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Original article

Psychosocial adjustment to end-stage renal failure: comparing haemodialysis, continuous ambulatory peritoneal dialysis and transplantation

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Abstract. Seventy-three children and adolescents in end-stage renal failure (ESRF) undergoing haemodialysis (n = 32), continuous ambulatory peritoneal dialysis (CAPD) (n = 28) or with a functioning transplant (n = 13), were assessed, with their parents, on adjustment to dialysis and psychological functioning. Quantitative assessment techniques were used; the three treatment groups were compared using the Mann-Whitney U test. Findings showed a number of advantages of transplantation over dialysis, and of CAPD over haemodialysis. Children with transplants suffered less functional impairment (P = 0.007), less social impairment (P = 0.001) and fewer practical difficulties associated with treatment (P = 0.000) than children undergoing dialysis. Parents of children with transplants also reported fewer practical difficulties than parents of children on dialysis (P = 0.002). Dialysis and transplant groups did not differ on children's or parents' reports of psychological stress associated with treatment, parents' reports of marital strain, children's and parents' levels of anxiety and depression or children's behavioural disturbance. Compared with children undergoing hospital haemodialysis, those using CAPD suffered less social impairment (P = 0.004), reported better adjustment to dialysis (P = 0.031) and fewer practical problems associated with treatment (P = 0.005), had lower depression scores (P = 0.054), and showed less behavioural disturbance (P = 0.013). Parents of children undergoing either CAPD or hospital haemodialysis reported similar practical difficulties, psychological stress or marital strain associated with treatment, but mean depression and anxiety scores were lower in the parents of children undergoing CAPD (P = 0.042 and P = 0.054). The findings have clear implications for clinical practice and may help to choose the most appropriate renal replacement therapy for children in ESRF.

Key words: Chronic kidney failure – Psychological adaptation – Haemodialysis – Peritoneal dialysis – Kidney transplant

Introduction

Currently, the types of renal replacement therapy most commonly used for children in end-stage renal failure (ESRF) are haemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and transplantation. On physical criteria the relative merits of these treatments have been established: while transplantation is almost always the first choice treatment, CAPD has a number of advantages over haemodialysis. These are in the areas of hypertension and anaemia control, management of diet and fluid intake, and avoidance of the dialysis disequilibrium syndrome [1]. It is often assumed that the relative merits of these treatments in terms of psychosocial adjustment of the children and their families, follow the same pattern. While this view may be backed by clinical experience, to our knowledge the assumption has never been empirically tested. Systematic research evidence of differences in psychosocial adjustment, and of the particular problems associated with particular therapies, would be useful not only in selecting the type of renal replacement therapy most suited to a patient's needs, but also in directing the provision of psychosocial support in paediatric dialysis centres.

This paper describes a multi-centre study in which 73 children and adolescents in ESRF, undergoing either haemodialysis, CAPD or with a functioning transplant, were assessed, with their parents, on adjustment to treatment and psychological functioning.

Patients and methods

Patients. Subjects included all children who were undergoing or commenced chronic haemodialysis or CAPD at either St. James's University Hospital, Leeds, Alder Hey Children's Hospital, Liverpool, or The Royal Hospital for Sick Children, Glasgow in the period between 1 October 1986 and 31 October 1988. Children on chronic dialysis who were attending Nottingham City Hospital or Glasgow Western Infirmary during 1988, and children with functioning kidney transplants who were at least 8 months post transplant and attending the Leeds centre during 1988, were also included in the study. Initially an informal approach was made to the child and/or parents during a haemodialysis session or an outpatient clinic. The purpose and methods of the research were explained

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Table 1. Age, dialysis centre and type of renal replacement therapy of patients

		Type of renal replacement therapy (n = 73)				
		CAPD (n = 28)	Hospital haemodialysis (n = 28)	Home haemodialysis (n = 4)	Transplant (n = 13)	Total
Age range (years)	2–6	6	1	0	0	7
	7–12	7	5	0	5	17
	13–18	12	18	4	8	42
	19–21	3	4	0	0	7
Dialysis centre	Leeds	17	5	3	13	38
	Liverpool	2	13	0	0	15
	Glasgow (Royal)	5	5	0	0	10
	Nottingham	0	2	0	0	2
	Glasgow (Western)	4	3	1	0	8

