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Longitudinal Assessment of the Psychological
Well-being of Parents Caring for Children with
End Stage Renal Failure

by

Jacqueline Collier

Doctoral thesis
Submitted in partial fulfilment of the requirements
for the award of
Degree of Doctor of Philosophy of the Loughborough University
of Technology

October 1995

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Abstract

The study followed parents of 26 children with End Stage Renal Failure (ESRF) for two years to investigate the cumulative effects of caring for a child with ESRF. The mean age of the children was 10.24 (range 2yrs - 17yrs), and 25 mothers and 18 fathers participated. The study assessed the stress, anxiety and depression levels of parents, as well as their information needs and perceived impact of the illness. This data was collected by questionnaires which were administered on seven occasions (four monthly). Data was also collected on socioeconomic factors. Qualitative data was obtained by attending the parents support group, and later transcribing the discussions.

Parents of 23 children with Insulin Dependent Diabetes Mellitus (IDDM) were used as a comparison group for the longitudinal questionnaire data. The mean age of the children was 11.96 (range 3yrs - 17yrs), and 23 mothers and 18 fathers participated. A general population sample of parents was used as an additional comparison for the stress data (n=123), anxiety and depression data (n=66).

Results from the impact of illness questionnaire showed that ESRF care places greater restrictions on the life of the child and family than does childhood IDDM (p=0.06); the impact was greatest when there was a change in the renal replacement therapy from dialysis to transplant (p=0.013). Data from the information needs questionnaire demonstrated that for the parents of children with ESRF the need for information was reduced by an active programme of information provision (p=0.011). When caring for a child in ESRF, parents are significantly more anxious (p=0.0022) and depressed (p=0.006) than parents in the general population sample.

Caring for a child with ESRF was shown to result in increased demands and reduced psychological well-being, compared to parenting healthy children or to children with IDDM.
Acknowledgements

I would like to thank all those families who took part in the study over the two years, and to the staff of the paediatric renal and diabetes teams for all their help and support. I would especially like to thank Dr Alan Watson and Mrs Dorothy MacKinlay of the Nottingham Paediatric Nephrology Unit for their advice and encouragement. Many thanks to the British Kidney Patient Association for the funding which made the work possible and allowed me to carry out such worthwhile research. Thanks are also due to Dr David Middleton of Loughborough University for putting me in contact with the Nottingham Paediatric Nephrology Unit and for supporting my work there.

I owe much gratitude to Dr Helen Pattison, my supervisor for her guidance, patience and reassurance, and for her part in helping two dissertation students gather the general population sample of parents. Thanks also to Niki Louch and Tracey Parslow who were those students.

Many thanks to my colleague Charlotte Sheard for inputting the data into SPSS and introducing me to the package; and also to my other colleagues who have ensured that I have had time to dedicate to the thesis.

And finally a special thank you to Kevin, my husband for his support and understanding throughout the project, and for his constant faith in the work I do.
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Chapter One

Chronic Childhood Disease

Mortality rates at all ages have fallen steadily over the last 150 years in response to improved living conditions, diet and sanitation, birth control, advances in medical science, and increased availability in health care (Woodroffe et al., 1993, p28). Child mortality in the late 1980's (1,000 per million child population) had dropped to approximately one thirtieth of that of 1928 (30,000 per million child population) (Forfar, 1988). Mortality rates though do not reflect the health of the children who survive.

Many children who would have died in the past now survive. Many may survive because modern medicine has saved them, but medicine cannot yet cure all of these children (Forfar, 1988). For numerous hereditary diseases and congenital abnormalities a cure is not yet possible, instead treatment can ameliorate symptoms, often allowing the child to survive as long as successful treatment regimen are maintained.

Medicine has been able to improve the mortality figures most dramatically in the treatment of infectious diseases, either directly through the treatment, and near elimination of disease such as tuberculosis and poliomyelitis, or indirectly through treatment of infections that, if untreated might be fatal when contracted by children who already have a chronic disorder, eg. bronchitis in children with cystic fibrosis (Court and Alberman, 1988).

The incidence of childhood chronic illness is on the increase, more than doubling between 1972 and 1991 (Woodroffe et al., 1993, p39).
Although this rise could be a result of improved assessment of morbidity, there is evidence of an actual increase in the prevalence of chronic diseases. The increase is partly caused by the improved survival rates of children with many chronic medical conditions. Children with insulin dependent diabetes mellitus (IDDM) are now expected to reach old age providing they follow the prescribed diet and insulin regime. Prior to the discovery of insulin in 1922 this was not the case and the children died.

Children diagnosed as having Cystic Fibrosis (CF) in the early 1960's were predicted to live to only about six or seven years of age. For those born in 1975 the predicted median survival was to the early twenties, and many of those children are alive today. Now the prediction is that for those children born in the early 1990's, the median age of survival will be about forty years of age (Elborn et al., 1992).

Such improvements in survival rates clearly increase the number of chronically ill children. In these medical conditions there is an exchange between the mortality rates and the morbidity rates. A further contributing factor to the increase in the number of chronically ill children is that the incidence of some conditions, such as asthma and diabetes mellitus, is actually increasing (Hanestad, 1989; Woodroffe et al., 1993, p39 & p67).

Davis (1993) lists the prevalence of some chronic diseases that affect children, and these can be seen in Table 1:1. Most of the conditions require continued therapy for the duration of life, and many can be life-threatening without treatment.

Estimates of the prevalence of chronic childhood illness vary but are minimally estimated to be around 8% (Westbom, 1992a).
Table 1.1 Prevalence of some chronic childhood diseases (Davis 1993)

<table>
<thead>
<tr>
<th>Condition</th>
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<tr>
<td>Asthma</td>
<td>2.5%</td>
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<tr>
<td>Diabetes</td>
<td>1.8%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>0.26-0.46%</td>
</tr>
<tr>
<td>Sickle cell disease</td>
<td>0.046%</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>0.02%</td>
</tr>
<tr>
<td>Haemophilia</td>
<td>0.015%</td>
</tr>
<tr>
<td>Kidney disease</td>
<td>0.008%</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>0.006%</td>
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Medical and nursing care of sick children: A historical perspective

Prior to the establishing of the National Health Service (NHS) there were few specialists in paediatric medicine. This was apparently a reflection of the low financial rewards associated with treating children (Forfar, 1988). With the advent of the NHS, paediatricians were able to treat children as a speciality as the financial disincentive was removed. Changes in the medical treatment of children did not occur in isolation, and there have been dramatic changes in the way that children are cared for too.

Since the mid 1800’s sick children had been treated in Children's hospitals, where they were subjected to a regime of care that we today would consider severe, if not harmful. Not only were many of the medical treatments ineffective, as they were for adults, but there were extreme restrictions on the visitors a child might receive.
Visiting was often discouraged on the grounds that the child was calmer and less troubled if the mother did not visit. There was an ignorance about the way children demonstrate their distress at being separated from their mother, especially younger children.

Children who are unable to understand the necessity of being removed from their home and mother, and of being placed in a severe and spartan hospital environment respond in a fairly consistent way when this occurs. Initially when the mother visits, the child protests, is weepy, and demonstrates demanding and clinging behaviours towards the mother. They actively seek to hold the mother's attention and are reluctant to let the mother leave again. If the mother is then persistently absent for a period of days the child enters a phase of despair and intense grief. Finally as the period of separation becomes prolonged the child becomes detached, not responding to contact from the mother, yet playing with toys and responding to other adults (Bowlby, 1960).

This behaviour can be mistakenly interpreted as the child 'settling down', and can also lead to the belief that maternal visiting has a negative influence upon the child. In 1960 Bowlby described these three stages of children's responses to being left in hospital without their mother as separation anxiety, and identified it as a pathological condition (Bowlby, 1960). Bowlby's theory suggests that contrary to a reduction in maternal visiting such a condition requires that the mother should be encouraged to visit as frequently as possible.

At the turn of this century, Children's Hospitals continued to discourage visiting, and as late as the 1920's hospitals such as the Nottingham Children's Hospital did not allow parents to visit their children unless critically ill. Instead the sister from each ward would sit at a table in the out-patients department hall every
Saturday afternoon to interview parents, to inform them of their child's progress and to collect fruit, books, etc. (Crothall, 1978). With the advent of the telephone there were slight improvements. Whilst visitors were still not allowed, patient enquiries were permitted any day by telephone as long as it was between 1pm and 3pm. Parents could come to the entrance lodge on Saturdays to make enquiries between 2 and 3.30pm. Crothal reports that this information was obtained from an undated information leaflet of the Nottingham Children's Hospital. It is likely that such a leaflet would have been issued prior to 1959 when the findings of the Platt Committee on the Welfare of Children in Hospital were reported (Platt Report, 1959).

The Platt Report

The Committee on the Welfare of Children put forward a number of recommendations aimed at improving the non-medical aspects of the treatment of children in hospital. The recommendations were made within a framework which acknowledged dramatic changes in the appreciation of children as individuals in the home and in the school since the turn of the century, and also in the increase in health care services for children that parents had been able to access since 1948 with the establishing of the NHS (p2).

The Committee was unanimous in the opinion that the emotional needs of children in hospital need constant consideration, and that separation from familiar people is upsetting and can lead to emotional disturbances which may sometimes last into adult life. The report adds that the discipline of hospital life ought to recognise the authority of parents and respect their methods of handling their children (p3).
Among the many recommendations made by the Committee two were to receive the most attention. First the Committee recommended that the mother be admitted with the child (p17), especially when the child is under five years old. Second the report considered it to be desirable for the majority of children to be visited daily, and also with as few restrictions on visiting as could be consistent with the efficient running of the ward. The report adds that the younger the child the more important it is that they be visited frequently (p18). The report lays out the arguments for and against unrestricted visiting (p19 & p20), but concludes with the hope that all hospitals where children are treated will adopt unrestricted visiting (p20).

The Ministry of Health accepted the recommendations of the Platt report in 1959 and advised hospitals to allow access to the parents of child patients under school age at any reasonable time. Some hospitals were very resistant to such changes and by the early 1960's progress towards the recommendations appeared slow in many hospitals (Stacey, 1970). As late as 1970 some Children's wards still had notices proclaiming "Parents may visit on Saturdays and Sundays between 4 and 5pm" (Meadow, 1988). The organisational changes that were to accompany the recommendations of the Platt report had not been recognised (Stacey, 1970), nor had the practical difficulties that arose both for families and for hospitals when a parent wished to be resident with his or her child.

Following the slow implementation of the recommendations of the Platt Report, a young group of parents formed the National Association for the Welfare of Children in Hospital in 1961. This group brought pressure to bear on hospital authorities and staff to adopt the recommendation of the Platt Report. The acceptance and
adoption of the new concepts in child care called for a change in the attitudes and duties of the paediatric nurse and paediatrician (Stacey, 1970). The Platt Report represented the advent of a new, child-centred, approach to the care of sick children.

Twenty years after publication of the Platt Report, visiting rules from a Nottingham 1978 patient information booklet showed great changes, stating "it is very important that parents visit often", although at this time there was no process which encouraged parents to be residential. The booklet continues "even though he cries when you leave, your visits will make him feel more secure, so do visit as often as you can". It was also stated that the enquiries via the telephone could be made at any time. The current policy of the Nottingham Paediatric Unit, as at many other specialist units, is reflected in practical measures such as the provision of residential facilities for parents. Open visiting for close family members and the ability for entire families (if necessary) to stay in hospital are clear indication of full acceptance of the findings and implementation of the Platt Committee Report.

The move to home-centred care

There has been a cultural shift in the way children are cared for when ill. Areas used for child health needs are now often child-centred with playrooms and nursery nurses available. Hospitalised children are no longer restricted to bed unless it is unavoidable, and the majority of child patients are to be seen in their own clothes, and playing with their own toys. Nurses on paediatric wards are frequently seen, not in the traditional nurses uniform, but instead wearing a more 'friendly' outfit, such as casual clothing covered by a decorated tabard.
The in-patient admissions of children are not only different in their quality, they are different in their duration and purpose. The number of children who are being admitted to Paediatric Units has continued to rise over the last fifty years, but the average length of stay has been shorter (see Table 1:2). No longer are children likely to be patients for many weeks, instead most children are admitted only for short periods of time.

Table 1:2  In-patient admissions to the Nottingham Paediatric Unit

<table>
<thead>
<tr>
<th>Year</th>
<th>Total number of in-patients</th>
<th>Average length of stay (days)</th>
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<tr>
<td>1948*</td>
<td>3657</td>
<td>11</td>
</tr>
<tr>
<td>1975*</td>
<td>5223</td>
<td>5</td>
</tr>
<tr>
<td>1994†</td>
<td>9315</td>
<td>2.84</td>
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*(Crothall, 1978)
†Obtained from Paediatric Nursing Administration in personal correspondence

For children with chronic medical conditions an admission to hospital is rarely for the provision of routine care. Admissions are for investigations, to initiate new treatments or to alter existing ones, for surgery, in episodes of acute illness or relapse and, on occasion, for respite care. Most daily treatments for children with chronic illnesses in the UK now take place in the family home.

Whilst the Platt Report did not go into great detail about home-centred care for chronically ill children the Committee did make recommendations that supported its development. The Committee recommended that special attention be paid to devising methods of management of the sick child which avoid admission to hospital (Platt Report, 1959, p4). The Platt Report however was not the cause of this trend. The move to home-centred care has taken place not only in pediatrics but also in adult health care. In part this has
been as a result of patient pressure to reduce the amount of time spent in hospital (NAWCH, 1974), but it has occurred mainly as a financial necessity for the National Health Service.

As children are increasingly subjected to chronic illness, so too are adults. The majority of chronically ill children grow into chronically ill adults, and many other adults also develop chronic illnesses later in life. The reduced mortality from infection in the chronically ill has enabled many more people to prolong their lives, and therefore to require treatment for many more years. Medical advances have also extended the number of medical conditions that can be treated. The overall increase in demands upon the NHS could not have been met either financially or within the NHS capacity if hospital based treatments involving prolonged admissions, had been maintained (Wells, 1987).

There came together a combination of medical advances, which allowed treatments to be adapted for home administration, of technical developments (especially of sterilised, disposable equipment, and of the rapid development of computerised equipment capable of supporting the delivery of sophisticated treatment regimens), and of a cultural shift to more liberated family-centred health, with accompanying patient rights and empowerment. These factors all coalesced and, as part of a dynamic process, generated the conditions required for home care. In paediatrics this was encouraged still further by many parents who, seeing the distress caused by hospital admissions, preferred to deliver the care themselves, and to give their child a more 'normal' life. This child-centred philosophy of caring for chronically ill children, rather than the traditional disease-centred philosophy associated with the medical profession, is now commonly found in
paediatrics.

Many studies which profess to examine parental responses to chronic childhood illness have, on further scrutiny, only collected data from one parent, usually the mother (Sabbeth, 1984; Keller and Nicolls, 1990). Whilst more recent articles are more likely to consider the father, the earlier reports which examined the transition to child-centred care were written in the 1960's and 1970's. During this period it was the mother who was considered to be the main child carer, especially during childhood illness. The articles from that time reveal the concentration of attention on the mother. Although discussion of that research reflects the views reported, it must be recognised that these reports neglected to consider the role of the father, they did not provide evidence of fathers' non-participation in childcare.

