

How parents and families cope with chronic renal failure

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SUMMARY We studied the effects on the family of childhood chronic renal failure by contrasting children with varying degrees of severity of illness with healthy controls. Disruption of family life was most common in families with the more severely ill children (on hospital haemodialysis) and there was a tendency for more mental health problems in the parents in this group. Although more of these parents reported that the child's illness had had an impact on the marriage, marital break up was not related to illness status. There were indications that illness had resulted in an increase of subjective stress but also of support in a number of psychosocial areas for parents, especially those in the more severely affected group. Nevertheless at the time of assessment, fewer mothers in this group were deriving support from their social life and fewer fathers of ill children from their jobs or finances.

It is well recognised that chronic illness in children may result in psychological suffering and social stress for the children themselves and their families, but little systematic research has been carried out in this area. Much still remains unknown about the extent, nature, and implications of family difficulties caused by various childhood conditions.

High rates of parental mental distress have been reported in children with cystic fibrosis and spina bifida,^{1,2} but not in a recent study of parents of children with chronic epilepsy.³ These studies did not use healthy controls and while the variations in the results may reflect different pressures associated with individual conditions, they clearly highlight the need to use comparison groups. The study of the effects of chronic childhood illness on the marriage shows that, although stress on the marriage is often apparent, when control designs are used there is no evidence of raised divorce rates in couples with chronically ill children.⁴

As part of our clinical work in a paediatric nephrology unit we became interested in the psychosocial effects of the illness on families. Previous studies have noted family disruption in children with end stage chronic renal failure, on haemodialysis, or after transplantation.^{5–9} These studies, however, were for the most part uncontrolled, they did not differentiate between children at different stages in the condition, nor was the nature of the difficulties always clearly defined.

We decided to study the impact of chronic renal failure on the families with children requiring dialysis when compared with children with less severe forms of chronic renal failure. Because illness may have positive as well as negative effects, in addition to stresses we studied the possible supports mobilised by the illness and considered separately the long term and the current areas of difficulty. The effects of the illness on the psychiatric adjustment of the children themselves were also studied and have been reported elsewhere.¹⁰

Subjects and methods

All children attending Booth Hall Children's Hospital for a minimum of six months hospital haemodialysis between September 1983 and August 1985 were included in the study. The 22 children (16 boys and six girls with a mean age of 13.8 years) were matched for age and sex with 22 children with chronic renal failure also attending the paediatric renal clinic, but not on dialysis. Children in this latter group all had a creatinine clearance of less than 25 ml/minute/m² and were possible future candidates for dialysis or transplantation, or both. Over and above their superior renal function, these children were less severely affected by their illness than children in the hospital haemodialysis group. Their growth was considerably less compromised, and fewer had asymptomatic congestive cardiac

failure, were anaemic, or had difficulties running or walking, and there was a tendency for fewer hospital admissions in this group.¹⁰

A second comparison group of 31 healthy children (21 boys and 10 girls) was studied. Controls for the school age children were selected from four ordinary schools attended by dialysis patients, chosen to represent different socioeconomic areas. Controls for preschool children and school leavers were obtained from the register of a general practice attended by one of the dialysis patients, which covered a socioeconomic area broadly representative of the general population. The first 22 controls were individually matched for age and sex with the dialysis patients, the name of children closest in age to the patients being taken from the class or general practice register. The size of the healthy control group was then increased to allow comparison with the combined sample of ill children, ensuring that the additional group of healthy control subjects was comparable in age with the whole group. All the families in the group on dialysis, 22 out of 23 (95%) of the ill group not having dialysis, and 31 out of 36 (86%) of the healthy families approached for the study agreed to take part.

The age range in the whole group was wide (2 to 18 years, mean of 13 years) including seven preschool children and 14 who had left school; over half the children were of secondary school age. All subjects were living at home with either a parent or guardian. The three study groups were comparable for family variables such as parental age and size of the family. There were no significant differences in socioeconomic level, although there was a tendency towards higher parental unemployment in the group on dialysis, for more parents to be in the manual classes in the ill group not on dialysis, and for more non-manual families to be in the healthy group. Five children came from families with immigrant parents (three in the dialysis and two in the non-dialysis group).

The families interviewed all came from the North West Health Authority region covering a wide geographical area. Interviews were conducted by a social worker with the parents either at home or at the hospital. The assessments of ill children were all made at a relatively stable point in the child's illness and 'crisis' times, such as admissions or important changes in treatment, were deliberately excluded. All parents of children in the study were invited to participate and 65 (89%) mothers and 31 (46%) fathers took part. Nine fathers were interviewed alone: in most cases these were single parents or members of immigrant families where the mother experienced some language problems. One grandmother, with whom the child lived, took part.