CAPD, Continuous ambulatory peritoneal dialysis

and agreement was sought for the researcher to visit and interview the patient and both parents (where applicable) at home. Only 1 patient refused to take part in the study. Four older adolescents preferred their parents to be excluded, and were interviewed alone in hospital; the parents of 2 adolescents were excluded for practical reasons. In the case of 6 families an interview could not be scheduled which was convenient for both the father and the researcher, in these cases only the mother and child were included in the study. All other patients and parents participated fully.

The final sample comprised 29 females and 44 males. Their age range was 2–21 years (mean 13.4, SD 4.50 years). Table 1 shows the patient age groups, dialysis centres and the type of renal replacement therapy. The family's economic status was rated on the basis of the mother's or father's occupation (in families with two parents working the higher status occupation was used). The rating categories used and (in parentheses) the numbers of families assigned to each were as follows: (1) (n = 5) top level professionals, managers and business people (equivalent to the Registrar General's social class I); (2) (n = 21) middle/ lower level professionals and managers, skilled workers and trades-people (equivalent to social classes II and III); (3) (n = 25) semi-skilled/unskilled workers/trades-people (equivalent to social classes IV and VI); and (4) (n = 22) unwaged. The age of children undergoing dialysis (n = 60) ranged from 1 to 19 years (mean 11.5, SD 4.94 years) at the start of dialysis. The time they had been undergoing dialysis ranged from 1 to 72 months (mean 19.1, SD 18.90 months). Fifteen had experienced more than one type of dialysis. Seven children undergoing hospital haemodialysis had previously used CAPD and 8 children using CAPD had previously used haemodialysis. Nine of the children on dialysis had had one kidney transplant which was no longer functional, and 2 children had had two kidney transplants which were no longer functional. Eleven children with a functioning transplant had had one transplant only, and 2 had had two transplants. The age at which the children had had their first transplant ranged from 6 to 15 years (mean 11.0, SD 3.06 years). The survival time of the current graft ranged from 8 to 40 months (mean 17.1, SD 9.80 months). The length of time spent on dialysis prior to the first transplant ranged from 3 to 54 months (mean 18.2, SD 13.50 months). The groups of children undergoing the different types of renal replacement therapy were similar with regard to sex and economic status; however, there were differences with regard to age and dialysis centre attended (Table 1). The different treatment groups were equivalent with respect to the proportion of children not living with two natural parents (around 35%), however, a larger proportion of children using CAPD lived with single parents while a larger proportion of children using haemodialysis lived in "step-families" (with one natural parent and one step-parent), or were in care or adopted.

A parent or parents were present in 67 of the inverviews (65 mothers, 43 fathers), of these 62 mothers and 5 fathers were identified as the parent taking the main responsibility for the child's treatment (prinicpal carer).

Measures of health status. A questionnaire was designed to provide two simple indices of the child's health status. This comprised a six-item functional impairment scale and a five-item social impairment scale. Items of the functional impairment scale covered tiredness, aches and pains, feeling ill, sleep problems, ability to walk unaided and ability to run (e.g. do you often feel tired; are you able to run?). The social impairment scale asked: "Does your state of health affect your life in any of the following areas – friends, hobbies or interests, family, school (or college or work), holidays?" Each scale item required a yes or no response (scored 1 or 0), thus maximum impairment scores obtainable on each of these scales were 6 and 5 respectively. Two versions of the questionnaire were used, with slightly different wordings, one for self completion by older children and adolescents, and one for completion by parents on behalf of younger children. These measures were designed and implemented after the commencement of the main study, being completed by or on behalf of 42 of the children in the main sample.