The implementation of unrestricted visiting and resident mothers placed both nurses and mothers into new roles (Stacey, 1970). Initially there were stressors for the nursing staff as they considered the ward to be full of strangers, that they themselves were always on show, and that mothers might be critical of the way their children were cared for. Mothers initially found themselves with their child, but not able to provide care for their child. Nurses gradually began to transfer some of the routine care of the child, such as washing and dressing, to the mother. Nurses in turn had certain new tasks to perform for the mother, such as providing extra information and support. The sharing of the child care was negotiated by trial and error much of the time, rather than by planned strategy.

Personal preferences of mothers and of nurses have been influential in how hospital policies on shared care have developed (Stacey, 1970), and also in how individual children are cared for as in-
patients. External factors are also known to exert pressures upon mothers and other care-givers in their decisions regarding being resident or regarding the length of time they can visit. If there are others at home who require care, be they other children, a spouse, or an elderly relative, it may not always be possible for a care-giver to dedicate as much time to the one child in hospital. Some employers are more sympathetic than others to the demands of parenting a sick child.

A far greater change in the role of mother and nurse in the care of chronically ill children has been a result of the shift to home-centred care, where the majority of treatments are delivered at home, usually by the parents. For example, treatment for diabetes mellitus has been carried out at home for many decades - it is the only way a child with IDDM who requires insulin each and every day and a restricted diet at every meal could be treated. Episodes of instability, when the blood sugar becomes too high or too low were frequently treated in hospital until the 1980’s. Now it is only on infrequent occasions that in-patient treatment is required. New technologies allow all families with a child with IDDM to be able to monitor blood sugar levels at home, rather than urine glucose levels. This development allows the parents and child to know accurately the risks of a hypo- or hyperglycaemia attack thus enabling them to avert such an attack before it occurs, by administering insulin or glucose.

Paediatrics has become increasingly specialised, and is likely to continue to do so (MacFarlane and Mitchell, 1988). Paediatric Endocrinology, Paediatric Nephrology, Paediatric Oncology, and other specialities often have their own wards or units, staffed by specialist consultants and equipped to care effectively and
specifically for children with the requisite condition. There have been additional nursing staff appointed to care for the most demanding and the most common chronic childhood illnesses.

Inclusion of liaison nurses for patients with specific medical conditions at many paediatric units gives the parents a source of information and advice at the end of the telephone. Specialist liaison nurses have often completed post registered training courses in caring for children with specific medical conditions such as diabetes, cystic fibrosis, asthma, cancer and renal failure. As many chronic childhood conditions also require other specialist care some units have their own dietitians, physiotherapists, psychologists, social workers and play therapists. These staffing units are known as "multidisciplinary teams" and team members plan and coordinate the treatment of the child together with the parent. Most care still takes place in the home setting, being delivered by the parents, but there is guidance, support and expert knowledge available to all the parents and children.

The transition to parent-delivered, home-centred care has had tremendous organisational effects in the paediatric units, as well as upon the families themselves. Paediatric units are now required to provide the facilities and knowledge for parents to deliver care in their own home. Nurses may encounter the children only at clinic or at times of change or crisis in the ward. Parents of newly diagnosed children have to meet the multidisciplinary team, identify who provides which information and services, and to recognise the best routes for care of their children. Nurses and other health care professionals are now required to assess not only the child and his or her health, but also the parents' ability and requirements to carry out the home treatment. Whilst diagnosis of a
chronic illness or disability in a child represents a major stressful event for all family members (Leonard, 1994), it is but the start of a long process of day-to-day management of the child and their illness (Canam, 1993).

End Stage Renal Failure (ESRF) has only recently been treated in children. It is a condition with substantial treatment demands on the parents, uncertain outcomes and is reported to have considerable effect on the family situation. The thesis will further examine the parental consequences of caring for a child with ESRF, and will draw comparisons with other chronic illnesses.

**Parental adaptation to chronic childhood illness**

Parents, rather than the children themselves, are usually responsible for the administration of treatments. This is especially the case with younger children. For most families there is a gradual transition of responsibilities and tasks from parents to child, until either in late adolescence or early adulthood the 'child' assumes the care themselves. In families where the child has a debilitating or progressive condition this transition may never be fully achieved.

Parents of chronically ill children face a number of tasks in adapting to their child's illness. The main tasks not normally encountered by parents of healthy children but that parents must face when caring for a chronically ill child include: the day-to-day management of the child's condition; coping with ongoing emotional demands and stressors, and also with crises as they arise; educating others about the child's disease; and establishing an effective support network for family members (Krušik, 1980; Deatrick *et al.*, 1988; Hauenstein, 1990; Butler Simon and Smith, 1992; Canam, 1993).
Day-to-day management of the child's condition.

Day-to-day management is mediated by specific characteristics of the chronic illness, age of the child and family situation. Parents caring for chronically ill children have to adapt their lives, and those of their children, to accommodate the extra tasks involved in the treatment. Such adaptation may include reducing the hours spent outside the family unit, decreasing the hours spent in paid employment outside the home, reducing social contacts and leisure time and learning new skills and knowledge (Cowen et al., 1985). There have though been few studies which have included an estimate of the parental burden in chronic childhood illness (Hauenstein, 1990). Some examples of day-to-day management tasks required of parents when caring for children are outlined below.

Children with IDDM require insulin by injection two or three times every day. They also require the diet to be well balanced, and to contain a recommended amount of carbohydrate. Whilst approximately 15% of children aged five years and under begin to administer the insulin themselves, the mean age at which children start to inject their insulin themselves is about eight years old (Parker et al., 1994). It is probable that children administering their own insulin at such young ages will have it drawn up by their parents, or at least under their parents supervision. Parents of children diagnosed at an early age will be required to give insulin injections for many years, and will be responsible for the preparation and monitoring of the child's food.

It can be difficult for parents to manage their child's food intake when the child starts to attend school, where parents can no longer keep such a close eye on the child nor on what they are eating, or
drinking. As children enter adolescence most begin to want greater independence from their parents and to take on some of the tasks involved in daily care. It might be anticipated that the transfer of diabetes management to the adolescent child could be difficult both practically and emotionally for the parents. IDDM can become a little unstable in puberty due to children experiencing growth spurts and hormonal changes as well as an increase in life stresses (Cerreto and Travis, 1984). This may make parents cautious about allowing their child to make decisions about their food intake and the insulin administration.

Children with chronic renal failure may need the replacement of renal function via either dialysis or transplant, combined with a parallel dietary regime. Even conservative treatment requires medications to alter biochemical effects of food combined with the parallel dietary regime (Watson et al., 1988). Children on hospital haemodialysis need to attend the hospital three times each week for approximately four hours a session. They need to follow a special diet to help reduce build up of metabolised waste products or harmful minerals. Minor surgical procedures are required to provide access for the dialysis. Children on home peritoneal dialysis usually need to be dialysed on at least six days or nights a week. Those children who have undergone a successful transplant are still required to take daily medications and attend outpatient clinics regularly (Balfe and Watson, 1986).

Generic issues that parents caring for children with chronic childhood illnesses have to address include: maintaining an appropriate level of vigilance for symptoms of their child’s illness (Hauenstein, 1990); attending out-patient clinics and liaising with the multidisciplinary team (Bodkin et al., 1982; Henley and Hill,
Family structure and resources affect the way in which parents care for their child. In practical terms, the number of children in the family, whether parents are working outside the house, the tangible resources available to the family such as transport, housing and finances, require taking into account when considering a family's management of their child and their condition and treatments (Steinhauer et al., 1974). Also, the information and knowledge that parents have about the disease and the treatments affect how well they can make informed decisions about which treatment option their child will receive (Waissman, 1990), and how effectively they can manage their child's illness (Henley and Hill, 1990; Butler Simon and Smith, 1992; Canam, 1993).

**Coping with ongoing emotional demands and stressors.**

Emotional adaptation when caring for a chronically ill child may be a long process, with changes in the health of the child affecting the parents' well-being (Fraley, 1990). Stressors associated with the day-to-day management of the disease may be constant or of a more varied nature, and have to be addressed alongside the every day stressors of parenting (Grey and Thurber, 1991).

When the emotional responses of parents caring for children with chronically ill children have been investigated, the findings have been mixed, with poor parent psychological adjustment reported by some but not by others. Many of the reports have been criticised for not using comparison or control groups, for not taking the age of the child into consideration and for only assessing the parents on one occasion (Henry Sawyer, 1992). There are studies that do however address at least one, if not all of these criticisms.
Fife, Norton and Groom (1987) investigated family adaptation in the case of childhood leukaemia, collecting data over the initial 12 month treatment period. They found that anxiety levels in both mothers and fathers decreased over the study period, from diagnosis, through radiation therapy, and to 12 months post diagnosis.

Golberg, Morris, Simmons et al (1990) compared stress between parents of infants with cystic fibrosis, parents of infants with congenital heart disease and with infants of children with healthy babies. Using the parenting stress index, scores were available for child, parent or life stress. Parents of chronically ill children consistently reported more stress than those of healthy children, and these differences were most consistent among Child domain scores. There were few differences in the Parent domain scores, except that parents of ill children reported more depression. Parenting stressors were increased for mothers compared to fathers. However some of the difference in the parents' stress levels was a result of the infant's age. Parents of babies with congenital heart disease reported the highest stress score and had the youngest (mean 3.4 months) infants, Parents of children with healthy babies had the lowest stress scores, but also had the oldest infants (mean 6.3 months). However when the child's age was considered as a covariate in the analyses there was no significant reduction of the effect of diagnostic group on the total stress scores.

Walker, Van Slyke and Newborough (1992) also carried out a comparison study of mothers of children with one of three chronic medical conditions, cystic fibrosis, diabetes, or mental retardation and of mothers of healthy children. The study utilised measures of family stress, maternal depression, maternal parental esteem and
child adjustment. The results indicated that reported generic stress of those families where a child with a chronic medical condition was present was similar to that of families with healthy children. This suggests that the family functioning is not significantly disrupted by the presence of a child with a chronic condition. However within the medically diagnosed groups there were differences in the report of stressors specific to the child's disability, with cystic fibrosis eliciting more concerns. Mothers reporting greater care-taker burden also reported higher depression scores, and lower levels of parenting satisfaction or efficacy. This study suggests that severity of illness or a greater care burden have negative effects upon the psychological well-being of mothers (Walker et al., 1992).

**Educating others about the child's disease**

Parents need information to help understand the child's medical condition, to be able to make informed decisions about the treatments, and to carry out the prescribed treatment regimen. Parents also need information for other, less treatment focused reasons. The parents live, with their child, in a social world. Parents relate to their ill child and to their other children, to other close relatives such as grandparents, and to friends and work colleagues. Parents also have social interactions with other adults on their child's behalf, such as general practitioners and teachers. Within this social setting some people want to be informed of the child's illness and treatments, not least the child themselves, and the parents often find themselves in the position of educator.

Parents often inform their sick child about the illness, treatments and future. Sometimes this may be explicitly requested of the parents, but often it is just assumed that parents will know best not
only what but also how, and when, to tell their child about the illness.

Little research has been carried out to investigate where children gain information about their illness from, but it is acknowledged that in the doctor-parent/child consultation the majority of information is provided to the parents, not the child. Korsch, Gozzi and Francis (1968) reported that in paediatric visits 12.6% of interactions were with the children, but that only 0.8% of interactions were in non-social areas of communication (Korsch et al., 1968).

More recently Pantell, Stewart, Dias et al (1982) found that children were involved in a greater percentage (45.5%) of interaction with doctors than found by Korsch et al (Pantell et al., 1982). Pantell et al also found that children were more involved in substantive information. Further analysis though, revealed that children were primarily involved with imparting information (about symptoms etc.) rather than in receiving information. Physicians provided feedback primarily to the parents, who received more than three times as much information about diagnosis and treatment than did the children (Pantell et al., 1982). Pantell et al explore possible causes and outcomes of physicians low levels of communication with children, but conclude that "it is parents who bear the responsibility of interpreting and implementing the physician's judgement's" (p400, italics added).

Paediatricians know that in the majority of cases it is the parents who deliver the care and therefore direct most information to the parents. Outcomes of this practice might be that children receive less information about their medical condition and treatment than they might wish, and that they will probably be reliant on their
parents for the majority of their information. Some studies which have investigated the amount of illness-related information that children possess report worryingly low levels of knowledge (Bennett Johnson et al., 1982; Auslander et al., 1991).

Parents need information to educate the child, to be able to explain to them the reasons for certain treatments and the likely consequences of health related behaviours. Krulik identified that in families with children suffering from either cancer or cystic fibrosis it was unusual for the treatment regimen to be imposed on the child without giving them some input on the decisions that were made (Krulik, 1980). This process cannot occur without the imparting of some information to the child, and a semblance of understanding on the part of the child. If provision of information is not often occurring in the doctor's consulting room then parents are required to do it themselves. This process of parent as information-provider is not inappropriate however, as all parents are the providers of much information to their children both formally or informally.

Paediatricians and other members of the multidisciplinary team can recognise explicitly that parents have a major role in educating their child about the medical condition and treatments. Parents may need guidance, perhaps from a child psychologist or from parent support groups (Canam, 1993), and the health care professionals can ensure that they are aware of what information parents have imparted to the child. Also health care professionals might try not to use children solely to gain information without providing further in return. Children are interested in clinical information (Lewis et al., 1991), and those children who are involved in discussions about their treatments, and who are able to explain their condition to others are reported to cope more effectively (Canam, 1993).
Parents may also educate other family members about the child, the condition and the treatments. Which family members might need or want such information will depend upon the family structure and social contact. If there is more than one child in the family, siblings will often want to be informed about the ill child.

If there are grandparents they will want to know 'what is wrong' with their grandchild, and what the treatments will entail. The majority of grandparents consider their grandchildren an important aspect of their lives (Papalia and Wendkos Olds, 1992, p523), and so will be anxious to understand as much as is possible and to know what to expect for them. Grandparents are usually informed about their young grandchildren from the parents, and although grandparents may attend outpatient clinics on some occasions it is not typical for most families. An illustration of how interested grandparents are in the health of their grandchildren can be seen from a study carried out in a paediatric outpatient clinic in Birmingham, UK (Rylance, 1992).

Paediatricians tape recorded 304 consultations with the consent of the parents. The parents were then free to take the tape home with them, 72% thought that grandparents would wish to listen to it. 286 parents returned a completed questionnaire at a later date which provided information about how the tapes had been used. 151 (52.8%) tapes had been listened to by grandparents, and this had been considered helpful in all but one case (Rylance, 1992). The report did not disclose the length of time between the recorded consultation and the returned questionnaires, but it is possible that the discrepancy between number of tapes anticipated to be heard by grandparents (72%) and those actually heard by grandparents (52.8%) could be due to lack of time or opportunity. The
discrepancy could also be due to parents not wanting the grandparents to hear it even though acknowledging that the grandparents might wish to do so. In 49 cases other relatives (excluding siblings) had also listened to the tape recording (Rylance, 1992).

Siblings of chronically sick children have information needs about their brother or sister. It has been reported that sibling illness can rank amongst the most stressful life events in childhood (Siemon, 1984). The Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) have included "The Need for Information" in their charter (ACT, 1993), and have stated:

"Information shall be provided for the parents, and for the child and the siblings according to age and understanding. The needs of other relatives shall be addressed"

(page 11)

ACT explain further that "brothers and sisters, who may be left out, need information to explain the devastation and turmoil that has engulfed the family." (p11). ACT recognise that there are occasions when no formal effort is made to ensure that siblings of serious medical conditions are adequately informed.

