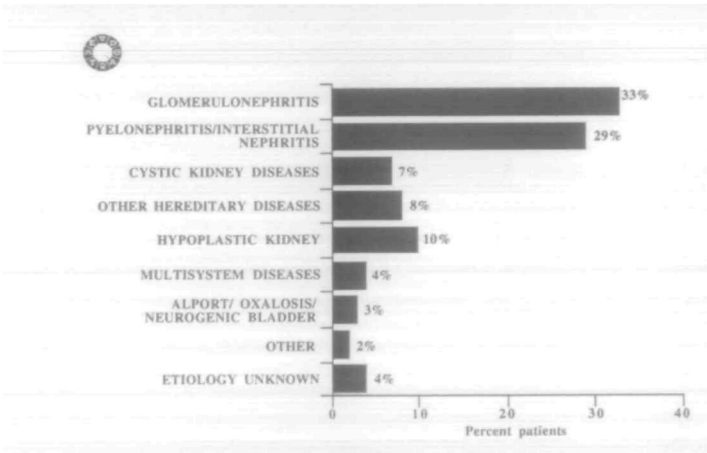

Fig. 4. Proportion of patients according to different primary renal diseases. 'Pyelonephritis/interstitial nephritis' includes patients with obstructive nephropathy, reflux nephropathy, and urolithiasis. 'Cystic diseases' include polycystic kidneys and medullary cystic disease. 'Other hereditary diseases' include cystinosis, Fabry's disease etc. 'Multisystem diseases' include diabetic nephropathy, lupus erythematosus, Henoch–Schönlein purpura, Goodpasture's syndrome, and haemolytic uraemic syndrome.

centre haemodialysis in 37%, home haemodialysis in 7%, and peritoneal dialysis in 2%. The vast majority (85%) of patients had been transplanted at least once, whilst 15% had always been on dialysis. Treatment changes such as change to haemodialysis when CAPD or a graft were failing, or retransplantation, are common in the career of patients on RRT. Nevertheless, no more than three treatment changes were recorded in 78% of patients, whilst 19% had four to six changes and only 3% underwent more than six changes of the method of treatment. Not surprisingly, the number of treatment changes was particularly high in patients with a functioning regraft or who had gone back to dialysis after a failed regraft (Figure 5).

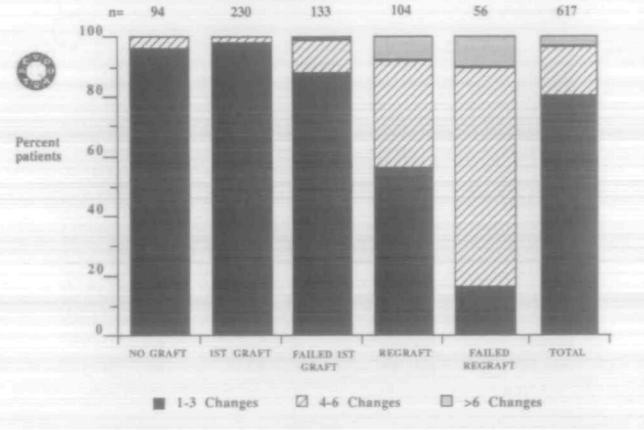

Fig. 5. Number of treatment changes according to last method of treatment. Patients may be alive with functioning graft ('first graft' or 'regraft') or without having been grafted ('no graft') or after graft failure ('failed first graft' or 'failed regraft').

Prevalence of disabilities

Information on four categories of disability, motor, visual, auditory, and mental were requested. At the start of renal replacement therapy, 20% of patients had one disability, 12% had two or more disabilities, whilst no disability was recorded for 68%. On 31 December 1986, the proportion of patients with disabilities was of the same order: 20% had one disability and 11% had more than one (Figure 6). The majority of disabilities were mild (Figure 7) with males and females being equally affected. Motor disabilities were found in 16% of patients at the start of treatment and in 15% on 31 December 1986. Similarly, the percentage with hearing or sight disabilities remained almost unchanged. The proportion of patients with mental disabilities declined from 16% to 12% between the start of treatment and December 1986. The presence and severity of disabilities did not correlate with the duration of RRT.