Structured family interviews. A structured family interview was carried out to obtain information on: sociodemographic variables, treatment history and adjustment to treatment. Questions regarding adjustment to treatment covered adjustment to dialysis, practical problems associated with treatment, psychological stress associated with treatment, and effects of treatment on the parents' marital relationship. The interviewer used mainly open questions, such as: "Can you tell me what happened?", "What problems does the treatment cause for you?" The interviewer attempted, where possible, to obtain responses to each of the questions from each of the interviewees. The interviews were tape-recorded (with informed consent) to allow subsequent analysis. A coding system was devised to categorize and rate answers; checks of inter-rater agreement showed this to be reliable.

Measures of psychological functioning. Immediately after the family interview children and parents completed a number of questionnaire scales aimed at assessing their psychological functioning. Those completed by the child included:

1. Childhood depression inventory (CDI) [2]. The CDI consists of 27 items which allow the child to select among alternatives on a three-point scale that reflects the absence, presence and frequency of occurrence of particular symptoms. The possible range of scores is 0–54. A mean score of 9.3 for a sample of 875 healthy children has been reported [2].
2. State-trait anxiety inventory for children (STAIC) [3]. The STAIC assesses two conceptually different areas of anxiety. The state anxiety scale measures situationally determined feelings of tension and apprehension that vary in intensity over time. The trait anxiety scale measures individual differences and the tendency to experience anxiety state in general. The possible range of scores is 20–60 on both scales. A mean state anxiety score of 31.0 and a mean trait anxiety score of 36.7 have been reported for a sample of 817 healthy children [3].

The questionnaire scales completed by parents included:

1. Rutter A scale [4]. This provides a measure of behavioural disturbance in the child. High scores are known to be associated with increased risk of psychiatric disorder. Scores are classified as deviant or non-deviant depending upon whether they are above the cut-off point of the scale (scores $\geqslant 13$).
2. Leeds scale for the self-assessment of anxiety and depression (Leeds SAD) [5]. The Leeds SAD consists of seven items which measure general anxiety and seven items of general depression. A cut-off point of 7 for anxiety and depression scores has been used to indicate the dividing line between sick and healthy populations.

Analysis. The study data were analysed using SPSSX [6] on the University of Leeds' mainframe computer. Mann-Whitney U tests were used to compare the scores of children undergoing different types of renal replacement therapy (and the scores of their principal carers) on each of the study measures.

Results

The analyses showed significant effects ($P \leq 0.05$) of the type of renal replacement treatment on 9 of the 14 independent variables (i.e. indicators of either children's or their principal carers' psychosocial adjustment to ESRF) considered in this study. The significant findings are presented in Table 2. Only 4 patients were using haemodialysis at home. The analysis of treatment group differences showed that scores of children using haemodialysis at home (and of their carers) were comparable to scores of children (and carers) using CAPD, on all of the study measures. To ease presentation, children using either CAPD or home haemodialysis are here considered as a single group. The figures in parentheses in Table 2 indicate variations in the sample size used in the analyses. These occurred for three main reasons: (1) due to limitations of children's age or memory; (2) 6 adolescents participated without their parents; (3) the health status measures were implemented later than the other study measures.

Health status

Functional impairment scores of children undergoing dialysis treatment (CAPD, home dialysis or hospital haemodialysis) were significantly higher than those of children who had a functioning transplant. However, there were no significant differences in functional impairment scores between children using CAPD or home haemodialysis and those using hospital haemodialysis. Social impairment scores of children on dialysis were also significantly higher than those of children with functioning transplants. Furthermore, children using hospital haemodialysis had significantly higher social impairment scores than children using CAPD or home haemodialysis. Thus social impairment was greatest for children using hospital haemodialysis, least for children with functioning transplants, and intermediate for children using CAPD or home haemodialysis.

Interview ratings of children's adjustment to treatment

Adjustment to dialysis was significantly poorer in children using hospital haemodialysis than in those using CAPD or home haemodialysis. Children using hospital haemodialysis also reported more practical difficulties associated with treatment. Children undergoing dialysis treatment (haemodialysis or CAPD) were more likely to report practical difficulties associated with treatment than children with functioning transplants (no children with transplants reported practical difficulties associated with treatment). There were no significant differences between the treatment groups in reports of psychological stress associated with treatment.