In a small but detailed study of ten siblings of children being treated in a hospice, none had spoken to a doctor about the illness, although three of them expressed a wish to do so (Stewart et al., 1992). In the study of tape-recorded paediatric consultations, 45 of the tapes (15.7%) were reported to have been listened to by siblings, suggesting interest on their part and also parents willingness to use extra resources to inform their children (Rylance, 1992). Unfortunately the parents only considered that the sibling listening
to the tape was useful in just over a third of cases. This could reflect either the level at which the information was pitched, or perhaps due to the siblings being relatively uninformed to begin with.

Siemon (1984) reports that siblings can arrive at theories of illness based on their own fears and developmentally immature perceptions, which often lead to faulty conclusions. Siemon notes that siblings rarely have direct access to professional sources of information, often gathering their knowledge from what they overhear doctors telling parents and parents telling relatives (Siemon, 1984). Doyle (1987) identifies hospitalisation of a sick child as a particular risk time for siblings, especially if they are left at home far removed from the discussions and may not hear about developments at the hospital (Doyle, 1987).

Parents have to make decisions about their children, and a commonly reported dilemma is what to tell a child about their brother or sister's serious illness, and what can he or she be expected to understand (Sabbeth, 1984). Parents can sometimes decide to 'protect' siblings of an ill child by excluding them from full participation in family problems and by restricting the information to which siblings are privy (Siemon, 1984). Siblings are sometimes reluctant to ask questions, either because they do not wish to burden their parents further (Siemon, 1984), or because they may feel guilty or frightened about what they may hear (Doyle, 1987). Silence can be misunderstood by the parents as understanding, acceptance or indifference.

Siemon (1984) compiled a list from the literature, which identified six broad categories of questions that siblings of chronically ill children may have; about causation/prognosis; about their own health; about the unfairness; about feelings; about the future of the
Some children may be reluctant to discuss a sick sibling even when their brother or sister is seriously ill. In the study of siblings of children being treated in a hospice, five had a reasonably clear idea about the sick child's illness, but the other five had very little idea and had never really discussed it with anyone (Stewart et al., 1992). Some siblings might use denial as a short-term coping strategy, but when they do want information it appears that their main source is the parents. Again, in communicating information to child-siblings parents may need guidance, perhaps from a child psychologist or from parent support groups (Canam, 1993).

As children spend more time at school than in any other setting outside the home consideration needs to be given to the informing of school employees, especially teachers. During their training teachers are not routinely given much medical information or advice about teaching ill children (Westbom, 1992b). One report showed that even experienced teachers rate their knowledge of childhood illness as low, and express fears of medical emergencies in the classroom (such as asthmatic attacks and epileptic fits) (Eiser and Town, 1987). The authors suggest that in co-operation with the parents, school doctors and nurses have to inform the teachers about individual children's illnesses and needs. However for children with uncommon or complex diseases it may be that the specialist doctors and nurses may provide information at some point.

In a study of parents' opinions and experiences of informing schools about children's chronic illnesses, 85% of the parents indicated that they had spoken to school personnel about their child's illness (Good Andrews, 1991). 21% of parents indicated that the physicians
had been in contact with the school. Parents indicated that, whilst they wanted the physicians to provide the school with information on some aspects concerning the physical considerations, they overwhelmingly believed that they should be the primary informers. Parents reported that it was the teachers that needed the most information about their children's health problems, but that the principal and school nurse would also need to be informed about some issues too. When the chronic illness was likely to worsen, likely to lead to emergencies or was visible in some way parents were more inclined to support more information being provided. Parents indicated that there were limited aspects of the child's illness that their classmates needed to be informed about (Good Andrews, 1991).

Parents are identified by these studies as the primary informers of teachers about a child's chronic illness and treatment. Moreover parents appear to support this position. However there is evidence that parents would still appreciate input from the health care professionals involved with their child. This may be for doctors to directly educate the teachers regarding some topics, but may also include provision of further information to the parents so that they can then decide which details they wish to communicate to the teaching staff.

**Establishing an effective support system for family members**

To deal effectively with a chronically ill child parents must establish a support system in order to meet their needs for esteem and emotional support (Canam, 1993). A support system can consist of both formal and informal sources of support, which are usually of a social nature. The types of support that people receive can include: emotional support (empathy, caring and concern), esteem support
(expressions of positive regard, encouragement or agreement, the building up of an individual's feelings of self-worth), tangible support (direct assistance, such as help with the housework, financial support), and informational support (giving advice, suggestions and feedback).

Social support plays an important part in all peoples lives, and Cobb (1976) suggests that people with social support believe they are loved and cared for, esteemed and valued. Social support is thought to be useful not only because of the positive emotional feelings it can produce, but also because there is evidence that it can reduce the stress that people experience (Turner, 1981).

Whether people receive social support depends in part upon their social network, that is the links they have with people in their family and community. Social networks can differ in size (the number of people with whom one has contact), frequency of contact (how often one sees these people), composition (whether these people are friends, family, work colleagues and so forth), and intimacy (the closeness of individual relationships). One common and often continuous source of support is found in adult long-term loving relationships such as marriage.

Canam (1993) reports that for families of a child with a chronic medical condition it is often difficult to develop support networks (or even to use existing resources) because of the demands on the family's time and energy. Cowen, Corey, Keenan et al (1985) investigated family adaptation where there was a preschool child with cystic fibrosis. As part of the study, parents completed the Problem Inventory. Analysis showed that problem-ratings corresponded with what could be interpreted as negative descriptions of consequences of the child having cystic fibrosis, such
as "extra demands on time", "pressure to do the right thing to take proper care of the child", "life centred around the child", "need to constantly watch the child".

Analysis of a control group of parents of healthy children revealed however that their rating of problems were very similar for "extra demands on time", "life centred around the child", "need to constantly watch the child". It was only "pressure to do the right thing to take proper care of the child" that parents of children with CF rated highly that control parents did not. The authors suggest that this ranking of problems revealed more about parenting children of this age than it did about caring specifically for children with a chronic medical condition (Cowen et al., 1985).

This finding of Cowen et al. (1985) demonstrates the need for caution when interpreting research about the adaptations required of parents when caring for chronically ill children. Caring for children, whether healthy or otherwise, will always involve parents in child-rearing tasks that create their own physical and emotional demands and psychological consequences. Unless studies consider a comparison group of parents it may be inadvisable to draw conclusions about aspects of care specific to the child’s chronic illness.

Loneliness can occur as a result of low social support, and Florian and Krulik (1991) report that mothers of children with chronic illnesses experience higher feelings of loneliness than mothers of healthy offspring. Mothers of chronically ill children did report that the perception of social support lessened some of the feelings of loneliness, however this was not the case for those mothers whose children were suffering from a life-threatening disease (Florian and Krulik, 1991).
Much of the social support a married (or cohabiting) person receives may come from their partner. If caring for chronically ill children has detrimental effects on the marital relationship it may reduce the social support available to the parents. Using qualitative research Butler Smith and Simon (1992) examined parents' perceptions of living with a child with chronic severe liver failure. Parents identified intimate communication between themselves and their partner as very important. Also sharing the responsibilities of care with the spouse was seen to reduce the burden (Butler Simon and Smith, 1992).

Sabbeth and Leventhal (1984) carried out a critique of the literature to assess marital adjustment to chronic childhood illness. They found that divorce was no more common in families of chronically ill children than in families of healthy children. Analysis of the 19 studies of marital distress revealed that only seven used a comparison group. Of these seven studies, four found that parents of chronically ill children experienced more marital distress than parents of healthy children. Although the other three studies did not show such differences they were considered to be methodologically less robust (Sabbeth and Leventhal, 1984). The authors conclude that marital distress does appear to be increased when there is a chronically ill child in the family, but suggest further research be carried out into the possibility that marital conflict may have an adaptive function in some families.

In a study of family adaptation to childhood leukaemia, Fife, Norton and Groom (1987) investigated the marital adjustment of parents. Whilst there was no comparison group, a measure was selected for which values had previously been obtained for couples experiencing marital difficulty and for couples judged to be well-adjusted.
their longitudinal study (from diagnosis and then for 12 months after) Fife et al found that initial scores taken at the time of diagnosis were considerably lower than the previously reported score for well adjusted couples; however they were also above the mean for couples known to be experiencing marital conflict. Further analysis indicated a decrease in marital happiness for both parents over the year of the study (assessed on six occasions) (Fife et al., 1987).

Parents caring for chronically ill children may find that they have less opportunities for social contacts outside the house. Westbom (1992a) found that parents of severe or moderately severe chronically ill children participated in leisure activities less often than parents of healthy children. Also whilst 85% of parents of healthy children found it possible to go out together this was the case for fewer parents (75%) of severe or moderately severe chronically ill children. Using babysitters was also considered possible by fewer parents of chronically ill children than by parents of healthy children.

As severity of the illness increased so did the difficulties parents had of obtaining help when needed. Difficulties obtaining help were reported by 33% of parents of severely ill children, 22% of parents of moderately ill children and only 11% of parents of healthy children. Parents of children with only minor illnesses reported a greater tendency for relatives, friends and neighbours to provide help than did parents of more severely ill children (Westbom, 1992a). This study suggests that for families with children who have more severe everyday limitations due to illness, there are decreased opportunities to develop, sustain or utilise social support.

Henry Sawyer (1992) also reported that parents of preschool children with cystic fibrosis were not satisfied with their current
amount of time for leisure and recreational activities; however this was also the case for parents of the healthy preschool children (Henry Sawyer, 1992). Again this may reflect more about the demands of parenting children in this age group than it does any specific information about caring for a child with a chronic illness.

Parents of children with cystic fibrosis also reported no significant differences with their satisfaction with the relationships they had with their friends and relatives nor with relationships at work (Henry Sawyer, 1992). It has been reported that mothers may be more likely than fathers to suffer loss in their social life when their child is seriously ill (Stewart et al., 1992). Finally, in qualitative research findings it was noted that mothers expressed great appreciation for people who voluntarily stepped in to carry out necessary activities such as babysitting, housework, sibling activities or who helped relieve the parents constant vigil when their child was hospitalised (Butler Simon and Smith, 1992).

When asked about social support they might receive, mothers of chronically ill children do not always include formal caregivers as a perceived source of emotional or tangible support (Florian and Krulik, 1991). Parents can sometimes be helped by other parents in a more formalised setting. Self-help support groups organised by or for parents caring for chronically ill children can be useful to those who attend. Support groups allow parents to exchange information about their experiences and to reassure themselves about their child’s future (Argles et al., 1994).

Peer support can also help parents of chronically ill children to further acceptance and understanding of their child’s condition, to develop adequate coping strategies and to benefit from the experiential learning of other parents (Hartman et al., 1992). Peer
support networks can be encouraged by health care professionals responsible for the child's treatment.

In Michigan a coordinated network of parents with special needs has been established (Hartman et al., 1992). Initial training was provided to parents. Trained parents then organised the support network themselves and trained other parents to provide peer support within a framework of confidentiality and privacy for the assisted families. Peer support parents carry out a number of tasks which may involve liaising between parents and professional service providers, it may involve gathering information or provide one-to-one support for a family. It is reported that support parents can offer the advantage of shared experiences and can also be positive role models within a new social reference group (Hartman et al., 1992).

The report does not acknowledge any drawbacks to the provision of peer support through such a network, but acknowledges they can be powerful tools in the adaptation of parents to the care of their child. Such a powerful tool will have potential drawbacks if managed inadequately or incompetently. The setting up and running of such a programme of support would perhaps require access to professional advice from psychologists and other support workers.

**How parents cope with caring for a child with a chronic illness.**

Coping refers to responses to life strains, responses that serve to prevent, avoid or control emotional distress. Coping depends upon the resources available to an individual such as social support, skills to solve problems, and a system of beliefs (Gibson, 1988). Individuals employ different tactics to prevent, avoid or control
emotional distress, and these are referred to as coping strategies.

Coping resources and coping strategies

Social support is frequently mentioned as a valuable resource which assists parents with chronically ill children in the efforts to cope with the concerns and the burden of care (Gibson, 1988; Eiser and Havermans, 1992; Jennings, 1992). As discussed earlier there can be difficulties for parents trying to develop or maintain a support network. In one study of parents with chronically ill children it as found that even though 26% of the mothers had no relatives living within 30 miles radius, the extended family was still considered to provide the most support (Jennings, 1992).

Health care professionals can help families maintain their social support network by considering whether a babysitting service might be initiated, or by encouraging the parents to begin a support group. Professionals can sometimes be aware of both local and national organisations that can help introduce parents to other parents caring for chronically ill children.

As it is the spouse that is frequently reported as the most helpful source of support (Gibson, 1988; Butler Simon and Smith, 1992), providing support to both parents is often a beneficial goal of a multidisciplinary team. For example, if a mother has primary care for the child but is in need of greater support it may be possible to increase the father's support to her, perhaps through educating him so that he can help more, or understand the mothers difficulties more. Such support will be available for more of the day and for a longer period of time than any formal support could be. Nurses may be able to encourage mothers to allow the grandparents greater responsibility in the care of the child. Such an approach can help
improve the support resources available to parents caring for chronically ill children.

Parents can also be helped to cope by assisting them to develop problem-solving skills. If parents are trained to look after their child without understanding the mechanisms behind the disease and treatment then they are more likely to feel inadequate and unable cope when problems arise. By teaching the parents to understand the condition it is more likely that parents will be able to formulate solutions to problems as they are encountered. Developing parents' problem-solving skills can enable them to draw upon their own resources more, to feel less overwhelmed and indirectly to contribute to a more positive attitude to the treatment of their child (Gibson, 1988).

Parents also have a system of beliefs, about the health of the child, their own capabilities and the competence of the medical and nursing teams. Beliefs about personal efficacy and ability, and of love for the child can be strong motivating forces for parents to do one's best when dealing with the difficulties encountered when caring for a chronically sick child (Gibson, 1988). Religious beliefs can also help parents to cope, and over one third of mothers caring for children with either cystic fibrosis or tracheostomies reported that they used prayer as a coping strategy (Jennings, 1992). Hoping for a miracle has also been reported as a helpful belief for some parents (Gibson, 1988).

There are several theoretical models of coping but most models make the assumption that coping can be construed in two ways (Eiser, 1993, p94). Individuals can attempt to cope by either attempting to change or control some aspects of the individual or the environment, or by attempting to manage or regulate the
negative emotions associate with the stressors. Coping strategies are therefore usually action oriented or psychologically oriented (Gibson, 1988). Action oriented coping strategies are referred to as problem-focused strategies in the cognitive appraisal model of Lazarus and Folkman (1984), or as active strategies by Shapiro (1983). Shapiro further defines strategies as either active-positive or active-negative depending on whether the outcome of using the strategy was beneficial or not.

Psychologically oriented coping strategies are referred to as emotion-focused in the cognitive appraisal model (Lazarus and Folkman, 1984), or as passive by Shapiro (1983), again classified as either passive-positive or passive-negative depending on the outcome. Whether a coping strategy is more successful than another is in part dependent upon the nature of the problem. A coping strategy that is effective in one situation may not necessarily be so in another (Miller et al., 1992).

A common action oriented coping strategy is that of delivering the care according to the treatment regime. Delivering effective care to the child can help counteract the threat of the child getting worse, provides the parents with positive feedback regarding their personal efficacy and reinforces the parenting role (Gibson, 1988).

