Nephrol Dial Transplant (1992) 7: 579–586

Nephrology Dialysis Transplantation

Registry Report

Rehabilitation of young adults during renal replacement therapy in Europe

2. Schooling, employment, and social situation

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Abstract. The educational status, employment rate and social situation were studied in 617 patients between 21 and 35 years of age who started renal replacement therapy (RRT) as children. The data were derived from a special questionnaire concerning disability and rehabilitation sent to dialysis and transplant centres reporting to the EDTA Registry. Fifty-six percent of patients completed secondary school and one in three went on to vocational training. Eleven percent of patients attended university, and 16% were reported to have gone to a special school for the handicapped. Up to one-third of patients who attended different school types failed to complete their education. There were notable geographical differences in schooling and in employment. Fifty-six percent of all patients were employed. Lack of schooling was considered to be a major reason for unemployment. Sixty-one percent of patients with disabilities and 34% without disabilities were receiving invalidity payments. The place of residence of these patients aged 21–35 was usually the parental home. Compared to the general population of similar age, only a few patients were married (13.5% of the total study group) and 8% had children. In summary, the present report shows that the major factors influencing rehabilitation on RRT are the

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Key words: Dialysis; transplantation; rehabilitation; employment; schooling

presence of disabilities, the method of treatment, geographical factors, duration of RRT, and the underlying primary renal disease.

Introduction

The EDTA Registry holds data on some 150 000 patients who were alive on renal replacement therapy at the end of 1988 [1]. Analyses of the outcome of dialysis and transplantation focusing on survival and other clinical parameters have been published regularly in the Combined Reports [2,3]. An equally important issue is the degree of rehabilitation, which depends on the control of physical and mental disabilities and can be estimated from the schooling, employment status, and social integration of patients. This was the subject of a study conducted by the EDTA Registry concerning young adults alive on RRT at the end of 1986, who had started RRT as children [2,3]. In a first report, the presence and evolution of disabilities was described [4]. This second report analyses schooling, employment, and social status in these young adults from different parts of Europe.

Subjects and methods

Data for this study were obtained by a survey of 617 young adults on RRT from different dialysis and transplantation centres throughout Europe. The methods used for analysis of data reported to the EDTA Registry have already been reported [5], and data on clinical status and disabilities were published in part 1 [4]. Information on schooling, employment, and social situation were collected by a special questionnaire. To account for national differences in types of schools the following categories were used: 'secondary school', 'university', 'special school', 'other forms of schooling'. 'Special schools' included schools for the handicapped. 'Other forms of schooling' included vocational training. Data for schooling for the normal population were unavailable for all countries. Employment status was ascertained by asking which of the following best characterized the current employment status: 'employed' ('normal work place' or 'sheltered work place'), 'unemployed'. Reasons for unemployment were specified. Information on invalidity or disability payments to patients were requested. Categories used for patients' domicile were: 'own home', 'parents home', 'institution', 'other domicile'. Further information on the social situation of the patients concerned the marital status.

Data on employment and marital status of patients with RRT were compared with that of the normal population in France, Federal Republic of Germany (FRG), United Kingdom, Italy and Spain in 1986. Reference values for age groups 20–24 years and 25–29 years were obtained from the Statistisches Bundesamt, Wiesbaden, FRG.

Results

Schooling

Schooling of patients on RRT is summarized in Table 1. Although some patients attended secondary school until the age of 24 years, 41% of the study group never attended, or failed to complete, secondary school. Sixteen percent of patients attended a special school for handicapped or disabled children, in some instances until the age of 28. One-third undertook vocational training and some of these patients had further education until 30 years of age. Eleven percent of the study population went to university. The proportion of patients who attended university increased with age and reached 17% in patients aged over 28 years. Twenty-one percent to 33% of patients who attended different school types or universities failed to complete their education.