A number of methods of assessment were used, either separately for each individual parent or, in some cases, jointly for both.

(1) All parents underwent a structured interview during which they provided detailed information about background family and socioeconomic factors. Details about the children's psychological adjustment were also collected.¹⁰ In addition, parents of ill children provided a description of the illness and its impact on the family.

(2) Current stresses and supports for the parents were assessed with the Social Stress and Supports Interview (SSSI)^{11 12} and current mental distress in parents by the general health questionnaire (GHQ 28).¹³ The latter was completed by all but three parents interviewed. For the analysis of data, statistical tests were used as appropriate (χ^2 or Kruskal-Wallis one way analysis of variance).

Results

LONG TERM IMPACT OF ILLNESS ON THE FAMILY

The child's illness was reported to have caused disruption in family life by most parents in the dialysis group (77%) significantly more often than by parents in the non-dialysis group (31%) ($p=0.002$). Disturbance was commonly explained in terms of the restrictions imposed by the child's condition or treatment, including dialysis, which made family outings or holidays difficult to organise. Day to day family life was often disrupted with physical care of the ill child taking priority over other activities—such as spending time with the other children, or pursuing hobbies—for example, when there were difficulties in management of a urinary diversion or problems with diet or fluid restrictions. The situation was exacerbated during hospital admissions.

We asked parents about the impact of the child's illness on the marriage and on other specific areas of their lives, about the nature of the impact (whether it had led to increased stress, to more support, or to both), and about changes in parenting and sibling relationships (figure).

Appreciably more parents in the group on dialysis (65% compared with 27% of parents in the group not on dialysis; $p=0.05$) reported that their marriage had been affected. Parents in both groups commonly reported that the illness had had an impact in other psychosocial areas, and this also tended to be more noticeable in the dialysis group. As can be seen from the figure, however, the effects were not necessarily detrimental.

As regards impact on the marriage, as many parents in the group on dialysis reported increased support as increased stress. Changes in financial

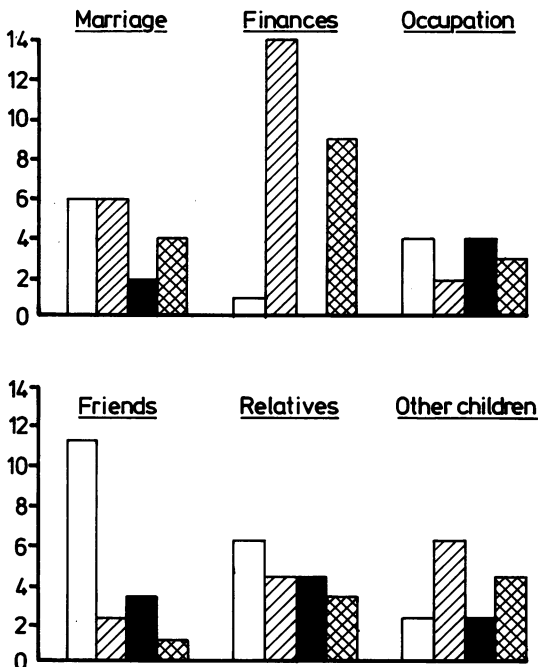


Figure Impact of illness on aspects of parents' lives. No of parents reporting stressful and supportive changes in the two groups of ill children. Parents of group on dialysis (n=22): increased support □, increased stress ▨; parents of group not on dialysis (n=22): increased support, ■, increased stress ▩.

status were, in all but one family, causing increased stress, usually because of the extra costs incurred through hospital visits and admissions. Impact on the relationship with other children in the family had also been causing stress for both groups. There was a trend, however, towards increased support from jobs and in the relationship with relatives and friends.

About 60% of the parents in each group felt that their handling of their children had been affected by the illness and that they had become more protective of the ill child than of their other children. There was a trend for more parents in the group on dialysis than in the group not on dialysis to report increased leniency towards ill children (60% compared with 32%) and to have lower expectations of them (55% compared with 32%). Similarly more parents of children on dialysis perceived changes in siblings' attitudes towards the ill child including worrying, protectiveness, and giving in to the ill child; jealousy by siblings was reported by one third in each group.