To enable them to deliver the care parents may use other action oriented coping strategies, such as seeking knowledge (Eiser and Havermans, 1992; Jennings, 1992; Miller et al., 1992; Thompson et al., 1992). Seeking knowledge was the fourth most popular coping strategy reported in one study of mothers of children with cystic fibrosis (Jennings, 1992), and had been reported as the most important type of help that parents had received from professionals (cited by Miller et al (1992) from an unpublished doctoral

Other action oriented strategies might include rearranging employment hours to better suit the treatment regime, or actively increasing the resources available by contacting a local support group or by asking grandparents to babysit.

One common psychological coping strategy is adopted when parents develop a perception of 'normalisation'. This does not entail thinking that the disease is normal, rather that the child, and the efforts taken to manage the child's treatment are normal (Gibson, 1988).

Anderson (1981) obtained parents' accounts of their child's illness, and their management of the treatments. The children had a variety of chronic illness, all of whom were cared for at home. Parents emphasised how normal their child was, and recounted how the treatment was managed so that the child would not stand out as being different (Anderson, 1981).

Krulik identified how parents employed action oriented coping strategies to facilitate the normalising process. An example of this would be preparing themselves, the child and others about what to expect, so that when treatment-related events such as hair loss occurred they could be considered normal. To be able to employ such strategies parents require information and knowledge about the condition and the treatments. Information is also required for parents to care for a chronically ill child at home and to be able to carry out the practical aspects of care.

Holaday (1984) also identified normalisation as a common coping strategy of parents caring for a chronically ill child. Some psychological coping strategies have been reported to have negative
effects on the well-being of parents, such as internalising feelings of frustration (Miller et al., 1992), or increasing depression (Thompson et al., 1992)

Situational factors are reported to influence whether a certain coping strategy will have a positive outcome or not. Miller et al (1992) report that emotion-focused coping was associated with increased psychological distress in mothers of disabled children, this was not the case for control mothers of nondisabled children. They also identified that problem-focused coping strategies reduced psychological distress in mothers of disabled children, though again this was not the case for the control mothers.

Summary

This chapter has introduced the topic of chronic childhood illness in general terms. Parents of children with chronic childhood illnesses now bear the burden of home care. Whilst this is probably the only economic option within the NHS, and also allows the child to live a more normal life than one spent in hospital much of the time, there may be a price to pay.

Parents have to undergo a process of adaptation to enable them to deliver the care for their child in the home setting. Parents have to cope not only with the usual tasks of parenting but also with the day-to-day management of the child's condition, with the ongoing emotional demands and stressors, with education of others about the child's disease, and yet still establish and maintain an effective support network for family members.

It is possible to consider some aspects of caring for children with chronic childhood illnesses using a generic framework to identify the common difficulties for these parents. This may be beneficial
when parents or health care professionals are trying to convey needs or difficulties to others, as the needs can be seen to be shared by a greater number of parents or children. Where conditions are rare there may not be sufficient numbers of families with that disease to be able to demand better facilities or information provision. However, when the total number of children with chronic childhood illnesses is estimated to be at least 10% it may be of use to discuss them as one group.

There is a risk though that by treating families with chronically ill children as a homogenous group, researchers might obscure some important but specific problems that parents encounter caring for children with specific medical conditions. For example, some diseases carry a much greater social stigma than others and this will have effects on parents being willing to seek social support. Factors such as the predictability of an illness, threat to life and complexity of treatments also impact upon the family, and it is sometimes questionable how some reports generalise from studies on one subject base.

There is need for caution when interpreting research about the adaptations required of parents when caring for chronically ill children. Studies ideally include comparisons groups both of parents of healthy children and of children with other chronic illnesses. This would permit researchers to identify with more certainty whether findings relate to all parents generally, to parents of chronically ill children generally, or more specifically to parents caring for children with one illness. This does not however eliminate the problems of ensuring that groups are matched for other potentially influential factors such as the age of the child.
Chapter Two

End-Stage Renal Failure in Children

The kidneys are the body's main organs of excretion, filtering the blood as it passes through the very tiny vessels of the kidney. Blood, carrying waste products from the body's normal metabolism, urea, toxins, mineral salts, enters the kidneys where the waste products are removed into a solution we know as urine. The urine is sent from each kidney, via a ureter, into the bladder. The blood leaving the kidney returns to the main circulation cleansed and able to collect more waste products. The kidneys are immensely effective, filtering 180 litres of plasma each day (Lote, 1994), also if one kidney is missing or damaged the remaining kidney can continue to cleanse the blood just as effectively as two.

Renal failure is when the function of the kidneys is insufficient to clear all of the body's waste products. This condition can either be acute or chronic. Chronic renal failure, in contrast to temporary, reversible acute renal failure, is marked by not only an irreversible decline in the capacity of the kidneys to remove poisonous wastes, but also an irreversible decline in the kidney's inability to extract excess fluids. The decline of renal function eventually reaches a point where it is fatal without treatment and renal replacement therapy. The condition once at this point is known as end-stage renal failure (ESRF).

Renal Failure & Renal Replacement Therapies: A historical perspective

Successful treatment of ESRF is a modern phenomenon, and has
been carried out only over the last 30 years or so. Renal replacement therapies (RRT), as their name suggests, are treatments which are able to carry out the most vital functions of the kidney, removing waste products, and removing excess fluid. These therapies are in contrast to conservative treatments which manipulate and reduce the amount of waste products and fluids that the kidneys need to excrete. Conservative treatments usually combine fluid and dietary restrictions, and may also include medication to reduce some mineral salts.

Renal replacement therapies replace lost kidney function either by dialysis (removal of the excess waste products and fluid via a dialysing membrane and dialysate fluid), or by the surgical transplantation of a replacement kidney. Dialysis is carried out either by haemodialysis which cleanses the blood using an artificial dialysing membrane and dialysate fluid outside the body, or by peritoneal dialysis which uses the patient's own peritoneum and an introduced dialysate fluid to cleanse the blood. Peritoneal dialysis became a possibility after Putman extended studies initiated in the nineteenth century and in 1922 defined the peritoneum as a dialysing membrane (Putman, 1922). The first reported use of the peritoneum to remove uraemic substances in man was reported the following year by Canter (Salusky et al., 1982). Wide use of peritoneal dialysis in the clinical setting was initiated by the report of Maxwell et al. in 1959 (Maxwell et al., 1959).

Work had also been going on to develop artificial dialysing membranes, and the first haemodialysis machine was designed as early as 1943 by Kolff, a Dutch physician, which was improved and effective enough to save a life just two years later (Halper, 1989, p3). The widespread clinical use of haemodialysis was made
possible by a device invented by Scribner and colleagues in the late 1950's which enabled repeated haemodialysis to be carried out without destroying sections of blood vessels for each session (Quinton et al., 1960).

It can be seen then that these two alternative methods of RRT were developed and introduced into clinical practice concurrently. Coincidentally, kidney transplantation was also developed and introduced over the same time period.

The earliest human kidney transplants took place in the first decade of this century (Hamilton, 1988), though none functioned successfully either to produce urine or to prolong life. A revival of interest occurred in the 1950's as evidence grew that immunological mechanisms were involved in the previous failure to transplant a kidney successfully. Two groups simultaneously restarted human kidney transplantation (much work had continued on attempted animal kidney transplants), in Paris and in Boston with limited success.

Due to the problem of rejection, only transplants where the kidney allograft was obtained from a monzygotic twin were successful during this time, but the experience did help increase and improve knowledge about the requisite surgical techniques (Hamilton, 1988). Initial attempts at immunosuppression were carried out in the early 1960's and some sibling transplants were successful, thus indicating that further success might be obtained in non-twin cases.

It was the discovery and introduction of azathioprine (a derivative of an anti-cancer drug, 6 M-P) in 1961 that led to the first extended successes with kidney allografts (Murray et al., 1960). With the regular use of prednisolone (a corticosteroid) in combination with
azathioprine, transplants from live related donors were very successful. Tissue typing was introduced into the transplant routine in 1962, and then the direct crossmatch between donor cells and recipients in 1966 (Hamilton, 1988). These techniques for matching donor and recipient reduced the amount of rejection and made cadaveric (those from dead donors such as accident victims) transplantation a much more successful and attractive treatment.

Transplantation was also helped by the concurrent development of dialysis as a successful treatment, as this provided a 'holding' treatment until a donor kidney became available. In the mid 1970's cyclosporine was added to the drug regime to fight rejection (either alone or with azathiaprine and prednisolone) and successfully extended the success of kidney transplantation still further.

Most of the early work on renal replacement therapies concentrated on adult patients, as success was much harder to achieve with children. It was only in the late 1960's that dialysis and transplantation was offered to children with end-stage renal failure (ESRF), and then only in a few specialist centres (Chantler et al., 1980). It was still reported in the mid 1970's that at that time half of the children with ESRF were dying untreated because of the lack of facilities (Chantler and Barrat, 1976).

There were several reasons why treatment was not routinely offered to children in the early days of renal replacement therapies. Firstly there were technical difficulties, especially with smaller and younger children. Holliday et al. reported in 1971 that whilst living related donor transplants were quite successful, the mortality rate for children receiving cadaver transplants were alarmingly high, with 6 of the 16 recipients at their centre dying. All of those who died weighed less than 20 kg (Holliday et al., 1971). A further four of the
16 recipients rejected their kidney graft.

By the mid 1970's new shunt materials and surgical techniques allowed application of haemodialysis to children, but their small vessel size continued to present a challenge, especially in children weighing less than 10kg (Mauer and Lynch, 1976). Arteriovenous fistulas remained unsuitable for children weighing 20kg or less, and cannulas which had been developed for venous access were also difficult to use in children under 15kg (Mauer and Lynch, 1976). Secondly there are always financial constraints on the health care providers. When chronic dialysis was introduced only hospital-based haemodialysis was feasible, which was very expensive, both in manpower and money, with ongoing maintenance costs far beyond any previously contracted in medical care. Rehabilitation (and the ability to support oneself) was also less than complete, so this form of therapy was initially reserved for a few selected patients, usually between 20 and 45 years of age (Holliday et al., 1971). In the early years of transplantation there were high rates of complications that were debilitating, often fatal, very costly to cope with, and the treatment remained dependant upon the availability of donated organs (Riley, 1964; Korsch et al., 1971; Hamilton, 1988).

Neither dialysis nor transplantation are curative, and there is no treatment for ESRF that is a "one-off" affair, instead they involve a heavy, continuous commitment for the rest of the patient's life. The introduction of renal replacement therapies meant that each patient accepted onto the programme had to be considered as a consumer of potentially tens (if not hundreds) of thousands of pounds during their lifetime (Halper, 1989c). Accepting children onto a programme was therefore resisted by many health care providers until the success rates for treatments improved to be comparable to
those of adults.

By the 1980's progress in treating children with ESRF had become sufficiently rewarding that few physicians in the UK considered denying children with ESRF access to the treatment available (Chantler et al., 1980; Fine et al., 1987; Winterborn, 1987). The cost of renal replacement therapy was also reduced by the introduction of home based peritoneal dialysis. The transition of care to the home and family had immediate and lasting implications for reducing manpower requirements, and their associated costs. It had also been argued that the rehabilitation of children is more successful when hospital care is minimised and home care is maximised, thus peritoneal dialysis had considerable influence on the increased treating of children with ESRF.

Lastly there were grave concerns about the outcomes of treating children with ESRF. Concerns were expressed regarding the success of the child's rehabilitation and their future; over fear of growth or developmental retardation; about the stress and suffering that may be caused by the treatments; over possible psychological reactions to the erratic medical course; and to the pressures on the parents to carry out the home care regime, and perhaps even to become a live related donor.

In the UK treatment for ESRF has developed within the framework of the National health Service (NHS). NHS resources are strictly limited, and demand for services greatly exceeds supply. The success of dialysis units established in the late 1960's, combined with the increasing number of successful transplants created intense pressure to provide these life-saving treatments (Dennis, 1971). The potential requirements of financing these expense and open ended treatments were beyond the financial scope that the Ministry of
Health was able, or willing, to supply and so the UK policy on treating ESRF was very cautious and modest in its beginnings (Halper, 1989b). So from the onset treatment for ESRF within the NHS framework has always relied on the allocation of resources.

Since these early days peritoneal dialysis has developed greatly and the vast majority of patients are able to receive home centred care and treatment. This is obviously cheaper. More than that however both dialysis and transplants are now much more reliable and likely to prolong life with quite respectable levels of rehabilitation. Both dialysis and transplantation have become technically more sophisticated, and have specific adaptations and regimen for treating young children.

The dietetic management of children in ESRF has also improved. The diet of children in ESRF can, if expertly managed, reduce many of the complications both short term and long term. Dietary restriction of protein and phosphate is beneficial to patients with chronic renal failure. Lowering of the protein intake appears to prolong kidney function, and lowering phosphate reduces parathyroid hormone (Jureidini et al., 1990). Renal osteopathy is also reduced via vitamin D and calcium balance, and high calorie intake to encourage optimal growth rate is also part of the regime.

Management of the child in ESRF also tries to balance the minerals and electrolytes important to healthy functioning of the body, especially potassium which can lead to sudden cardiac failure if allowed to reach to high a level.

Technical advances have meant that chronic dialysis can now be carried out on children of all sizes and ages (even the newborn) and most clinicians are happy to consider transplantation for children
once they have reached 10kg. This combination of factors has led to
the treatment of ESRF being made readily available to children. Of
course decisions about treatment do still take place. The decision of
whether to treat a child with ESRF is made between the paediatric
nephrologist, the general practitioner and the parent. In practice it
is rare for the option not to treat a child's ESRF to be supported
unless the child is newborn and in very severe renal failure, or if the
child has other severe medical problems.

Outcomes of treating children with ESRF have been monitored quite
intensely, with much attention being directed to the long term social
and psychological outcomes, as well as the physical therapeutic
measures.

**Childhood ESRF in the 1990's**

The incidence of ESRF in children is reported at varying rates from 4
to 15 new cases per year million child population (age group 0-15
years) (Donckerwolcke *et al.*, 1983). There is a general consensus
among paediatric nephrologists that renal transplantation is the
main goal for any child with ESRF (Chantler *et al.*, 1980; Almond *et
al.*, 1991; Watson, 1993). Although no treatment for ESRF is a cure,
there are benefits, especially in the rehabilitation and lifestyle of the
child, once they have a successful transplant, over those they have
with chronic dialysis therapy (Gradus and Ettenger, 1982).

ESRF in young children can affect both their mental and physical
development. Infants who have ESRF in the first year of life
frequently have concomitant neurological abnormalities (Fine *et al*.,
1987). Though the etiology of these neurological manifestations has
not been precisely identified the main cause is thought to be the
effect of uraemia upon the brain (Raskin and Fishman, 1976).
However longitudinal testing of infants with onset of chronic renal failure in the first year of life has shown significant improvement in the testing scores following initiation of peritoneal dialysis.

Growth retardation is a common occurrence in children with ESRF, especially for those who have ESRF before the age of two years. Growth lost during that period is rarely able to be compensated for (Fine et al., 1987), although rigorous therapies to address growth can reduce the amount of growth retardation. Ultimate adult height in children with ESRF is frequently more than 2SD below the mean, and short stature is a condition that clinicians have tried to ameliorate (Van Dop et al., 1992).