There were notable geographical differences in schooling. Special schools were attended more often in France (25%) and FRG (24%) than in Nordic countries (7%) and Italy (3%). Other schooling, including vocational training, was offered to patients on RRT in Spain, France and FRG more often than in other countries. Attendance at university of young adults on RRT was especially high in the Benelux countries, Austria and Switzerland (16%); it was less frequent in Nordic countries (13%), France (11%), the United Kingdom (7%) and FRG (5%).

Employment

Fifty-eight percent of all patients were reported to be employed. Sex had no major influence on employment rate in the study group as a whole. However, there

Table 1. Educational level achieved by the total study group

	Attended, completed (%)	Still attending (%)	Attended, not completed (%)	Never attended (%)
Secondary school	56	3	27	14
University	5	3	3	89
Special school	11	1	4	84
Other form of schooling	19	7	7	67

were marked geographical differences. In the United Kingdom 73% of the patients without specific disabilities were employed; in Spain this proportion was 38% (Figure 1). In each country, the proportion of all patients (with and without disabilities) employed was considerably lower in patients on RRT in 1986 than in the normal population (Figure 2); for example, in Spain 73% of males and 83% of females on RRT who were 21–24 years old were unemployed compared to 42% and 47% in the normal population of similar age. The proportion of unemployed patients was especially high in those who had one or more disabilities and who were treated with dialysis (Figure 3). Unemployment was lower in the patients without disabilities and in those with a functioning first graft or regraft. One of the major reasons for unemployment in these 21–35-year-old patients, with or without disabilities, was a 'lack of training' (Figure 4). Even though the clinicians in charge did not record specific disabilities, physical and mental reasons for unemployment were given in up to 10% of their patients without such disabilities. For patients with one or more specified disabilities, physical or

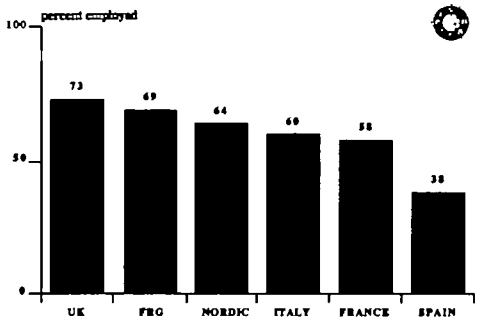

Fig. 1. Proportion of patients without disabilities employed on 31 December 1986, shown for selected countries (Nordic countries include Denmark, Finland, Norway, and Sweden).

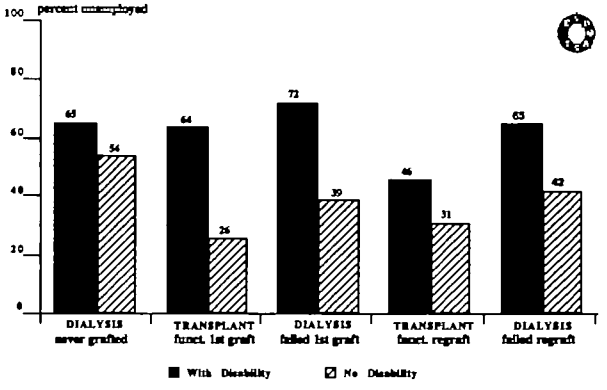

Fig. 3. Proportion of unemployed patients according to presence or absence of disabilities and according to current method of treatment.