Severity of disabilities

Although the overall prevalence of disabilities was found to have changed little, there were considerable

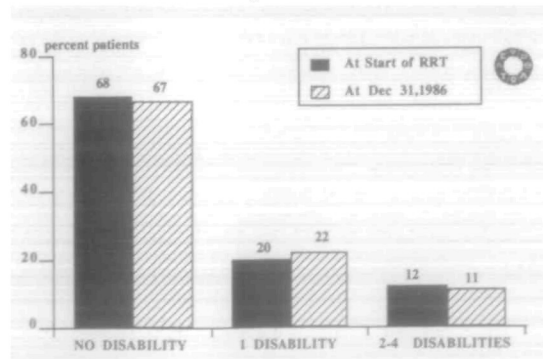

Fig. 6. Proportion of patients with zero, one, and two or more disabilities at the start of RRT and at 31 December 1986.

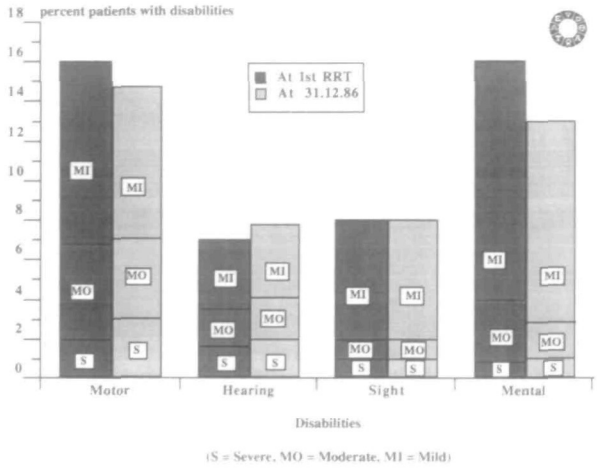

Fig. 7. Proportion of patients with various types of disabilities at start of RRT and at 31 December 1986. Disabilities were recorded as mild, moderate, or severe by the clinician in charge.

changes in the severity of the disabilities in many individuals between the start of RRT and 31 December 1986 (Table 1). Motor disability improved in 8.4% of patients and healed completely in 7.1%. However, motor disability worsened in 2.2% and developed anew in 5.9% who had been free of motor disabilities at the start of treatment. No change in the severity of motor disability was recorded for 5.3%, and the proportion of patients who were recorded not to suffer from a motor disability at both the start of RRT and the end of 1986 was 78.2%. Changes in hearing disabilities were less frequent and sight disabilities neither improved nor worsened in the 8.1% of patients so affected. Fortunately more patients showed an improvement in their mental situation than deteriorated mentally during RRT.

Primary renal diseases and method of treatment

Predictably, patients whose cause of ESRF was Alport's syndrome, oxalosis, or neurogenic bladder in contrast to patients with other primary renal diseases, were more often afflicted by disabilities. In patients with these diseases, 68% had one or more disabilities compared to 30% of patients with glomerulonephritis (Figure 8). Disabilities were reported to be less frequent in patients who were alive with a functioning first graft or a regraft, compared to dialysed patients (Figure 9). The proportion of patients with disabilities was 26% in the transplanted group, whereas it was 36–44% in the dialysed patients who had either never been grafted or who were alive on dialysis after a failed first graft or regraft. Geographical differences concerning the presence or absence of disabilities were negligible.

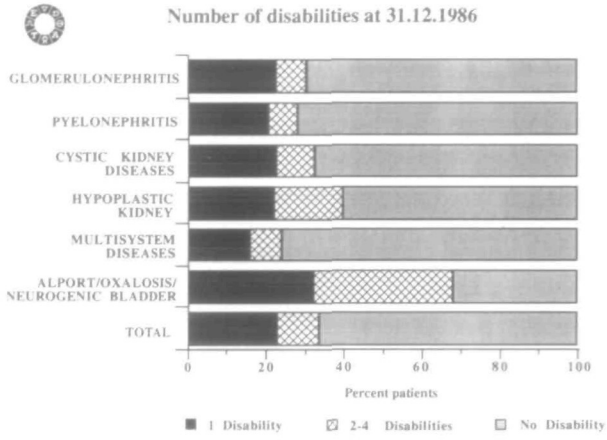

Fig. 8. Disabilities on 31 December 1986 according to primary renal disease.