As anorexia is also one of the effects of uraemia it is often difficult to attain a suitable level of calorie intake, especially if a restricted diet (low protein, low phosphate etc.) is being implemented. If poor appetite is allowed to reduce the dietary intake this can exacerbate some of the effects of renal insufficiency such as bone disease. Older children can be encouraged to take oral supplements despite their lack of appetite, but that is much more difficult in infants and toddlers. They may require a mechanical aid for feeding such as a nasogastric tube (Fine et al., 1987), or a gastrostomy button (Coleman and Watson, 1992).

The gastrostomy button is a small silicone rubber device with a one way valve placed directly into the stomach from the abdominal wall (Steele, 1991). This is a small plastic device inserted directly into the stomach from the child's abdominal wall. Insertion of the gastrostomy requires a small surgical procedure under general anaesthetic, but once in place the button remains insitu until it is no longer required. It is very discrete, and is not visible once the child is clothed nor should it interfere with normal eating and drinking.
Bolus doses of supplementary liquid food can be taken via the tube during the daytime, but there can also be a more continuous feed overnight with delivery being controlled via a mechanical pump.

Bone disease is also a possible complication of ESRF in children. Renal osteodystrophy in infants can result in marked bony deformities, and once these arise complicated and lengthy orthopaedic procedures may be required, which even then may not be able to produce a perfect result.

The main thrusts of treatment in children with ESRF are the replacement of renal function via either dialysis or transplant, combined with a parallel dietary regime, which may or may not include supplements, medications to alter biochemical effects of food (eg. phosphate binders), or even mechanical aids such as nasogastric tubes.

**Management of renal replacement therapy**

*Treatment choices:*

1) Peritoneal dialysis
   - Home CAPD
   - Home CCPD
   - Hospital IPD (intermittent peritoneal dialysis)

2) Haemodialysis
   - Hospital
   - Home

3. Transplantation
   - Cadaveric donor
   - Living-related donor
The preferred mode of dialysis has changed markedly during the past 20 years with the introduction of CAPD for children in 1978 (Balfe and Watson, 1986), and then CCPD in the 1980's (Fine et al., 1987). Prior to this there was only haemodialysis.

**CAPD** involves the manual emptying of fluid into the peritoneal cavity and then drainage out of the same fluid 6 to 8 hours later. Each fill and drain takes 30 to 45 minutes. **CAPD** occurs at intervals during each day with 3 or 4 cycles and 6 or 8 connection/disconnection procedures.

**CCPD** involves the child being attached to a peritoneal dialysis machine overnight, usually for 10 to 12 hours a night, 6 nights a week. It entails only 2 connection/disconnection procedures and is able to deliver with precision exact amounts of fluid. It should interfere less with schooling and parental employment.

Although **CCPD** entails fewer aseptic connection/disconnection procedures it may be more disruptive to the parents and child's sleep as there are occasions when the dialysis machine gives an alarm to alert one to the fact that it is not functioning correctly. This usually occurs when the child is lying on the dialysis tubing.

**Hospital IPD**. A few children may be treated by intermittent peritoneal dialysis (using the same automated cycler as with **CCPD**) overnight in the hospital several times weekly. This might be used when home circumstances are not satisfactory, for example if a parent is disabled, or for a period of time to allow parents to gain confidence with the automated cycler before starting **CCPD** at home.

**Haemodialysis** is nearly always hospital based and is usually carried out three times weekly, with each session taking approximately four hours on the dialysis machine. Traditionally
access is via an arteriovenous fistula which involves needling. The
distress involved can now be reduced with the availability of local
anaesthetic cream to relieve pain in cannulation (Watson et al.,
1988a), or the option of internal jugular catheters to enable 'no-
needle' haemodialysis (Watson and Gartland, 1989). Home
haemodialysis is expensive to set up and creates enormous demands
on the family. Few children or adolescents now experience this
form of treatment.

Transplantation. Most children with ESRF in the UK receive a
donor kidney from a cadaveric source. The alternative is a kidney
donated from a living-related donor (mostly parents). The latter
operation accounts for only approximately 10% of transplants in the
UK, but 42% in North America (Watson, 1993). Prospective living-
related donors have to undergo rigorous physical and psychosocial
assessment before donation is possible.

Choosing the therapy requires the parents to decide in partnership
with the physician and multidisciplinary team. This decision
process should also include the patient if in adolescence. Home
peritoneal dialysis is now the most popular treatment in many
countries as it allows the child a more normal life with the
development of school and peer relationships. The need to travel
frequently, a dependency upon the unit, and the need for vascular
access are some of the disadvantages of haemodialysis. However
haemodialysis remains popular in some European countries where
there may be strong physician preferences, financial considerations
and lack of home support facilities. If there is a well organized and
functioning haemodialysis unit already set up with highly trained
staff and a large investment in the required technology then there
will be resistance by some doctors to move away from this.
The geographical proximity of a family to the unit can influence the modes of dialysis available. If distances are too great then travelling to the hospital three times a week for haemodialysis may not be feasible, likewise the technical support required to run an overnight cycling machine may not be available. In these cases CAPD would seem to be the second best option to transplantation.

In infants 0-2 years old prolonged haemodialysis is not considered by some to be a viable option, while both CAPD and CCPD are feasible long-term dialytic options in infants (Fine et al., 1987). It is only in recent years that renal transplantation of the infant has begun to enjoy success, but it is still recommended that where possible the transplant be delayed and instead the infant in ESRF undergo dialysis until approximately 2 years old (Fine et al., 1987) and over 10 kg in weight (Watson et al., 1988b).

In pre-school children haemodialysis is feasible but considered less desirable than CAPD or CCPD due to the necessity for repeated venepuncture and the stricter dietary requirements. Children of these younger years have been shown to demonstrate high levels of distress when requiring venepuncture even when performed by a skilled phlebotomist (Bennett Humphrey et al., 1992). CCPD is now the favoured dialysis modality of choice in our units and most others in the UK. The rigours of four sterile bag changes a day and the logistics of arranging changes at school make overnight dialysis more attractive. CCPD can also be easier than CAPD if there are other children around and demanding attention during the day.

In older children, 5-11 years, haemodialysis is equally effective but now the children's schooling must be considered, and also their preferences as well as those of the parents. Transplants are favoured at an early age especially when growth is suboptimal, as
data appear to indicate optimal post-transplant growth following transplantation when younger (Ingelfinger et al., 1981).

Adolescents may choose CAPD or CCPD depending on whether they prefer their evenings free or whether they wish to avoid procedures at school which might increase an adolescent's sense of being 'different'.

Research findings have shown that parents of children on haemodialysis interpret their children as having more behavioural and maladjustment problems than the parents of those receiving alternative renal replacement therapies. (Brownbridge and Fielding, 1991) found that those children on CAPD suffered less social impairment, reported better adjustment to dialysis, had fewer practical problems associated with treatment, had lower depression scores and showed less behavioural disturbance, than those on haemodialysis. (Reynolds et al., 1988) studied the impact of chronic renal failure on the families with children requiring hospital haemodialysis when compared with children with less severe forms of renal failure requiring no dialysis. They found that family disruption was clearly more noticeable in children on hospital haemodialysis, as were increased financial stress and problems with siblings.

The mean kidney transplant graft survival in current reports is approximately only 50% at 5 years (McCauley and Johnson, 1994). These figures may be improved with better immunosuppression drugs but it is still likely that more than one transplant may be necessary in the child's lifetime. This point requires reinforcement, as families and others often have the expectation that the treatment progression is linear rather than cyclical. Parents may often inappropriately view transplantation as the end point of treatment.
rather than just one treatment in the cycle (Watson, 1993).

Whichever form of renal replacement therapy is selected, there is potentially a tremendous burden of care on the parents of those children requiring dialysis. Even when a kidney transplant has been successfully carried out there remain problems of compliance with lifelong medications, continued hospital visits and the fear of graft rejection.

Those embarking on a program of care for a child in ESRF need to consider the quality of life for the child, and this should be reflected in the therapeutic approach taken. Parents and doctors must also take into consideration the burden of care that will fall on the family, and also the impact upon the child that the treatments and investigations will have (Winterborn, 1987; Collier and Watson, 1994).

**Concerns of parents caring for children with ESRF**

Poor appetite, or anorexia, is a common effect of renal failure which can have serious consequences. It has been reported that ultimate dietary failure, death due to starvation, resulted in four deaths per every thousand (adult) patients on dialysis in Europe in 1978 and 1979 (Wing, 1982). When there is little or no appetite, children especially young ones and infants, may simply not eat. Parents are informed about the importance of diet in the care of the child with ESRF who is receiving dialysis therapy. There can be tremendous stress put on the family, usually most intense on the mother, when a child has no appetite and refuses to eat (Norman et al., 1995).

There are many social aspects to eating and family dynamics can be threatened by the anorexic child. Parents have reported that dialysis is the easy bit, and that it's the feeding that's really difficult
(Norman et al., 1995). When young children do refuse to eat it places great strain on the parents, and on all those who are trying to improve the child’s state of health. Aggressive dietary regimes have been proposed as therapeutically beneficial, yet may place tremendous strains on the parents.

Most units advocate the use of tube feeding rather than force feeding the child. Nasogastric tubes have also been reported to be tolerated poorly by many children, and the passing of the tubes can be quite difficult for parents, but also once the tube is in place it can intensify the problem of nausea and vomiting that is often found in children with ESRF. For young children a gastrostomy button has been suggested as a beneficial alternative to nasogastric tubes (Steele, 1991; Coleman and Watson, 1992). Both nasogastric tubes and gastrostomy buttons allow the child to receive nutritional supplements without having to eat.

The children are still encouraged to eat and this is for several reasons. Eating food is not simply a process to feed the body with essential nutrition. Eating also fulfils other functions. Generally, food is considered to be pleasurable to consume, and meal times are also social times for families. There are concerns that young children should not be brought up without experience of the diverse flavours and textures that are found in food. Children also need to learn about socially acceptable behaviours associated with the eating of food. Children are also encouraged to eat to further improve their dietary intake.

As the prognosis for the child in ESRF has improved so has greater importance been placed on optimising growth potential. It is recognised that short stature has a significant impact on the daily lives of young patients in ESRF, by diminishing self esteem and
hampering rehabilitation (Schärer and Gilli, 1984). Growth is reported to be major concern for parents and for children with ESRF (Hulstijn-Dirkmaat and Damhuis, 1994; Reynolds et al., 1995). Growth is affected not only by the poor nutrition intake of the child with ESRF but also by other physiological factors such as a change in the secretion of growth hormone and luteinizing hormone (Schärer, 1990).

Reports indicate that there is better growth after transplantation compared to dialysis, especially in younger children (Ingelfinger et al., 1981). However whilst growth is improved after transplantation there is seldom any catch up growth to compensate for earlier poor growth rates (Benfield et al., 1993). Loss of growth in the first two years of life may not be regained and hence many units pursue aggressive feeding regimen in the younger child. Administration of growth hormone is a recent addition to the therapies available for children in ESRF, and has been shown to increase children's growth rates after transplantation (Van Dop et al., 1992).

The combination of better nutritional support and the availability of growth hormone therapy has increased the likelihood of a reasonable adult height being attained. Parents will need such information to enable them to understand the importance of dietary intake, and whether to consider their child being prescribed growth hormone therapy. Growth has also been shown to improve following transplantation. Parents may take this factors into consideration when deliberating whether to put their child onto the transplant list, or whether to consider being a living-related donor.

Adequate nutritional support also reduces the likelihood of osteodystrophy (abnormalities of the bones). Renal osteodystrophy results from elevated phosphorous levels, and low calcium levels.
that accompany reduced renal function. (Gower, 1991) Bones can become soft and deformed, and slow to grow. By increasing Vitamin D levels, and giving medications to render the phosphorous harmless (phosphate binders) the osteodystrophy can be minimalised. Younger children are particularly at risk because of the sensitivity of new bone growth to these chemical imbalances, and of the longer period of bony growth being subjected to these conditions (Grossman, 1984).

A further concern to parents of children with ESRF is the psychological development of their child. Parents are concerned about the cognitive and emotional development of the child and whether they will be equipped to cope with adult life later on.

A child's education is an important factor in how they integrate socially and in how they develop as adults. When parents are considering the treatment options available for their children, whether the child is of school age or not will have an influence on how suitable treatments are considered to be. Absences from school due to ill health or treatment requirements can have an obvious effect on a child’s education.

Selecting the dialysis modality which most effectively enables children to attend school is one way in which parents and health care professionals can assist a child to live more 'normal' and social lives. Hospital haemodialysis may be the only treatment option available to some children, or there may be a well-equipped haemodialysis unit already established. When hospital centred care is delivered there is educational provision for the child, either a school teacher attending the sessions, or evening dialysis instead. Unfortunately it is not only the time consumed by treatments that can affect the educational standards achieved by children in ESRF.
There may be developmental delays due to uraemia, especially if the renal failure developed in infancy, with the risk increasing further if treatment is delayed or ineffective. Scores on IQ tests have been found to be positively correlated to the age of the child at onset of the renal failure (Lawry et al., 1994).

However this disturbing finding may not reflect the IQ of young children currently entering the renal replacement programme. Treatments for children have improved considerably over the recent years, with the most dramatic progress being made in the treatment of infants and younger children. Adequate dialysis or a successful transplant can alleviate uraemia to a large extent in children of all ages.

**Long term outcome of renal replacement therapy in childhood and adolescence**

Studies have followed up adolescents or young adults that have been through the paediatric renal replacement program, and many have examined not only physical outcomes but also social functioning and psychological well-being.

Chantler, Carter, Bewick et al (1980) reviewed ten years of paediatric nephrology delivered to 75 children under 15 years old who entered the treatment programme prior to 1978, in London. The authors reported that "Despite growth, and psychosocial and rehabilitation problems, the overall results were encouraging, particularly for the 46 children who had successful transplants" (page 435).

80% of the patients were still alive. Short stature was common. 50% of the children were followed up to assess their rehabilitation. 80% of the children on home dialysis maintained full-time
education, but this was acheived by only 64% of the transplanted children. The explanation for this can be found in the description of the very hospital oriented monitoring of newly transplanted children. Daily clinical assessment was carried out for the first month and the frequency was then gradually reduced depending on the progress to weekly by 4-6 months, and then to monthly by 12-18 months. Children undergoing such regular assessments would clearly be unable to maintain a comprehensive education, especially as the unit treated patients from as far afield as Nottingham (the Nottingham Paediatric Unit was only established in 1985).

Eight years later a further assessment of long term outcome of treating ESRF in children, was carried out from the same London unit, by Henning, Tomlinson, Rigden et al (1988). The study was concerned with the children accepted onto the renal replacement program between 1972 and 1977. 69% of the patients were still alive. Short stature remained common. The study was designed to focus on the rehabilitation of the patients, as the clinicians were concerned that "...the likely benefits of such lifelong treatment must include the possibility of an enjoyable and satisfying adult life if they are to outweigh the considerable burden of treatment" (page 35).

A questionnaire to obtain factual information on education, employment, marital status, any psychiatric problems, and areas of possible dissatisfaction within social and personal lives was sent to the 31 survivors, and also to a comparison group of 32 patients with insulin dependent diabetes mellitus (IDDM). 29 and 17 patients replied from each group respectively. The authors report the results for those children with ESRF due to cystinosis separately as there are "peculiar growth and metabolic problems" associated with this disease (p36).
Of the children with ESRF 46% reported that their social life had been adversely affected by their disease (mainly to do with their short stature and drug side-effects, 23% were specifically restricted from driving). This reported adverse effect was 80% for those with cystinosis (mainly short stature and body shape, as well as driving restrictions), and 59% for those with diabetes (travelling abroad and organised social events).