Interview ratings of parents' adjustment to treatment

Parents (principal carers) of children undergoing dialysis treatment reported greater practical difficulties than parents of children with functioning transplants. Parents' reports of adjustment to dialysis and of psychological stress or marital strain associated with treatment were comparable across treatment groups.

Children's psychological functioning

Children's depression scores on the CDI were significantly higher in children using hospital haemodialysis than in those using CAPD or home haemodialysis. There was no significant difference in depression scores between children undergoing dialysis and those who had a functioning transplant. The three treatment groups were comparable with respect to children's state and trait anxiety as measured by the STAIC. For example, children's mean state anxiety scores across treatment groups 1, 2 and 3 (Table 2) were 28.8, 30.7 and 28.3, respectively. Parent's ratings of their children's behaviour on the Rutter A scale indicated significantly greater disturbance in children using hospital haemodialysis.

Parents' psychological functioning

Parents (principal carers) of children using hospital haemodialysis scored significantly higher on both the depression and anxiety scales of the Leeds SAD than did parents of children using CAPD or home haemodialysis. There were no significant differences between dialysis and transplant groups on these measures.

Discussion

The findings presented will largely confirm expectations. In general, renal replacement therapy by kidney transplantation has a number of advantages over dialysis treatment with respect to the psychosocial adjustment of children in ESRF and their parents, while CAPD and home haemodialysis have advantages over haemodialysis carried out in hospital. Children with functioning transplants suffered less functional and social impairment and fewer practical difficulties associated with treatment than children undergoing dialysis. Parents of children with functioning trans-

Table 2. Mean scores on study measures in different treatment groups (sizes of sub-samples in parentheses)

Measure	Treatment groups			Contrast tests (Mann-Whitney U test)	
	1 CAPD/ home haemodialysis	2 Hospital haemodialysis	3 Transplant	1,2 vs 3	1 vs 2
Children's functional impairment	2.21 (14)	2.13 (15)	0.85 (13)	$P = 0.007$	NS
Children's social impairment	1.64 (14)	3.00 (15)	0.85 (13)	$P = 0.001$	$P = 0.004$
Children's adjustment to dialysis (1 = good, 2 = intermediate, 3 = poor)	1.05 (20)	1.37 (24)	NA	NA	$P = 0.031$
Children's reports of practical difficulties associated with treatment (0 = none, 1 = moderate, 2 = severe)	0.90 (20)	1.45 (24)	0.00 (11)	$P = 0.000$	$P = 0.005$
Principal carers' reports of practical difficulties associated with treatment (0 = none, 1 = moderate, 2 = severe)	1.23 (30)	0.91 (23)	0.20 (11)	$P = 0.002$	NS
Children's depression (CDI)	6.26 (23)	8.95 (22)	7.27 (11)	NS	$P = 0.054$
Principal carers' rating of child's behaviour (Rutter A)	9.14 (28)	15.25 (20)	10.6 (11)	NS	$P = 0.013$
Principal carers' depression (Leeds SAD)	3.70 (30)	4.76 (21)	4.45 (11)	NS	$P = 0.042$
Principal carers' anxiety (Leeds SAD)	4.87 (30)	6.67 (21)	6.36 (11)	NS	$P = 0.054$

NA, Not applicable; NS, not significant; CDI, childhood depression inventory; SAD, self-assessment of anxiety and depression

plants also reported less practical difficulties than parents of children on dialysis. Compared with children using CAPD or home haemodialysis, those using hospital haemodialysis suffered greater social impairment, reported poorer adjustment to dialysis and more practical problems associated with treatment. Furthermore, their self-assessed levels of depression were higher, and they showed greater behavioural disturbance as rated by their parents. Depression and anxiety were also higher in parents of children using hospital haemodialysis than in those using CAPD or haemodialysis at home.