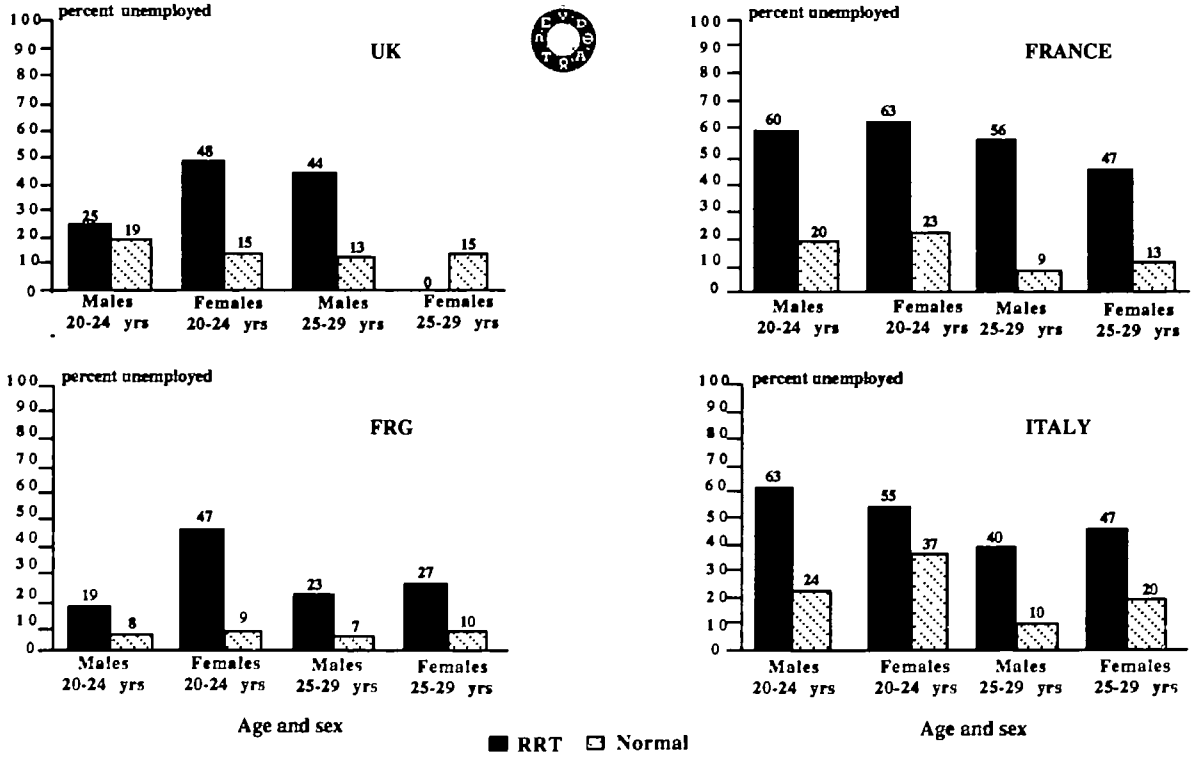

Fig. 2. Proportion unemployed comparing the study group (RRT) to the general population (normal) according to age groups and sex (patients with and without disabilities included).

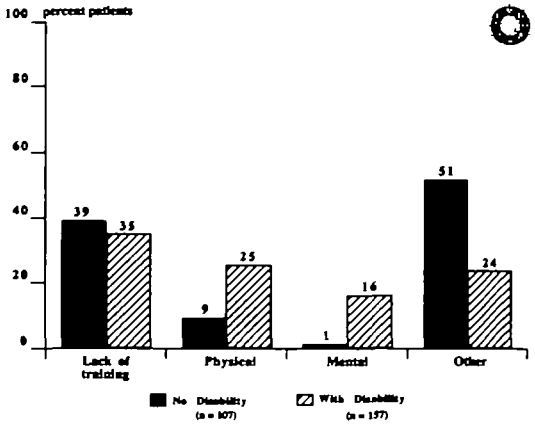

Fig. 4. Reasons given for unemployment in 264 patients with and without disabilities.