The authors report, rather confusingly, that children with ESRF compare favourably with the children with diabetes in educational achievement and employment "except that more failed to attain school qualifications and employment" (p37). The data looks significantly different between the children with ESRF and those with diabetes, however no significant test are reported. For those patients 18 years or over at the time of the study only 28% of those with ESRF were married or in a long standing relationship, compared to 76% of those with diabetes. Of those with ESRF in a relationship, over two thirds reported sexual difficulties, whilst none of those with diabetes reported any difficulties. Both patients with ESRF and diabetes expressed feeling victimised in personal and public relationships (71% and 53% respectively). Also both patients with ERF and diabetes commonly reported having seen a doctor for a persistent emotional or psychiatric problem (34% and 41% respectively).

The authors conclude that many of the reported problems of childhood ESRF were associated with short stature and poor physical appearance, and that clinical efforts should concentrate on reducing the growth failure of children with ESRF (Henning et al., 1988). The study did use a control group, and this was an important feature in the report. Had there have been no comparison group
then it may not have been realised that children treated for other chronic, albeit less invasive, diseases (and with lower mortality rates), also report high levels of dissatisfaction with social functioning. However this cannot obscure the many worrying findings of this paper. There was a high incidence of psychosexual problems and poor personal relationships in those treated for ESRF during childhood and adolescence.

Unfortunately the report was too unclear about the effects of ESRF on education and employment from this report, but the data did not look encouraging. The patients investigated in this study were treated early in the development of paediatric nephrology though, and it was hoped that improved treatments would lead to improved outcomes emotionally and cognitively as well as physically (Henning et al., 1988).

Roscoe, Smith, Williams et al (1991) collected information on 118 young adults who had been admitted to a RRT program as adolescents between 1966 and 1986 in Toronto. 83% of the patients were still alive, survival rates were better for transplanted patients. Short stature was common. Social functioning was assessed via telephone interviews and showed that the majority of respondents were still living with family members (68.9%), with 20% living alone, and 9.5% living with a spouse. Four of the patients had become parents. School achievement records showed that there had been some educational delay, although only 13% were neither employed or in an education program.

Social functioning of those patients who were transplanted was considered to be higher than those on dialysis. Patients on peritoneal dialysis were considered to be functioning better than those receiving haemodialysis. There was no correlation between
growth retardation and rating of social functioning (Roscoe et al., 1991).

Reynolds, Morton, Garralda et al (1993) investigated the psychosocial adjustment of 45 young adults who commenced treatment for ESRF as children. The study used standardised interviews concerned with objective indicators of social functioning, as well as subjective indicators of stress or support. A group of age and sex matched controls were also interviewed.

Educationally those with ESRF achieved significantly lower than the healthy controls, and the majority (71%) of those with ESRF considered that their schooling had been markedly affected by the illness or treatment. They also reported that the illness or treatment had also lead to difficulties maintaining friendships at school. One third of those with ESRF were unemployed, half of whom were registered sick and disabled. Reflecting this, significantly more of those with ESRF were in receipt of social security benefits. Unemployment was significantly associated with onset of ESRF before 11 years of age. Whilst lack of friends was not common limitations on this area of life was reported by 22% of those with ESRF, compared to 8% of the healthy controls. Both groups reported a high level of leisure activities.

Incidence of living with parents was higher in the renal group (68%) than in the healthy group (29%), with a trend towards living with parents for those who developed ESRF before the age of 11 years. Twice as many healthy subjects were married or cohabiting, but there was no difference in the mean duration of the relationships. This could suggest that those with ESRF are not simply delayed in the establishing of partnerships, rather that for some patients ESRF had not restricted their opportunity or inclination to seek and
maintain a one-to-one relationship, and that for others it had restricted them. There was a trend for those with ESRF to report less stress than healthy subjects, except in the area of marriage or cohabitation.

For those having experienced a full sexual relationship (50% compared to 92% of healthy subjects) the relationships were more frequently reported as problematic by those with ESRF. Lack of information about fertility was commented upon. Low energy levels were identified as commonly affecting sexual relationships or employment for those with ESRF. Concern about short stature was less than that regarding the physical appearance changes caused by the high dose steroids required for immunosuppression therapies.

**Parents: decision making for a child with ESRF**

Being informed that your child has life-threatening disease is an understandably distressing event (Fraley, 1990; Perlman et al., 1991; Sharp et al., 1992; Canam, 1993). Following such news, parents need to begin the process of acceptance (Canam, 1993), but they also need to begin considering the treatment options available for their child. In end stage renal failure the consequences of non-treatment are severe, and ultimately fatal. As current treatment of childhood ESRF is thought to offer a good prognosis it is only in exceptional circumstances that the withholding of ESRF therapies would be considered.

The way in which the diagnosis of ESRF is presented to the family can have a long term influence on how the family respond to, and cooperate with, the health care professionals who will share the care for their child. It is very important that the diagnosis of renal failure is given by a paediatric nephrologist as they have the most
recent and up-to-date information regarding prognosis and treatments. Non-specialists may not be aware of all treatments available.

Parents need to make an informed choice about the therapy most suitable for their child. The parents and child require full preparation for the future of renal replacement therapy. ESRF can be one of the most demanding of diseases and its life threatening nature can add to the unremitting burden of care. This is difficult information for the physician to impart without making it sound as if the future holds no hope.

Parents require information about the different treatment options that are available for their child. Options may be constrained by the facilities of the paediatric renal unit. It may be that the unit is better equipped to support the delivery of haemodialysis than peritoneal dialysis, or vice versa. The age and size of the child will also influence which therapy is considered most suitable. Information will initially be provided by the paediatric nephrologist, with additional input from the specialist nurse or dietician possible.

Many children do not require renal replacement therapy (RRT) immediately after diagnosis and their families can be given weeks, if not longer, to consider the information about treatments before they have to make a decision. For those parents who cannot be given this time because of the need for clinical haste in the initiation of dialysis, they may be able to consider long term options once the crisis is over.

Information from clinicians is usually not delivered impartially. Most clinicians have their own beliefs about which treatments provide the best route to health for a child in ESRF, and this can
influence how treatment information is presented to parents. As such beliefs often influence how the paediatric nephrology service has developed there is often a congruence between the therapy a nephrologist prefers, and the therapy that the unit is best able to support. Most paediatric renal units provide all renal replacement therapies to some degree or another.

Information is available from the consultant and the multidisciplinary team, and is also available from national organisations such as the Kidney Federation or the British Kidney Patient Association. Parents already delivering care for a child in ESRF may also be used as a useful source of information. Leaflets, books and videos are also available about RRT’s and parents may wish to use some of these resources. However the most useful sources of information remains the paediatric nephrologist and the team.

Parents will want information about the benefits that treatment is thought to provide. Being aware that non-treatment of ESRF has a fatal outcome, parents will clearly require information regarding child survival on RRT. Whilst survival rates are reported in many studies it is difficult to convey to parents how figures may not be as informative as they first appear. Survival rates are affected by the therapy chosen, but it is a multifactorial issue where survival is also affected by the aetiology of the kidney failure and by the expertise of the unit delivering the care. For example some nephrologists are reluctant to recommend renal transplantation for infants, especially if the infant weighs under 10kg (Fine, 1988). Graft survival rates at one year are reported to vary so greatly between units (33% to 100% (Najarian et al., 1990)) that parents would need to know what the nephrologist at their unit considers to be most successful for
Reading published medical articles can be misleading for parents sometimes, and if the child is being treated at a unit with only 33% one year graft survival rates then to demand that an infant be offered a kidney transplant on the grounds of 100% success elsewhere would be unwise. However it might be ill-advised for parents to be encouraged to accept what the nephrologist recommends without questioning the clinician's grounds for the preference.

The survival rates of children undergoing therapy have been increasing over the last twenty years (Chantler et al., 1980; Henning et al., 1988; Roscoe et al., 1991). However, children do still die from ESRF in the UK, Europe and America even when treatment is available and being delivered.

Once survival has been established as a likely outcome for treatments parents may need to consider other issues such as the child's quality of life, as well as the burden of care for themselves. Parents usually want more than just survival for their children, they also want an acceptable level of quality of life for their child.

Quality of life is an abstract and complex concept, and may mean different things to different people. One definition of quality of life which reflects that variation is by Hunt (1988) "... a subjective interpretation made individually, and grounded in uniqueness and situation". A more descriptive definition is offered by Goodinson and Singleton (1989) "... a person's sense of well-being, his satisfaction/dissatisfaction with life, or happiness/unhappiness in dimensions of health, activity, stress, life-goals, self-esteem, depression, social and family support".

Chapter Two

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A good quality of life for children could not necessarily be defined by the physical functioning of the child, but would also consider their social opportunities and emotional well-being too. Parents wanting to know how treatments affect their child may ask how well each treatment can address the consequences of chronic renal failure, such as poor appetite, stunted growth, developmental delays, tiredness and bone disease.

There can be psychological consequences of subjecting children to such an intensive treatment regime. With multiple scarring from transplant surgery and from surgery to create dialysis access (either for haemodialysis or for peritoneal dialysis), with the continued treatment and compliance demands, and with possible esteem problems associated with short stature there can be considerable reasons for apprehension about the psychological outcome of this demanding physical treatment regime.

Whilst many report psychosocial problems for those children with ESRF there is increased optimism about long term outcome as therapies become more comprehensive and tailored to the needs of children (Chantler et al., 1980; Henning et al., 1988; Roscoe et al., 1991; Reynolds et al., 1993).

**Nottingham Paediatric Renal Unit**

In the UK there are now sufficient regional centres to cater for children and adolescents, and there is little need for children to be treated in adult units. Most paediatric units treat adolescents up to school-leaving age and beyond, with transfer to the adult unit being determined not only by age but by the patient's maturity and wishes as well as local circumstances (BPA 1985, Gillies 1992). Nottingham is a regional centre for paediatric renal care. Care needs to be
concentrated into 'regional' units, in order to serve a large enough population for sufficient resources and expertise to be provided and maintained.

Although the inconvenience of travelling to Nottingham is a disadvantage for those families living further afield, it is outweighed by the availability of a multi-disciplinary team providing a family orientated approach. The Nottingham team comprises paediatric nephrologists, paediatric renal nurses, a child clinical psychologist, medical social workers and dieticians who provide services dedicated to the team. There is a permanent hospital teacher, and also specialised out-patient staff and a regular nursery nurse.

The policy of the Nottingham Paediatric Unit is to avoid haemodialysis whenever possible, and it is only used in acute in-patient situations or when chronic peritoneal dialysis is not a feasible option. This is to avoid the time that haemodialysis encroaches on the schooling of the child, and upon their social interactions there. The majority of those on chronic dialysis therapy attending Nottingham are on Continuous Cycling Peritoneal dialysis (CCPD), with few patients receiving Continuous Ambulatory Peritoneal Dialysis CAPD.

The Nottingham consultants support the consensus view amongst paediatric nephrologists that transplantation is the goal for children accepted onto ESRF programmes (Watson et al., 1988b; Collier and Watson, 1994). Indeed dialysis is seen only as a holding measure before a transplant becomes available. Due to the success of home peritoneal dialysis programmes even young infants are now routinely offered treatment. However the burden of care upon the parents can be considerable, and re-transplantation may be
necessary before or during adulthood.

Being under the care of a paediatric nephrologist and team allows timely discussion about ESRF choices in the future. Parents of all children are informed that it is likely that more than one transplant may be necessary in their child's lifetime. Dialysis and transplant information are given to the family to enable them to make an informed choice about the therapy most suitable for their child. The parents and child are given full preparation for a future of renal replacement therapy and with commencement of dialysis comes active preparation for eventual transplantation.

Parents are provided with written information about ESRF and the treatments required, and there is provision of leaflets or booklets. Videos are also considered useful especially for extended families and those with poor literacy skills. Parents are offered the opportunity to audio-tape important consultations. Again this can be very useful for extended families and those with poor literacy skills (North, et al 1992; Rylance, 1992). There is regular liaison with community services which allows information to be passed on to those in contact with the family in the community. Schools and GP's are visited and are found to be very receptive to information coming from the paediatric dietitian, nurse or social worker.

Practical support is considered vital for the families carrying out renal replacement therapies at home. This is achieved by the multi-disciplinary team through a policy of continuing care. Before a programme of renal replacement therapy is commenced the team assess the family. In addition to considering the medical condition, age and preferences of the child a full psychosocial assessment of the family is carried out. This includes parental attitudes, employment, financial situation, housing, number and age of siblings, as well as
the structure of support networks such as the extended family.

The nephrologist and team members are aware that it is relatively easy to recommend home dialysis but also that 'burn-out' due to the stress of long term dialysis can occur. The paediatric renal team consistently take this into consideration and provide as much support as is needed when it is required.

Dietetic advice and support are provided after the initial diagnosis of renal insufficiency, as growth is so important. Parents are worried by common symptoms of renal failure such as failure to thrive and poor appetite, especially in infants. If tube feeding is required dietitians and nephrologists at the Nottingham Paediatric Renal Unit advocate the use of a gastrostomy button in preference to long term nasogastric tubes (Coleman and Watson, 1992).

Nottingham paediatric unit has a policy of employing specialised paediatric and renal trained nurses. Each specialist nurse has a case-load of families that they are directly involved with, and for whom they are the primary nurse, responsible for the coordination of the child's care. Primary nursing has been found to be of great assistance for the families. The primary nurse is deployed for the majority of dialysis and transplant teaching for the family, she/he links all the other members of the team together for the strategy of care for that family and is the prime point of contact for that family. There is a policy for the primary nurse to be in regular (weekly) telephone contact with the parents, and they also make occasional home visits. Every six months families delivering dialysis therapy at home have a visit from their primary nurse and a dietitian to reassess and up-date the parents' (and child's) knowledge and practical skills.
An on-call service operates from the unit so that the parents know that they can always contact a paediatric renal nurse. This service is especially useful in crisis prevention and in reducing parental anxieties in the early days of home dialysis or immediately following transplant.

Two medical social workers are dedicated specifically to the paediatric renal team. They help the families in a multitude of ways. The social worker helps the family with the adjustment to chronic illness, complications, and changes that need to be made. Ongoing support of families and assistance with problems that arise lessen the need for crisis intervention. However responsibility is not taken away from the family, rather the family is encouraged to pursue self-determination and to work out individual strategies. Financial support is available to those in need and caring for a child with ESRF, both through the welfare state and also through other bodies such as charities and trust funds. The social worker assists families to claim the benefits to which they are entitled, and to assist in the practical management of bills and debt.

Respite care and support are provided to help the families maintain a high level of care. A respite care nurse is employed specifically for this purpose, and respite care can be provided be from an occasional one or two hours or for a more regular commitment during times of need. If a child is on home dialysis then parents find it difficult to get out in the evening together, as relatives are often reluctant, and often not able, to look after the dialysis process. One way in which the Nottingham paediatric renal team try to overcome this has been to provide a babysitting service of trained nurses. Supporting family holidays are another method that the Nottingham unit employs to help maintain the family's quality of life.
Facilitating contact between parents has proved to be of great benefit. Providing initial contact between families over coffee during out-patient visits permits them to meet others who may provide support, advice and comfort. A parent support group has been established by the social worker and clinical psychologist, initially aiming to reduce feelings of isolation. Creche facilities are provided to allow families to attend without the need to arrange babysitters and allowing them to have discussions without interruption or restraint by the presence of their child. The local support group often deals with issues too intricate for a parent run self-help group, and it has therefore continued to be run jointly by the social worker and clinical psychologist (Argles et al., 1994).