We know of no comparable study carried out with children in ESRF. However, the overall pattern of results reported here follows that of a study of the quality of life of adults in ESRF. Churchill [7] used a "time trade-off" technique to assess quality of life in 250 adults who were undergoing either hospital haemodialysis, home haemodialysis, CAPD or who had a functioning transplant. Quality of life with the different treatments was ranked in the same order as reported here. Quality of life was poorest for patients on hospital haemodialysis and best for those who had received a transplant. Previous studies of children on dialysis have noted the advantages of home haemodialysis and CAPD over hospital haemodialysis, with respect to children's adjustment [8, 9]. However, earlier reports have also suggested that CAPD or home haemodialysis will exact a greater toll on parents [9–11]. Where CAPD continues for many months family "burn-out" has been described [9]. The present results do not show increased stress in the parents of children using CAPD or haemodialysis at home (compared with parents of children undergoing hospital haemodialysis). In fact, the parents of children undergoing home dialysis showed better adjustment than those whose children were undergoing hospital dialysis. It seems likely that for parents and children, the advantages of CAPD or home haemodialysis in terms of greater personal control and involvement, outweigh the disadvantages of the personal time input required and of disruptions to family life. This interpretation gains specific support from the study data relating to the adolescents who were using haemodialysis at home. Patterns of results for these 4 patients were comparable with those of children using CAPD, and contrasted with those of children undergoing haemodialysis in hospital. This finding, albeit on a small number of patients, is interesting as it suggests that the differences in adjustment found between the CAPD and hospital haemodialysis groups are due more to the fact CAPD is done at home than to any differences in the actual nature of treatment.

Some specific methodological weaknesses of the present study should be noted. In the sample studied treatment type was confounded with age, dialysis centre and home situation. It is possible that these factors are responsible to some degree for the apparent differences in adjustment between treatment groups. Furthermore, the assignment of children to the different treatment groups was not random.

Accordingly it might be argued that the type of treatment being used by the child (particularly whether CAPD or hospital haemodialysis) may initially have been selected on the basis of an assessment of family capabilities. Thus families who were better adjusted in general may have been preselected to use CAPD. Some brief comments on these four compounding factors follow.

Firstly, a related study (D. M. Fielding and G. Brownbridge submitted for publication) showed that the age of children undergoing dialysis is negatively correlated with their parents' reports of practical problems associated with treatment and with parents' depression scores on the Leeds SAD. Thus, as children undergoing CAPD tended to be younger than those undergoing hospital haemodialysis, we might expect their parents to report more problems and have higher depression scores. In fact, parents of children undergoing CAPD or home haemodialysis rated themselves as less depressed than parents of children undergoing hospital haemodialysis. The children's age cannot be a contributory factor to this result.

The problem of treatment type being confounded with dialysis centre is not so easily discounted. However, as patient samples come from broadly similar socio-economic groups and were similar on many illness and treatment variables, it seems unlikely that any differences between the dialysis centres at Leeds and Liverpool, or between the geographical areas they serve, could account for the findings presented here. It is also unlikely that differences in the children's home situation could account for any of the present findings. Children undergoing CAPD were more likely to be living with single parents than those using haemodialysis. Single parents particularly might be expected to suffer the strain of CAPD. In fact the present findings showed depression and anxiety scores to be lower in parents of children using CAPD than in parents of children using haemodialysis. Taking a different view on this matter, it is possible that CAPD had been a contributory factor in bringing about and/or maintaining the single status of some parents. That is, the time taken up by the treatment may have contributed to the parents' initial separation and subsequently affected the remaining parent's ability and/or desire to initiate and maintain a relationship with a new partner. Further research on this possibility would be useful.

Finally, there is no doubt that psychosocial factors are (appropriately) considered by dialysis staff when choosing the type of treatment to be used by a particular child. However, physical factors, patient or parent preference, and the clinical experience of the particular consultant and dialysis staff team, will also be important. Given this situation it is doubtful that preselection on psychosocial criteria could account for a set of results as clear and consistent as those presented.

Research findings on psychosocial adjustment in chronic illness underline the importance of psychosocial factors in the management of such conditions. The present findings may be useful when considering the choice of treatment for children and adolescents in ESRF. Furthermore, they may allow the targeting of psychosocial resources in treatment centres for ESRF in children. Future research in this area should be urgently concerned with the development and evaluation of strategies of psychosocial intervention aimed at improving the adjustment of children with ESRF and their families.

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