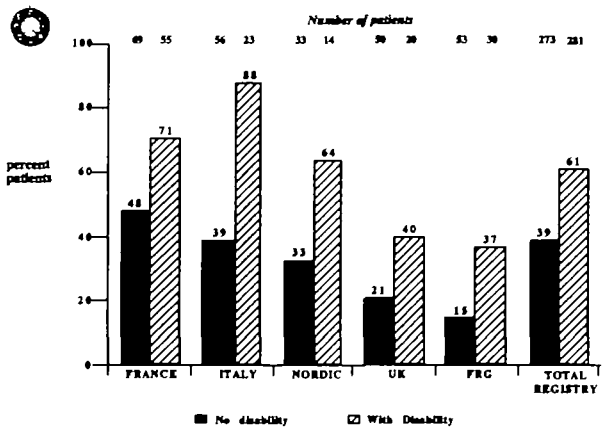

Fig. 6. Proportion of patients receiving invalidity/disability payment, shown for selected countries and the total Registry, and according to presence or absence of disabilities

mental reasons for unemployment were stated in 41% of cases. Other reasons recorded for unemployment were 'housekeeping', 'lack of suitable work', 'receiving training', 'no desire to work' and 'over-protection by parents'.

Sheltered working place and disability payments

Of those who were employed, a sheltered place of work was more often supplied for patients with disabilities (21%) than without disabilities (7%). The proportion of young adults who were employed normally, excluding those with a sheltered place of work, increased with the duration of RRT and with age (Figure 5).

Invalidity or disability payment was received by patients with specified disabilities more often than by patients without disabilities (Figure 6). Financial support of this kind was provided to French or Italian patients more often than to English or German patients.

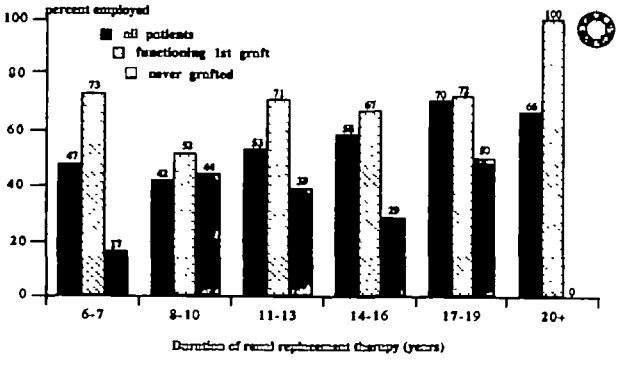

Fig. 5. Proportion of patients with a normal work place according to duration of RRT.

Place of residence

The parental home was reported to be the place of residence for 61% of patients (Figure 7). Thirty-four percent lived in their own homes and 3% lived in institutions. More females (43%) than males (31%) and more patients with a functioning graft compared to those on dialysis lived in their own homes. Disabilities affected the place of residence to a small extent; only 5% of patients with specified disabilities lived in an institution (Figure 8). The proportion of patients living with their parents varied between 38 and 83% in the different European countries (Figure 9). With increasing age the patients gained independence. After a period of 6 years of RRT 23% of patients lived in their own home and, after 18 years, the proportion had risen to 67%.

Marital status

In December 1986, 14.5% of these young adults on RRT were either 'married, 'divorced' or 'widowed'

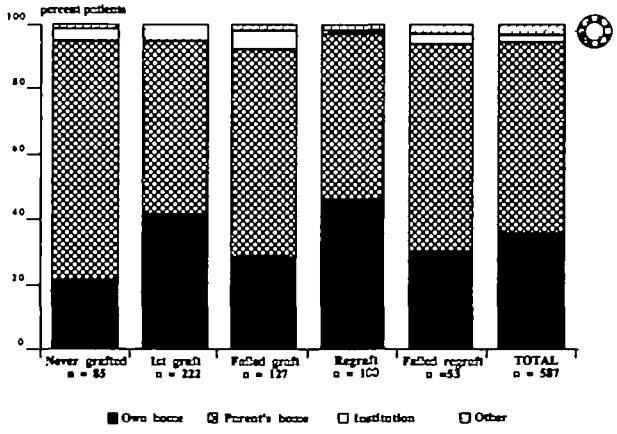

Fig. 7. Domicile of patients according to method of treatment.