A clinical psychologist has close links with the paediatric renal unit and is a member of the multi-disciplinary team. She provides many benefits, helping families to avoid behaviour problems in their children, as well as helping overcome such behaviour after it presents itself. Ongoing programmes of psychological preparation of families are also coordinated by the psychologist. The multi-disciplinary team use the access to the child psychologist to help the children develop the skills to help themselves deal with their illness and treatment.

Regular psychosocial team meetings to discuss such issues are the forum used for exchange of information, where team members discuss each family's medical, emotional and psychological well-being. The demands on parents caring for a child with ESRF are high, even when a comprehensive service of support and assistance is in place. Members of the Nottingham Paediatric Renal team were concerned about the psychological well-being of the parents of the children on the renal replacement programme. It was considered
that whilst the support mechanisms should be continued and where possible improved, there was still a need to assess the parents' psychological responses to the demands of care. Members of the team had anecdotal evidence of parents reporting feeling stressed, or unable to cope at times, although they also had parents expressing satisfaction with how home dialysis was working out. The author was employed to carry out research into the psychological well-being of parents caring for children with end stage renal failure, and to ascertain the degree of emotional difficulties experienced by the parents.
Chapter Three

Assessment of parental well-being when caring for a child with End Stage Renal Failure: Research design and methods

Origins of the study

Dr Alan Watson, the inaugural consultant Paediatric Nephrologist of the Nottingham Paediatric Renal Unit, initiated and then maintained a service of care for the children with chronic renal failure and their families. The service was family-centred, and where possible research-based. The unit opened in 1985 and by 1991 the staff complement included three full-time specialist renal nurses, a part-time day case/outpatient nurse, a medical social worker, a dedicated dietitian, and access to the paediatric clinical psychologist two sessions a week. Geographically the unit was based at the City Hospital, Nottingham, and shared one of the paediatric wards, and staff, with children's plastic surgery.

As a regional centre for paediatric nephrology, patients were accepted from as far south as Cambridge, and as far north as Doncaster. The case-load at late 1991 was approximately 13 children post-transplant, ten children on home peritoneal dialysis, 25 children in chronic renal failure not yet requiring renal replacement therapies and 13 children with nephrotic syndrome. Ten patients had been transferred to the adult unit, and three patients had died. Outpatient clinics were held every Wednesday and Thursday mornings at the Nottingham City Hospital. Other, less frequent, clinics were held at Derby, Lincoln and Leicester.
Members of the team were aware of stress that families said accompanied chronic dialysis or failed transplant. Some of the children were also observed to be quite distressed when undergoing investigations such as venepuncture or renal biopsy.

Dr Watson approached the British Kidney Patient Association for funding to support employment of a psychologist to research into hospital or treatment induced distress of children with ESRF\(^1\) and to investigate the psychological well-being of parents caring for the children. This thesis is the culmination of the research into the psychological well-being of parents caring for children with ESRF. The research data was collected between 1992 and 1994.

**Position as researcher within the multidisciplinary team**

The majority of the research data was collected during two years of employment with the paediatric renal team. The position within the team brought many benefits to the research. The families with children in ESRF became quite familiar and both parents and children would often talk about their life and kidney failure. Being a member of the paediatric renal team involved attendance at the weekly psychosocial meeting where in-depth assessment of both children's health and families' well-being took place. Admission to the parents' support group provided an invaluable insight into the lives and emotions of the parents caring for the children with ESRF. The researcher also went on one of the unit holidays for the children. Being a member of the team also allowed observation of parents being trained to deliver RRT, of families supporting the child through a successful transplant, or suffering the fear of

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For further information see Collier, MacKinlay and Watson (1993), and Collier and MacKinlay (1993)
rejection. Such close involvement also permitted greater appreciation of the function and structure of the multidisciplinary team.

There were however disadvantages to this position of researcher within the team. The position was a temporary one for the duration of the research, and such a post had not been a part of the paediatric team before. Some members of the multidisciplinary team found it difficult to understand the position of researcher within the team, especially as the brief covered a large range of areas. The position had quite vague boundaries, although where they overlapped with the clinical psychologist there was good understanding by the two parties, even if not by other members of the team.

Another, unanticipated, difficulty arose because of the researcher's previous nursing experience. Some of the multidisciplinary team had difficulty in identifying the role of the researcher, and considered there to be overlaps with the clinical psychologist and also with the nursing staff. This was not seen to be the case by the researcher but nevertheless it created some misconceptions that were not always of benefit to the research.

These difficulties did not however outweigh the benefits of the being a researcher within the multidisciplinary team. The close contact with the families and with the staff were instrumental in providing the insight and information necessary to consider the psychological well-being of the parents within the context of their family lives.

**Aim of the research**

The main aim of the research was to identify factors contributing to psychological well-being in the parents caring for a child with end
stage renal failure, especially those factors related to the delivery of treatment.

To meet this aim it would be necessary to appraise the psychological status of the parents caring for children with ESRF. Such consideration would require assessment using valid and reliable measures to be as free of observer bias as possible.

It would also be necessary to evaluate factors which could be influential on the psychological status of the parents. Ideally the study would also be able to identify whether any reported psychological distress was specifically attributable to illness-related factors.

**Study design and methodology**

**Subjects**

All parents with a child being treated for ESRF under the care of the Nottingham paediatric renal unit were invited to participate in the study. New RRT patients referred to the unit during the first year of the study, were also invited to take part. On the advice of the medical social worker one family were not invited to participate as their child was critically ill. Parents of 35 children with ESRF agreed to take part in the study. Out of these 68 parents (for two children the father did not agree to participate) 41 parents did become participants in the project, completing and returning at least one questionnaire (see p91-92 for further details).

Both mothers and fathers were invited to participate in the study for several reasons. When a child under the care of the Nottingham Paediatric Unit required dialysis, the treatment option recommended by the team was home peritoneal dialysis via an
overnight cycling dialysis machine. Both parents were trained to deliver the care as the burden was considered to be too great for one person to cope with. Fathers were also encouraged to attend the outpatient clinic when possible, especially for those consultations where important information was imparted to the parents. Fathers were therefore directly involved in the treatment of their child.

'Many studies which profess to examine parental responses to chronic childhood illness have, on further scrutiny, only collected data from one parent, usually the mother (Keller and Nicolls, 1990). It is also reported that most of the literature on the impact of chronic childhood illness has focused on the mother (Sabbeth, 1984). However research which has collected data from both parents indicates that mothers and fathers can both perceive, and respond differently to, stressors such as their child becoming ill. Differences between mothers and fathers may not necessarily be contradictory in nature, but rather reflect a difference in degree, extent or intensity in the response or perception (Eiser et al., 1992). Mothers and fathers have also been reported to cope differently with chronic childhood disease (Eiser and Havermans, 1992).

Data collection

In deciding how to collect the data several factors were taken into consideration. The clinical psychologist in the paediatric renal team had previously pursued formal assessment of parental well-being and had used a self-report measure of stress (the Perceived Stress Scale (Cohen et al., 1983)). Such a questionnaire allows quick, home administration, which allows simple collection of data even from a large size sample. This would not be the case if interviews were to be used as the method of data collection.
Another disadvantage of interviews would be the large geographical area covered by the unit. It would not be practical to travel to each home to interview parents, especially if both parents were to be approached. Evenings might be the only time the parents are available, and evenings are usually very busy for families with children on home dialysis.

Data collection during clinic time would also be problematic, first because the visit to clinic is often a stressful time anyway for parents. This would give rise to elevated perceptions of stress. Second, parents might feel more pressurised into participating in the study if taking place where members of the team might try to persuade them to take part. Third, the visits to the outpatient clinic were often quite lengthy, and involved seeing not only the consultant but on occasions could involve the child being X-rayed, having blood taken, providing a sample of urine, and having a dressing changed. They might also see the dietitian, the psychologist, their primary nurse, and the medical social worker.

Postal questionnaires seemed an ideal way to be able to approach all parents, and to allow them to participate at a time convenient for them, and without undue pressure. Questionnaires do however have disadvantages. Questionnaires are limited in the information they can reveal by the way the questions are structured and by the question content. They do not allow or encourage additional information to be given easily. Questionnaires also manage to hide much of the complexity behind the information they collect.

**Qualitative data**

To counter the limitations pertinent to questionnaires, qualitative data was also used. The parent support group had begun soon
before this study was considered. The initial meeting had been tape recorded and then later transcribed by a secretary. The transcript was strictly confidential to the social worker, the clinical psychologist and to the researcher. Inspection of the transcript carried out by the secretary revealed that it was rarely possible to identify who had said what, and there was no formal structure to the transcript.

Access to the parent support group meetings was arranged at the invitation of the medical social worker and the psychologist. Attending the groups provided great insight into the feelings and experiences of the parents. Furthermore, providing the tapes were transcribed, full (confidential) use of them was permitted.

Transcribing the group discussions was an formidable task, especially as the tape quality was often poor. There were also problems of more than one person talking concurrently, of people interrupting each other, of leaving sentences unfinished. It is only when transcribing conversation that one realises the ungrammatical way in which we speak. The conventions of transcription can be complex, though do not necessarily need to be so. The form of transcription carried out was adapted from a previously published style (Silverman, 1987). Transcription was made easier by attendance at the parent support groups.

Data on parents' psychological status, and on themes considered to be central to the effect of caring for a child with ESRF would be collected both via quantitative measures and via the transcription data.
Measures of demands and resources

Two themes considered to be central to the psychological status of parents caring for a child with ESRF were: the impact of the illness on the child and family's daily lives; and also whether the parents had the right amount and type of information. These two themes were identified following attendance at an early parent support group meeting, and also from listening to parents attending the clinic and ward. Discussion with the medical social worker and clinical psychologist affirmed this observation.

A search of the literature was carried out to identify any existing measures to assess impact of illness and information needs.

Information needs questionnaire

The seeking of information was reported to be a useful coping strategy in many papers (Skipper et al., 1968; Weichler, 1990; Jennings, 1992). However the literature search revealed a paucity of work on information needs. There was though one very useful study where the information needs of parents caring for children with Cystic Fibrosis were formally assessed (Henley and Hill, 1990). The questionnaire that was used included items that were general in nature and would be suitable for parents of children with other chronic illnesses such as ESRF.

An information needs questionnaire was adapted from Henley and Hill (1990). General questions, that is those not specific to the medical condition of cystic fibrosis, were left in their original state, and those questions that were disease specific were altered with the advice and assistance of the specialist nurses. This gave the questionnaire relevance to the condition of ESRF.
The benefits to adapting and utilising this questionnaire were twofold. First, it had already been validated. Second it gave a comparison group for the results of the general questions, so that the results from the parents of children in ESRF could be compared with those of the published study involving the parents of children with cystic fibrosis.

It is recognised that self-report methodology may not accurately reflect the actual information given, but it does reveal the parents' perceptions.

*Impact of illness questionnaire*

Burden of care has a psychological affect on parents, but it has been reported to be inadvisable to attempt to measure this burden solely on the grounds of treatment provision. Hauenstein (1990) notes that whilst the burden of care would seem to be a function of intensity of treatment, there are also other factors influencing parental burden. These include frequency of illness exacerbation, financial stability, and availability of alternative care providers for the child. It is the combination of such multiple factors that contribute to a unique burden for each family, and which renders the quantification of burden of care a complex task (Hauenstein, 1990).

Due to this complexity it was decided that, rather than measuring the burden of care either via observation or self-report, the impact of the illness on daily life would be assessed instead. This was primarily the perceived impact upon the child, but also included some aspects of impact on the family. The aim was to identify the areas of life that the parents considered were disrupted or restricted for their child.
A study was identified which used a questionnaire for parents to measure "perceived symptoms and disability" in children with asthma (Usherwood et al., 1990). Usherwood et al saw a need for quantitative measures of the effects that may be experienced by a person with a chronic disease. The measure assessed general disability (mainly restrictions on daily activities) and also nocturnal and daytime symptoms.

Their results suggested that looking at the general impact of illness was better at discriminating between severe and mild cases of asthma than was looking at specific symptoms. The questionnaire showed good validity and reliability.

An impact of illness questionnaire to measure restrictions on daily activities in childhood ESRF was adapted from this study of perceived symptoms and disability in children with asthma (Usherwood et al., 1990). Verbal permission to do so was given by Dr Usherwood. The 15 item questionnaire included general questions which remained the same as in the original. Disease specific questions were altered with the aid and advice of clinical nurse specialists.

Measures of psychological status

For assessing psychological status the Perceived Stress Scale (PSS) and the Hospital Anxiety and Depression Scale (HADS) were selected.

The Perceived Stress Scale

The PSS had already been found to be easily completed by the parents when it had been used by the clinical psychologist. Thorough review of the measure revealed several features making it
appropriate for the study. The PSS was a short 14 item instrument to measure the degree to which situations in one's life are appraised as stressful. The perceived stress scale considers not only demands upon an individual, but also the individual's perception of how adequately they are coping with the demands.

The PSS items tap the degree to which respondents find their lives unpredictable, uncontrollable and overloaded. Items are also general in nature thus allowing it to be applied to people whose stress is caused by demands in any aspect of their lives (personal, work, finance etc.). This made the PSS suitable for use in assessing the stress levels of parents carrying out a demanding care regime.

Rather than being used to measure psychological symptoms, the PSS is recommended for use in assessing a state that places people at risk of clinical psychiatric disorder (Cohen et al., 1983). The PSS is recommended as an economic tool for assessing chronic stress levels, as it is recommended for repeated administration. As a longitudinal study was being considered this was important.

The measure had been assessed as both reliable and valid. Norm values from a large sample (n=2387) had also been published (Cohen and Williamson, 1988). The PSS had also been found to be a better predictor of health than life-event scales (Cohen et al., 1983), suggesting it is a more accurate measure of stress. Research

\[\text{It was realised at the end of data collection that in 1988 the authors of the PSS published data which, following factor analysis which recommended four of the items be removed from the scale, naming the shortened version of the scale as the PSS10 (Cohen & Williamson, 1988). The PSS10 was more reliable and the authors recommended that this version rather than the original be used. For all analysis in this study the results are for the PSS10.}\]
including factor analysis of the PSS concluded "the PSS is a multidimensional and internally consistent measure of perceived stress" (Hewitt et al., 1992).

The PSS has been used in many studies, including a number assessing the stress levels of parents (Walker, 1989a, 1989b), and of carers (Chwalisz and Kisler, 1995).

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) is a 14 item self-report instrument designed to provide a screening device for anxiety and depression. It provides separate measures of the two constructs, anxiety and depression, and is considered suitable for detecting minor psychiatric disorder (Lewis & Wessely 1990). It has been shown to be valid in both hospital and community settings (Lewis and Wessely, 1990; Moorey et al., 1991).

The Hospital Anxiety and Depression Scale (HADS) was designed for use in the setting of general medicine (Snaith and Zigmond, 1986) but has also been used in a psychiatric population. The authors recommend the HADS for repeated administration as required in longitudinal studies. The questionnaires are accompanied by published ranges for 'normal', 'borderline' and 'probable disorder' scores. The HADS has been used in many studies, including a number assessing the stress levels of parents (Rydebrandt, 1990, 1991).