MEDICAL CONCERNS AND CONTACTS FOR THE PARENTS
 Parents were asked about their concerns connected with the child's illness and about the families' experience of supportive medical contacts. Understandably, prognosis was mentioned most commonly as an area for concern, but just as often parents of patients on dialysis mentioned the child's growth. A few parents voiced concerns about future employment (14% in both groups). Twenty three per cent of the parents of children not on dialysis, but none in the group on dialysis mentioned the children's marriage prospects.

There were clear differences between the groups in the parental perceptions of professional support from medical, social work, and other sources. Parents were asked whether they contacted the hospital if they needed advice or support, other than at routine outpatient visits. More parents of dialysis patients (77% compared with 33%; $p < 0.01$) were likely to turn to the hospital saying that they contacted a member of the medical, nursing, or ancillary staff. In addition, all parents in this group said they were in contact with the hospital social worker and saw her as a regular source of support; she was known, however, to only one third of parents of the group not having dialysis—a significant difference ($p < 0.001$). Parents were also asked whether they found their general practitioner a support in relation to their child's illness: more parents of the children not having dialysis reported that their general practitioner was supportive (77% compared with 36%; $p < 0.02$). Only a few parents in both groups were making use of support from community agencies, such as local social service departments or health visitors. Parental satisfaction with the overall support offered from varying sources was higher in the group on dialysis than in the group not on dialysis (77% compared with 32%; $p = 0.01$).

CURRENT LEVELS OF PSYCHOSOCIAL STRESS AND SUPPORT IN THE PARENTS

We investigated current psychosocial stresses and supports for the parents at the time of assessment by comparing the two ill groups with controls on the scores from the Social Stress and Supports Questionnaire. Total scores failed to show differences between the three groups in current stress, but there were significant differences in support (table 1). Somewhat surprisingly in view of the long term findings reported before, support was lowest in the group on dialysis (whether the scores of all parents were pooled together or whether the scores of fathers and mothers were analysed separately). When we examined the individual areas of psychosocial support, a different pattern emerged

for fathers and mothers. Whereas mothers of dialysis patients reported lower support from their social life with friends than mothers in the other groups (44% compared with 15% and 17%; $p=0.06$), fathers in both ill groups were experiencing less support than fathers in the healthy group in the areas of finance (54% in the group on dialysis and 33% in the group not on dialysis compared with none of the fathers of healthy children; $p=0.01$) and occupation (54% and 44% compared with none; $p=0.01$). In line with these findings fewer parents in the ill groups said they had people they could turn to in times of trouble (55% and 68% compared with 84%; $p<0.01$).

Although parents in the three groups were comparable in the degree of stress and support currently derived from their relationships with other children in the family, significantly more parents of ill children reported schooling difficulties (for example, under achievement, poor concentration, or truanting) among siblings (21% and 20% compared with 11%; $p<0.005$).

MARITAL STATUS AND PARENTAL MENTAL HEALTH

Finally, we considered whether illness in the chil-

dren and its severity had affected rates of marital breakdown and parental mental health, by comparing the two ill groups with the healthy controls. As will be seen from table 2 no significant differences emerged between the groups. The rates of family break up were comparable, as were those for current mental distress in the parents as measured by scores on the general health questionnaire. Parents interviewed were also asked whether they or their partner had had any recent mental or nerve problems (that is, whether they had consulted their general practitioner during the past two years for their 'nerves' or had taken psychotropic drugs). At a non-significant level there was a clear tendency for mothers of ill children and, to a lesser extent, for fathers of the group on dialysis to report this.

Discussion

Our study confirms previous findings of family disruption in a number of children with chronic renal failure and it shows that this is clearly more noticeable in children with the more severe conditions on hospital haemodialysis. There were indications that the illness had had a long term impact on a variety of psychosocial areas including the marriage

Table 1 *Current stress and support for the parents of ill children compared with healthy controls. (Results are scores on the Social Stress and Supports Questionnaire)*

	Parents of children on dialysis	Parents of children not on dialysis	Parents of healthy controls	
No of parents interviewed	27	29	41	
Mean (SD) total stress	9.2 (5.0)	7.2 (4.3)	8.5 (4.5)	NS*
Mean (SD) total support	24.2 (4.0)	34.2 (3.8)	33.7 (3.1)	$\chi^2=11.5$ $p=0.003$

*Statistics based on Kruskal-Wallis one way analysis of variance.