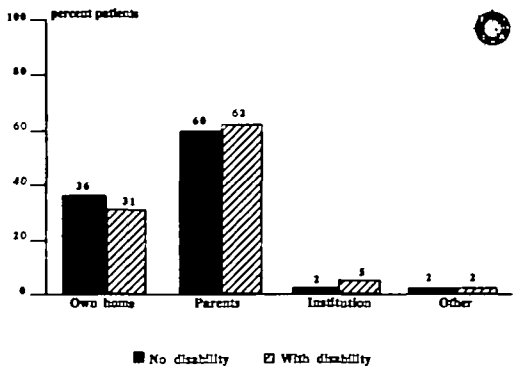

Fig. 8. Place of residence of 560 patients according to presence of absence of disabilities.

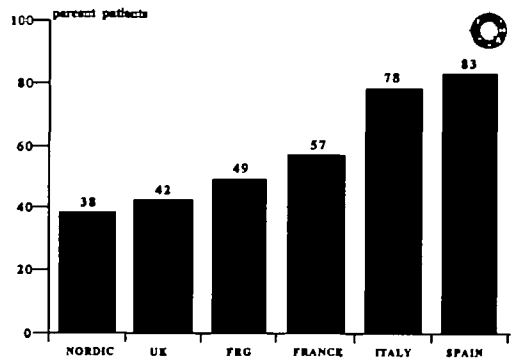

Fig. 9. Proportion of patients living with their parents, shown for selected countries.

(Figure 10). Of patients who were aged 21–24 years, 13% of females were married and 4% of males; of those aged 25–29, 28% of females and 12% of males. Patients in southern Europe were less frequently married than those in central or northern Europe (Figure 11). The proportion of unmarried patients is shown in Figure 12 for the United Kingdom, France, and FRG, and is compared with the normal population in these countries. For example, in Spain none of the males and 11% of the females on RRT, who were 21–24 years old, were married compared to 81% and 59% in the normal population of similar age. Some 8% of patients on RRT had children.

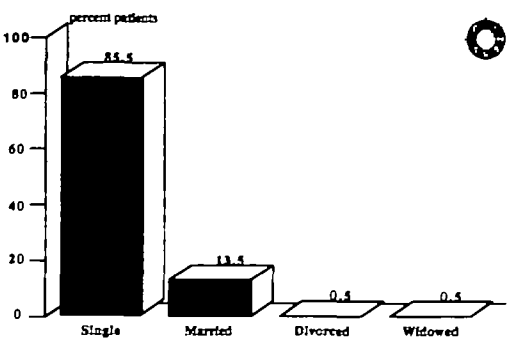

Fig. 10. Marital status of total study group.

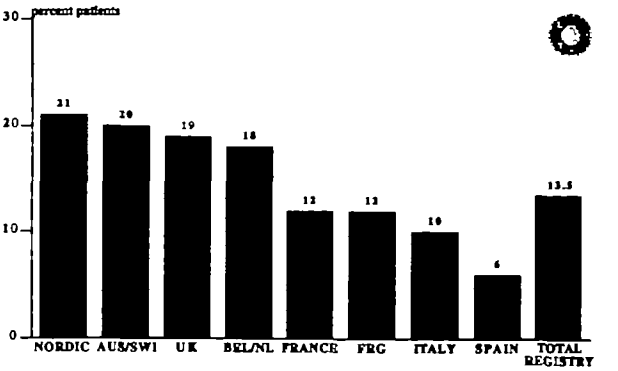

Fig. 11. Proportion of patients who were married. Data are shown for selected countries and for the total Registry.

