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Parental information needs in chronic renal failure and diabetes mellitus

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Abstract The information needs of parents of children with end stage renal failure (ESRF) or with insulin dependent diabetes mellitus (IDDM) were assessed by questionnaires over a 2-year period. Questionnaires were posted on seven occasions at 4-monthly intervals and were sent to both mothers and fathers. Most information needs were reported to be for detailed test results, for new information about the condition and about the child’s future social development. Questions responsible for the three highest scores were concerned with the future: the child’s fertility; their social, career and marriage prospects; and the hope for a new improved treatment. For the IDDM mothers, scores were significantly different depending on age of the child ($P = 0.02$). Change in treatment mode had no significant effect on the information needs of parents of children with ESRF ($P = 0.81$). Occupation was significantly associated with the mean general information needs scores for parents, with occupations of a lower socioeconomic status associated with higher information needs scores. There were no significant differences between the reported mean general information needs scores of parents of children with ESRF and of parents of children with IDDM ($P = 0.69$) or between mothers and fathers mean general information needs scores ($P = 0.58$).

Conclusion Multidisciplinary team members need to tailor information to the needs of the individual families and be sensitive to socioeconomic factors and communication issues.

Key words Chronic renal failure · Diabetes mellitus · Information needs · Psychosocial care

Abbreviations CF cystic fibrosis · ESRF end stage renal failure · IDDM insulin dependent diabetes mellitus

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Introduction

Parents of chronically ill children require information about their child’s illness, treatment options and prognosis if they are to participate in treatment decisions and give informed consent. Knowledge is also required if parents are to explain the illness to others such as relatives and schoolteachers. Whilst there has been research on patient satisfaction with communication [5, 10, 11], and on ability to retain information [6, 8], there has been very little work to ascertain what information parents require. Few studies have attempted to research this topic [7, 9, 14, 15].

One of the few studies that systematically researched information needs of parents [3] investigated families where there was a child with cystic fibrosis (CF). The majority of parents (99%) reported wanting access to all available information, and thought it to be their right (98%). Parents generally had fewer demands for information about symptomatology, treatment and genetics yet requested more information about psychosocial issues and future implications of the disease. However parents reported they had been given more medical than psychosocial information. Further findings [3] indicated that on over a third of the topics, fathers requested significantly more information than mothers did and that fathers from socioeconomic groups III, IV, or V reported that they had received significantly less than did those fathers from socioeconomic groups I and II.

We evaluated the information needs of parents of children with end stage renal failure (ESRF) and parents of children with insulin dependent diabetes mellitus (IDDM) over a 2-year period. These two groups were compared because despite higher treatment demands and risk of premature death in ESRF, they are similar in several important respects (no ‘cure’ only treatment, daily dietary demands, omission of treatments for just a few days can have severe consequences). Thus the comparison would enable the exploration of not only issues general to chronic childhood illness, but also the identification of any issues specific to this severe, life-threatening condition.

Methods

The psychological well being of parents of children with ESRF and parents of children with IDDM was assessed in a longitudinal study over 2 years [2], approved by the Nottingham City Hospital Ethics Committee. Permission was only given to approach parents of the study children. Inclusion criterion for the renal group in the study was all parents with a child post-renal transplant, or on dialysis or in ESRF and expected to commence dialysis within the very near future. Inclusion criteria for the diabetes group were parents of a child with IDDM and who could be matched with a renal patient of the same sex. Matching by age was also attempted, however this was a very approximate process as IDDM was not found in children as young as those with ESRF. As part of this study, the parents were sent an information needs questionnaire adapted from that of Henley and Hill [3], and originally used with parents of children with CF. General questions, that is those not specific to the medical condition of CF, were left in their original state; however those that were disease specific were altered with the advice and assistance of the specialist nurses. For each question, parents were asked to rate their information needs by estimating how much further information they required on a three point scale (a lot more information needed, a little more information needed, I have enough information).

Questionnaires were posted on seven occasions at 4-monthly intervals, and were sent both to mothers and to fathers, each parent also receiving a stamped return envelope.

Statistical analysis was carried out using SPSS for Windows using 5% probability as the accepted significance level. Analysis required both parametric (analysis of variance, linear regression) and non-parametric methods (Kruskal-Wallis, Fisher’s Exact test, Mann-Whitney U test) and for each section of results the test used is noted.

Results

Parents of 41 families met the renal inclusion criteria and were invited to take part in the study. Parents of 35 children with ESRF agreed to take part (85%). Out of those 68 parents, 164 replies were received from 43 parents (63%) of 26 children. Parents of 36 families met the IDDM inclusion criteria and were invited to take part in the study. Parents of 32 children with IDDM agreed to take part (89%). Out of those 59 parents, 138 replies were received from 41 parents (69%) of 23 children. There were no significant differences between those with ESRF and those with IDDM, for socioeconomic status ($P = 0.86$, $U = 185$), ethnicity (Fisher’s exact test $P = 0.49$) or sex of study child (Fisher’s exact test $P = 0.40$). Response rates and details of respondents can be found in Table 1.

Mean information need scores for each parent were calculated from all available data over the 2-year study. These scores were then used in the following analyses. Except for the analysis of the individual question scores, only the general information questions are analysed and reported in this paper, as disease specific questions could not be guaranteed to be of equal weighting or importance across conditions. The mean scores of parents were compared (Table 2) and two way ANOVA revealed no significant differences between the reported mean general information needs scores of parents of children with ESRF and of parents of children with IDDM ($F_{1,79} = 0.17$, $P = 0.69$) or between mothers and fathers mean general information needs scores ($F_{1,79} = 0.31$, $P = 0.58$).

ANOVA’s were also carried out to identify whether the age of the child had a significant effect on parents’ mean general information needs score. There were no significant main effect results for either mothers or fathers of children with ESRF, nor for fathers of children with IDDM ($P = 0.79$, $P = 0.81$ and $P = 0.69$ respectively). However, the mean general information needs score of the IDDM mothers was significantly different, depending upon age of the child ($F_{2,22} = 4.7$, $P = 0.02$). Post-hoc analysis revealed that mothers whose child was aged 10–14 years old had significantly greater information needs (mean question score = 0.99),