Table 2 *Family background and parental mental health for ill children and healthy controls*

	Children on dialysis (n=22)	Children not on dialysis (n=22)	Healthy children (n=31)
Family background			
No (%) of children from:			
Intact family	17 (77)	20 (91)	25 (81)
Single parent	5 (23)	—	4 (13)
Step parent family	—	2 (9)	2 (6)
No of parents with current mental distress/total interviewed (%)*†			
Mothers	6/15 (40)	6/20 (30)	8/29 (27)
Fathers	3/10 (30)	2/9 (22)	2/11 (18)
No of parents with mental/nerve' problems in last 2 years/total interviewed (%)*			
Mothers	12/20 (60)	11/22 (50)	11/31 (35)
Fathers	3/19 (15)	0/22	1/27 (3)

*Information on parental mental problems refers to all parents with whom children were living at the time of interview. All but three parents interviewed (response rate 94/97, 97%) completed the general health questionnaire.

†This represents a high score on the general health questionnaire.

and parents' mental well being. At the time of assessment, however, there was no significant excess of marital break up or psychiatric distress in the parents and, overall, most families appeared to be coping.

This may be due to the fact that our assessments were carried out at a stable point in the condition, and also that parents reported that over the years the illness had mobilised supports as well as stresses. Our findings on the effects of the illness on the marriage specifically highlight the fact that, although illness often has an impact in this area, it can operate in the direction of increased support. This would explain the lack of a significant increase in marital breakdown in the families of ill children, which is in keeping with Sabbeth and Leventhal's conclusions from their literature review.⁴

The areas in which parents reported difficulties consistently in the past and at the time of assessment were finances and other siblings at home. The findings of increased financial stress for the parents caused by the illness agrees with several previous reports of families with chronically ill children.^{5 8} Although some parents in our study were receiving financial help, for example from supplementary benefits or from voluntary hospital funds towards the cost of visiting, many commented that they only learnt about help or benefits to which they were entitled relatively late on in the child's illness.

The illness had also resulted in increased long term stress in the relationship between the parents and other children at home and, in keeping with studies of siblings of children with other chronic conditions,^{3 14 15} more parents in our sample reported schooling problems at the time of the assessment. It seems plausible that changes in parenting of the ill child may have caused strain in the parent/sibling relationship and affected sibling development. Our findings highlight this as an area deserving more attention.

Parents had concerns about their children's illness which encompassed both medical prognosis and developmental issues, such as growth. This emphasises the need to take a broad, developmental perspective in the handling of children with chronic illness, and in the supporting of parents. As regards medical support, we did find satisfaction was higher in the group on dialysis where support was offered primarily from the hospital. This raises the question of how best to provide medical and psychosocial support for the families of patients with less severe conditions.

At the time of assessment parents of ill children failed to report more mental health problems or psychosocial stresses than parents of healthy children. Parents of children on dialysis did report fewer

supports, however, which can be seen as a sense of decreased satisfaction, security, or well being.

Relatively fewer mothers of children on dialysis felt supported in their social life with friends and parents of these children also tended to have fewer people to turn to in times of trouble. Ferrari, in a controlled study, similarly found less social support in mothers of children with chronic diabetes.¹⁶ This finding might seem surprising in view of the fact that parents of children on dialysis had reported increased long term support. A probable explanation for this apparent discrepancy could lie in the fact that support for parents may be forthcoming on an intermittent basis, particularly at times of acute difficulty or problems in the child's condition. As we were interviewing parents at a relatively stable stage in the illness, this support would not be currently operating. Our findings suggest that mothers with the more severely ill children may be the ones most likely to benefit from regular social or parent groups, where there is an opportunity for contact with other parents in the same predicament.

The areas from which fewer fathers of all ill children derived support were work and finances. We noted that some of the fathers commented on finding the demands of work harder to cope with, particularly at times of problems in the child's illness. Other authors have reported work problems in fathers³ or feelings of resentment when work prevented them from being concerned with treatment and with the child at the hospital.⁷ It is worth considering whether a special effort to involve fathers more in various aspects of the ill child's care might result in an increase in their sense of satisfaction with other areas in their lives.

It should be noted that our results apply to children on hospital haemodialysis. Previous reports suggest that other procedures, such as home haemodialysis, cause a high level of stress for parents—arising from the degree of responsibility for treatment and the orientation of family life around dialysis.^{9 17} In these cases both the need for support and its availability are likely to differ from those identified in our hospital group. Our own results highlight the importance for paediatric and primary care teams to be aware of the vicissitudes of family life in severely ill children, and to direct their support to parents accordingly.

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