Discussion

There are no studies which address comprehensively the social and psychological rehabilitation of children and adolescents who undergo RRT. Such studies are complex and time-consuming. Even in adults, therefore, attempts to assess rehabilitation and the quality of life are fraught with problems and have employed a number of differing methods to obtain an objective or subjective analysis [6–26]. The viewpoints have included those of the patient [6], the family [9], and the care-givers [10,11]. The methods applied were the semiquantitative Karnovsky scale [6,15], psychological measurement techniques [1,7,8,12], and questionnaires on vocational rehabilitation [7,9,13], social status, and emotional functioning [12–14]. Prospective and retrospective studies have been performed in single units or multiple centres [16,17]. Moreover, studies have compared subjective and objective indicators of the quality of life among patients receiving different forms of treatment: haemodialysis [11,14,18,19], continuous ambulatory peritoneal dialysis [20] and transplantation [21–23]. However, it was the conclusion of many studies that the majority of patients enjoy a better quality of life after transplantation than during dialysis [6,24–26]. Also, previous studies were mostly restricted to single countries, and due to the different methodologies and criteria used, few valid data are available on the geographical or racial differences concerning rehabilitation of patients on RRT [27]. Lastly, few studies have been able to investigate patients of selected age groups, such as childhood [28].

Against this background the present study, which encompasses the European population and has access to a unique, large group of patients, has been undertaken to determine how well these young adults were coping with the impact of their illness and its treatment. The aim was to investigate rather simple facts such as employment and social status that could be used as basic data for further studies.

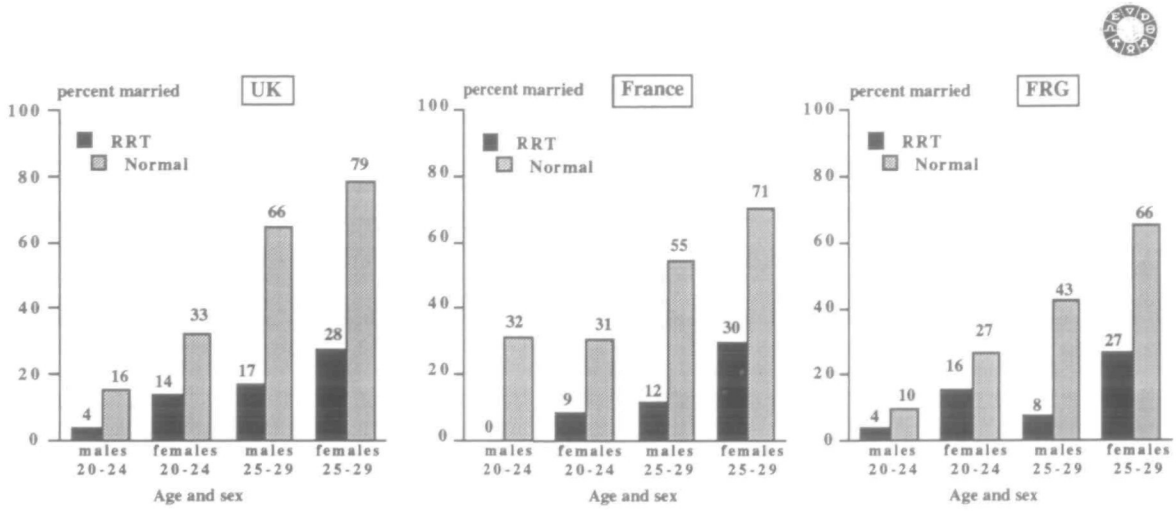

Fig. 12. Proportion married comparing the study group (RRT) to the general population (normal) according to age groups and sex

The study group of 617 young adults who had started RRT below age 15 was characterized in the previous paper, and it was shown that one-third of all patients were suffering from one or more disabilities [4]. Although the criteria for diagnosing disabilities may not be entirely comparable, the prevalence of disabilities is only 7% in the normal population of this age group in the United Kingdom [29]. With a higher prevalence of disabilities added to the time lost on dialysis and for clinic visits as well as hospitalization, it is not surprising that some 30% of patients on RRT who started secondary school or university did not complete their training. Furthermore, 16% of patients had to attend a special school for the handicapped. This confirms earlier reports that only 29% of dialysed and 51% of transplanted children were able to attend full-time schooling [27].