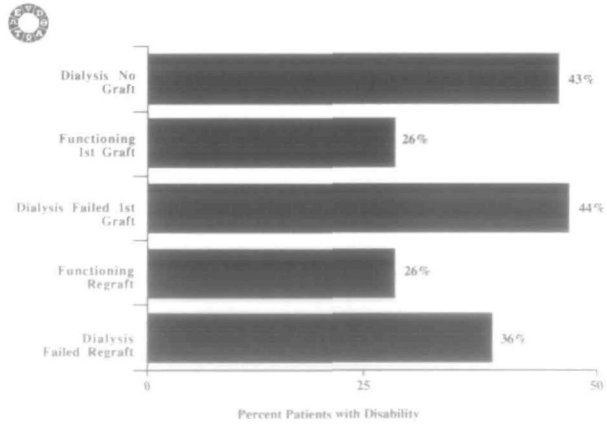

Fig. 9. Proportion of patients with one or more disabilities according to last method of treatment

Table 1. Change in severity of disabilities between start of RRT and December 1986

DISABILITY	Motor	Auditory	Mental	Visual
Worsened (%)	8.1	2.4	2.8	0
Unchanged (%)	5 3	5.0	8.6	8.1
Improved (%)	8.4	1.2	6.9	0
Not present at any time (%)	78.2	91 4	81 7	91.9

Discussion

Patient outcomes during RRT, including the quality of life, are affected not only by the treatment modality but also depend on many other factors including the type of primary renal disease as well as any 'comorbidity' which may be related or unrelated to the primary renal disease [7,8]. This study, which was retrospective and included many nephrological centres from different European countries, shows that ESRF was often associated with disabilities present during childhood and persisting during RRT into adult life. Thus the majority of disabilities in these young adults on RRT were reported as having been present already at the start of treatment before age 15. This clearly indicates that the maximum of effort to prevent or minimize disabilities needs to be made before the onset of severe renal failure.

Disabilities were recorded more frequently in patients with congenital or hereditary primary renal diseases and less frequently with acquired renal diseases such as the glomerulopathies and systemic nephropathies. Hearing or sight are regularly affected in Alport's syndrome, and motor function may be compromised due to bone and joint disease in oxalosis, or neurogenic motor dysfunction in patients with neurogenic bladder. It is not unexpected, therefore, that patients whose cause of ESRF was Alport's syndrome, oxalosis, or neurogenic bladder would be more disabled. Reported data was entirely consistent with this expectation and 68% of those patients had one or more disabilities. Nevertheless, the limitations of the study design have to be taken into account. For practical reasons the definition of disabilities was kept short and it was left to the medical persons in charge of the patient to make the judgement on the severity of disabilities.

Physical and mental disability may accompany all stages of chronic renal failure in children. Before RRT, patients show a high incidence of uraemic problems such as growth failure and fatigue. Dialysis therapy is not curative and patients often continue to suffer from one or several symptoms, e.g. bone pain, recurrent nausea, intermittent weakness, fatigue, or depression [9]. Disabilities may develop also in recipients of renal grafts and may limit the extent of rehabilitation. In these patients disabilities relate largely to immunosuppression. The side-effects of corticosteroids such as muscle wasting, cataracts, and aseptic necrosis of the bone may substantially impair the physical activity in patients who have had a graft for more than 10 years [10]. In the present study, the occurrence of disabilities was investigated in young adults who started RRT as children. This excluded a variety of factors which affect rehabilitation in older populations with a large proportion of diabetic patients and disability due to cardiovascular disease [11]. With less than 1%, diabetic nephropathy was a negligible cause of ESRF in the present study group. Although some of these young adults may have suffered from cardiovascular disease, this is likely to have played a minor role compared to that seen in older populations [12].