To assess the educational level from our questionnaire is difficult because the school systems vary between European countries and it is unknown what level of education the patients would have reached without renal failure. Nevertheless, there is little doubt that many of these young adults on RRT incurred sizable schooling deficits which would be expected to lead to a higher unemployment rate. Reported data was entirely consistent with this expectation and lack of training was reported to be one of the major reasons for unemployment.

The proportion of the patients who were employed was lower among dialysed patients than among those with a functioning graft. This continuing problem of high unemployment during dialysis also emerged from other studies [6,11,14]. Gutman *et al.* [11] found that, due to physical disability, 45% of dialysis patients were unable to perform activity beyond self-care. The present study underlines the important role of mental and physical disability for unemployment which was also shown by Hughson *et al.* [22] in transplanted patients. Unemployment was reported for a similar proportion of males and females despite the findings of Simmons *et al.* in the USA [17]. Previous studies have shown that employment was higher for patients in skilled professions than in jobs requiring heavier, physical labour [10,30]. The present study cannot give information on the influence of the job description on employment.

The increase of employment in patients who were older and had been on RRT for a longer period of time shows that coping strategies may improve and lead to better life satisfaction and self-esteem with more independence. The potential for employment appears to be especially high in recipients of a well functioning graft [10,23] and is correlated with a much greater sense of well-being in the transplant group [7,8].

Geographical differences of employment rates may reflect the overall employment situation of the normal population, e.g. unemployment both for patients on RRT and within the general population were higher in Spain and Italy than in northern European countries. High unemployment and the high proportion receiving invalidity payments are clearly linked in these countries. Furthermore, due to policies regarding invalidity payments, which may differ from country to country, patients might have been less motivated to seek and continue employment when financial support of this kind was offered to them. As stressed by Kaplan de Nour and Shanan [8], these data on unemployment indicate a need for improved vocational counselling for those under 30 years of age with special attention to the presence of physical disabilities and social integration before or during RRT [12,31].

Socioeconomic and community factors can influ-

ence patient rehabilitation during RRT [13] and this is especially true for the place of residence. In this group of young adults, the most common place of residence was the parental home. Patients in northern European countries lived more often on their own than those in southern Europe, and more females than males lived alone or with their married partner. The high proportion of patients in Spain may have been caused by a slightly younger age at study; however, the age distribution of Italian patients did not differ from that of other countries. A gain in independence was observed both in the transplanted group and also in dialysed patients with a longer duration of RRT and increasing age.

Quality of life also depends crucially on normal sexual relationships. Unfortunately, pubertal development is severely affected by ESRD during childhood [33] and, furthermore, sexual activity is often compromised in patients on dialysis [34]. This is likely to explain, at least in part, why the proportion of married patients on RRT was found to be much lower, particularly in males, than for the normal population as shown in Figure 12 for France, United Kingdom and FRG.

The present paper documents the major factors influencing the patients' physical, mental, social, and vocational rehabilitation potential, which are among others, the presence of disabilities, the method of treatment, geographical factors, duration of RRT, and the primary renal disease. Rehabilitation is considered to be a dynamic, interventional, and goal-orientated process, undertaken by doctors in co-operation with psychologists, physiotherapists and related professionals [29]. The present study does not answer the question to what extent the health care system has offered the patients the support and help they need and to what extent this might have contributed to alleviating their multiple handicaps. However, the data shows clearly that there is a need for help of this kind in addition to sustaining life on RRT.

Acknowledgements. The work of the EDTA Registry has been supported by grants from Governments and National Societies of Nephrology. Grants have also been made by the AKZO Group, Althin Medical AB, Asahi Medical Co. Ltd, B Braun Melsungen AG, Baxter Healthcare Corporation, Bellco SpA, Cobe International Ltd, Fresenius Ltd, Gambro AB, Hospal Ltd, and Sandoz AG. We thank all those doctors and their staff who have kindly completed EDTA Registry questionnaires, thus making the study possible. We also thank Lynne Saker for the preparation of this report.

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Received for publication 10.6.91
Accepted in revised form 3.12.91