After having spent more than 10 years on RRT, the frequency of disabilities in patients of the whole study group did not differ greatly from that at the start of therapy. However, only visual disabilities remained unaltered. Thus in young adults who started RRT as children, effective vision did not seem to be affected by RRT, whilst little can be done to improve visual disability present beforehand.

Motor dysfunction, in contrast to visual disability, changed in 76% of patients during the period of RRT. Motor function improved in 39% and close to one-third of these were reported to have recovered completely. A deterioration of motor function was reported in 37% of patients and one-fifth of these developed motor disabilities only after starting RRT. It is likely, therefore, that more could be done to improve motor disabilities that were already present at the start of RRT as well as to prevent new motor disabilities from developing during RRT. For reasons of practicality no detailed information was sought as to the type and pathogenesis of motor disabilities. It can therefore not be clarified to what extent the dysfunction was due to either the underlying disease, to the uraemic status, or due to side-effects of treatment. Similarly, the causes of the improvement of motor function, e.g. healing of renal osteodystrophy, could not be specified.

Forty-two percent of patients with hearing deficiency were considered to have experienced a change in the degree of disability. Two-thirds of these showed a deterioration in hearing function, with one-third showing an improvement. Whereas a worsening of hearing capacity during RRT can be explained by the underlying disease, e.g. Alport's syndrome or ototoxic agents, the causes of hearing improvement remained unclear.

Eighteen percent of patients were considered to have a mental disability, either at the start of treatment or by 31 December 1986. Of patients with a mental disability, 15% were reported to develop the mental disturbance during RRT. However, in 38% of patients with a mental disability at the start of RRT, clinicians reported improvement during RRT with 21% of these showing a complete recovery. It would be tempting to suggest that psychological support given to a young patient on RRT may play a part in improving the mental situation.

As was already shown in other age groups [13,14], disabilities were less frequent in patients with a successful renal transplant than in those undergoing maintenance dialysis. The proportion of disabled

patients was not only lower in those living with a successful first graft but also in patients with a functioning regraft and who had experienced frequent treatment changes during RRT. Carlson *et al.* [8] have pointed out that a high rehabilitation potential is one of the factors considered when selecting patients for transplantation. Data on the selection of patients for transplantation are not available in the EDTA Registry database. However, it is most unlikely that selection of patients was a major cause for the higher rate of disabilities in dialysed patients because both grafted and regrafted patients showed disabilities less frequently than patients being on dialysis for the first time or back on dialysis after a failed graft or regraft. The higher percentage of patients with disabilities in the dialysis group seems to be due to the more frequent occurrence of new disabilities. In contrast, the patients with a functioning transplant had an improvement in their disability status.

The data from this retrospective multicentre survey must be viewed with caution since they were collected in a descriptive venture that allowed only a restricted specification of disabilities. A limitation of this study is that the patients themselves could not be asked how they judged their disabilities. Strauch *et al.* [9] reported that only a quarter of adult patients on RRT assessed themselves as healthy although the clinicians had observed an improvement of physical well-being in two-thirds since start of RRT. The physician's assessment may thus be at variance with the patient's appraisal of his situation [15,16]. This is not borne out by the present study, which was intended to provide an assessment of specified disabilities among a large group of young adults on RRT. The data represent a broad base of information on patients of this age group living in different European countries. Overall the results suggest that 32% of patients on RRT aged 21–40 years, and who started treatment under 15 years old, have one or more disabilities which, although mild in the majority of patients, affected their rehabilitation. As was shown by other groups [17], rehabilitation potential is more limited in patients with a persistent physical disability.

The impact of disabilities on schooling, employment, and the social situation during RRT will be discussed in Part 2 of this study. It is obvious that special attention should be paid to the prevention and treatment of disabilities [18] in order to improve rehabilitation in patients with ESRF treated by dialysis and transplantation.

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