For a complete set of the questionnaires used in this project see Appendix A. Complete ANOVA tables for any results discussed in this chapter can be found in Appendix A(i).
Frequency of data collection

It had been noted by members of the paediatric renal team that families' stress levels fluctuated. It was postulated that patterns of stress behaviours were caused by differing stages of treatments and by the length of time on any given treatment, as well as by external non-illness-related events. Because of these variations there was a need to consider longitudinal assessment of the families rather than, as in much previous research, a single testing. This could help assess the impact of differing therapies, as families may move from one therapy to another during the course of the research project eg, having a kidney transplant to replace dialysis therapy. To observe the same family through different treatments might provide a more complete picture of any stressful effects.

It has been argued that much of the confusion and inconsistency in stress and illness research has in large part to do with stress researchers' failure to take advantage of prospective longitudinal designs (Kasl 1983). Longitudinal research permits greater exploration of relationships and associations between characteristics of an illness and treatments, with other variables such as support or the patient's emotional status (Ouelette Kobasa, 1985).

One of the major problems with longitudinal research is that of attrition, and it is generally recognised that attrition typically occurs even with the most careful of procedures (West, 1985). However if one wishes to study "career" patterns of behaviour, as may be the case in caring for chronically ill children, then longitudinal work is invaluable (Menard, 1991).

It was decided that the study would adopt a longitudinal panel design where the same set of parents were used in each period of
testing. It was recognised at the beginning that there would probably be some attrition during the study as patients were transferred to the adult unit, or to other paediatric units if the parents moved house or employment. It was also recognised that parents may not reply to every questionnaire. However the opportunity to be able to follow families through different treatments and through other life changes remained advantageous enough to pursue longitudinal data collection.

Data collection would need to occur frequently enough to be able to reflect any major treatment changes as recent, but would not be so frequent that parents would be unwilling to join the study. It was recognised that even those who joined the study might not manage to complete each and every questionnaire they received. Collecting data four monthly was considered suitable to meet both these criteria.

Comparison groups

There are many factors which can contribute to the psychological well-being in parents of children caring for a child with ESRF. Not all of these factors will be specific to the child having renal failure nor to the providing of illness-related care. For the study it was important to attempt to identify psychological states that could be attributed to the care specifically.

When reviewing previous research on chronic childhood illness and the effect on parents or child, it is difficult to separate stresses and demands of parenting generally and those specific to caring for a child with chronic illness (Miller et al., 1992). This has been reported as a considerable limitation of such research (Van Riper et al., 1992). However conclusions can be drawn more safely from studies which
use a comparison group of parents of healthy children (Henry Sawyer, 1992).

Tunali and Power (1993) note that there are fewer reports of increased marital problems or stress, or of poor psychological functioning in families with handicapped children, when well-matched control groups of families with non-handicapped children are used. A study looking at long term outcome of children with ESRF found that whilst it was possible for subjects to apparently perform poorly on conventional indictors of social adjustment, subjective adjustment was found to be comparable to those of a healthy controls (Reynolds et al., 1993). This important finding could not have been identified without the use of a comparison group.

Another difficulty when reviewing previous research on chronic childhood illness is identifying which stresses and demands of caring for a chronically ill child are specific to the particular condition of the child, rather than to chronic illness generally. It is argued by some that it is not beneficial or useful to differentiate between families of children with chronic illness on the basis of the child's diagnosis (Stein and Jones Jessop, 1989; Jessop, 1991; While, 1991). A considerable amount of literature does address problems of chronic childhood illness generically (Sabeth, 1984; Canam, 1993; Pless et al., 1993), suggesting that there are some common challenges to caring for children of any chronic illness. However certain aspects of a disease, such as threat-to-life, complexity of treatment, and severity of symptoms, will specifically influence how children and their parents respond to and feel about, the disease and treatments (Steinhauer et al., 1974; Eiser, 1993, p11-13).

These findings support the use of comparison groups of parents
whenever the affects of chronic childhood illness are to be studied. To that end not only parents of children with ESRF were included in this study. There was a comparison group of parents of children with another chronic childhood illness, insulin dependent diabetes mellitus (IDDM), as well as data from comparison parents of children not known to suffering from a chronic illness.

Parents of children with IDDM were deemed a suitable comparison group as childhood diabetes shares many common factors with chronic renal failure. Common features include: the fact that at present there is no known cure, only treatment; there is the daily need to maintain dietary controls, and to take daily medication (insulin injections); it only takes a short time without treatment for the child to become ill, probably requiring hospitalization, and with possible life-threatening effects.

There are also notable differences between renal failure and diabetes though, in prognosis and daily living. With childhood ESRF there is a greater risk of premature death, greater effect on development such as growth rate, and also a greater degree of uncertainty about the future especially regarding when a transplant might become available, or if already transplanted, whether it may fail in the near future. During treatment with dialysis the physical burden of care is also considerably higher.

The parents of children with IDDM were to receive the series of questionnaires as sent to the parents of children with ESRF (except that specific information needs and impact of illness questions were adapted to be suitable for diabetes, not renal failure). The children were age and sex matched to those children with ESRF whose parents had agreed to take part in the study. Parents were approached in the paediatric diabetes outpatient clinic and provided
with an explanation of the study. They were then asked if they would be interested in participating. As only one father was observed attending the clinic this meant that in effect 'mothers' had been approached rather than 'parents'.

Mothers of 28 children with IDDM agreed to take part in the study, and agreed in proxy for their partners to also take part. Out of these 57 parents (for one child the mother agreed on behalf of both the father and the stepfather) 41 parents did become participants in the project, completing and returning at least one questionnaire (see p91-92 for further details).

The need to have a comparison group of parents of non-chronically ill children was also addressed. Initially the intention and hope was that parents of healthy children would also be assessed over the two years. By having a comparison group of parents of healthy children, and measuring their stress, anxiety and depression levels using the same tools and under the same conditions as those parents with chronically ill children, it was hoped that it would be possible to interpret the results of the parents of chronically ill children relative to those of parents of healthy children.

Parents of children undergoing common, minor surgical procedures (such as hernia repair) were approached, provided with an explanation of the study and asked if they would be interested in participating. The children were age and sex matched to those with ESRF whose parents had agreed to take part in the study. Problems were soon identified with this method of ascertaining control measures. There were not many admissions of children within the age range of the study, most were younger. There was a particular difficulty with girls as fewer are admitted for surgery. However an even more problematic issue quickly arose.
The rate of attrition for control parents was rapid even by Time 2, and worse, the mean scores of those who did reply, especially fathers, were indicative of psychological distress. The mean stress, anxiety and depression scores were higher than those reported by parents of children with ESRF or IDDM (see Appendix B). It was concluded that there was a bias in the self-selection of those control parents who chose to reply. It was also concluded that this was likely to be a recurrent problem.

A longitudinal control group of parents was therefore considered unsuitable, and instead an alternative comparison group was sought. Letters apologising for this change were sent to those parents who had agreed to participate as controls.

Comparison parents of 'normal' children were obtained with a single testing. This was carried out with the cooperation of the Department of Human Sciences, Loughborough University, and the assistance of two of their psychology students. For dissertation research projects the two students, Tracy Parslow and Niki Louch, each obtained measures of psychological well-being from a sample of parents.

Ms Parslow administered the PSS questionnaire to parents who had at least one child aged 3 years-14 years. Parents from 67 families responded (mothers=64, fathers=59). The children were considered "free from significant illness", although parents of children with illnesses such as asthma were not excluded. The result was a sample of PSS scores from a typical group of parents.

Mr Louch administered the HADS questionnaire to parents who had children between the ages of one year and 19 years (mothers=41, fathers=25). Again parents of children with illnesses
such as asthma were not excluded from the results. Both studies sampled parents from both urban and rural areas. The comparison samples were therefore general population samples of parents rather than specifically parents with 'healthy' children.

This method of obtaining norm values for parents generally, was not ideal but was both useful and practical. The sample sizes were smaller than had been hoped for, and as is often the case, it was impossible to conclude that those who responded were representative of the whole sample approached. However it is still desirable to be able to make comparisons with general (UK) population samples of parents rather than simply comparing study parents' scores against published norms of adults - some of whom will also have had children with chronic illness, and many others who would not be actively parenting at the time of testing.

It has been advised that multiple comparison groups such as this can be one way to strengthen experimental design. West (1985) states that as control groups cannot be matched on all characteristics it is often useful to identify several nonperfect groups instead. He suggests that each control group will have its strengths and weaknesses, but that comparisons across the groups helps minimise the number of alternative explanations of the results (West, 1985).

**Response rates**

**General population comparison groups**

212 PSS questionnaire were distributed through schools to parents who had a least one child aged 3 years - 14 years. Parents from 67 families responded (mothers=64, fathers=59). The response rate was 31.6%
190 HADS questionnaires were distributed through school catchment areas. 66 were returned by parents who had children between the ages of one year and 19 years (mothers=41, fathers=25). The response rate was 34.7%

Data collection for the two year study

Parents of 35 children with ESRF, and of 28 children with IDDM were included in the study. Table 3:1 shows the response rate to questionnaires distributed throughout the study.

Parents were encouraged to reply to each of the seven questionnaires, but few responded on every occasion. Those who responded to 66% or more were classed as 'high responders', and those who replied at least once, but less than 66% of occasions were 'low responders'.

Table 3:1  Response rate of parents of children with ESRF or with IDDM.

<table>
<thead>
<tr>
<th></th>
<th>ESRF mothers</th>
<th>ESRF fathers</th>
<th>IDDM mothers</th>
<th>IDDM fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Replied at least once</td>
<td>71.4%</td>
<td>54.5%</td>
<td>82.1%</td>
<td>62.1%</td>
</tr>
<tr>
<td>Overall response rate</td>
<td>61.5%</td>
<td>51.30%</td>
<td>47.00%</td>
<td>33.10%</td>
</tr>
</tbody>
</table>

Table 3:2 shows the distribution of high, low and non-responders.

Parents of children with ESRF replied more frequently than parents of children with IDDM. Mothers of children with ESRF were significantly more likely to respond than mothers of children with IDDM (p=0.04, U=196.5). There was no significant differences between fathers (p=0.33, U=241.0).
Table 3:2 Distribution of high, low and non-responders.

<table>
<thead>
<tr>
<th></th>
<th>(n=)</th>
<th>High responders</th>
<th>Low responders</th>
<th>Non-responders</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESRF mothers</td>
<td>35</td>
<td>51.4% (18)</td>
<td>20.0% (7)</td>
<td>28.6% (10)</td>
</tr>
<tr>
<td>ESRF fathers</td>
<td>33</td>
<td>30.3% (10)</td>
<td>24.2% (8)</td>
<td>45.5% (15)</td>
</tr>
<tr>
<td>IDDM mothers</td>
<td>28</td>
<td>35.7% (10)</td>
<td>46.4% (13)</td>
<td>10.7% (5)</td>
</tr>
<tr>
<td>IDDM fathers</td>
<td>29</td>
<td>13.8% (4)</td>
<td>48.3% (14)</td>
<td>37.9% (11)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>125</td>
<td>33.6% (42)</td>
<td>33.6% (42)</td>
<td>32.8% (41)</td>
</tr>
</tbody>
</table>

This difference in response between chronic illness groups is possibly because the researcher was a member of the paediatric renal team there would have been a positive effect on the response rates of those parents being cared for by that team, leading to higher response rates from parents of children caring for a child with ESRF.

26 families (25 mothers and 18 fathers) of children with ESRF, and 23 families (23 mothers and 18 fathers) of children with IDDM actually participated in the study. The groups are outlined in table 3:3.

Only two factors were identified throughout the study that were significantly different for the high and low respondants. These factors were only significant for fathers and were: the number of times the study child was taken to the GP (p=0.0007, U=49.5); and the number of times the fathers themselves went to the GP (p=0.0005, U=51.0), both of which were reported as occurring more frequently for the high respondants.
<table>
<thead>
<tr>
<th></th>
<th>All Families (n=49)</th>
<th>ESRF families (n=26)</th>
<th>IDDM families (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
</tr>
<tr>
<td>n</td>
<td>48</td>
<td>36</td>
<td>25</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>36.65yr</td>
<td>38.72yr</td>
<td>35.17yr</td>
</tr>
<tr>
<td></td>
<td>(5.46)</td>
<td>(5.13)</td>
<td>(5.51)</td>
</tr>
<tr>
<td>Mean age of study child (SD)</td>
<td>11.05yrs (4.01)</td>
<td>10.24yrs (4.23)</td>
<td>11.96yrs (3.62)</td>
</tr>
<tr>
<td>Boys / Girls</td>
<td>25 / 24</td>
<td>15 / 11</td>
<td>10 / 13</td>
</tr>
<tr>
<td>Mean time since diagnosis (SD)</td>
<td>4.69yrs (3.31)</td>
<td>5.13yrs (4.04)</td>
<td>4.09yrs (1.81)</td>
</tr>
<tr>
<td>Mean age at diagnosis (SD)</td>
<td>5.65yrs (3.68)</td>
<td>5.03yrs (3.88)</td>
<td>6.51yrs (3.33)</td>
</tr>
</tbody>
</table>

**Overview of study methods and design**

A longitudinal study was carried out over two years, which involved the administration of questionnaires every four months. All questionnaires were posted to participants, one each for the mother and the father. Both parents were provided with stamped addressed reply envelopes for their return.

Socioeconomic family details were obtained at the beginning of the study, including age of parents, number and age of all children, occupation of both parents, and any chronic illness in any family member. A front sheet asking about the previous month accompanied...
each set of questionnaires for parents to complete, noting: any treatment or health changes for the child; the number of admissions or telephone calls to the liaison nurse; number of visits to the GP for the child, themselves or any other family member; and the frequency of outpatient appointments. A section also requested information on major life changes such as housing, finances, support etc. Changes could be for the better or for the worse.

Qualitative data were also collected during this period from the transcripts of the parents' support group (transcripts of discussions from seven meetings in total).

**Data Analysis**

*Analysis of quantitative data was carried out using SPSS for Windows.* There was both parametric and non-parametric data. Appropriate statistical tests were applied, taking the nature of the data into account.

The probability level of 0.05 was accepted as the statistical significance level. All results reported to be not significant can be assumed to be above this level unless specifically stated.

**Socioeconomic details**

*Basic socioeconomic data was collected from the PSS general population parents; occupation of parents, ages of parents, ages and number of children. More detailed information was available for families of children with ESRF and with IDDM.*

**ESRF, IDDM and General Population comparison groups**

Using a Kruskal Wallis ANOVA there were no significant differences in social economic class between groups as defined by
highest household parental occupation ($p=0.24$, $\chi^2=2.9$, DF=2).

Using one way ANOVA there was a statistically significant differences in the mothers' age, between parental groups ($F(2, 104)=3.81$, $p=0.03$). Post hoc exploration of these findings showed that mothers of children with ESRF were significantly younger than mothers of children with IDDM and than mothers from the general population sample. However the difference was only three years between the youngest mean and the oldest mean (a mean of 35.2 years for mothers of children with ESRF, and of 38.8 years for the mothers in the general population sample). This difference was not considered to be likely to represent a difference between the groups that was likely to affect parenting or coping style.

Using one way ANOVA there was a significant differences in the fathers' age, between parental groups ($F(2, 103)=6.50$, $p=0.002$). Post hoc exploration of these findings showed that fathers of children with ESRF were significantly younger (mean=37.7 years) than fathers from the general population sample (mean=42.3). Again, this difference was not considered to be likely to represent a difference between groups that was likely to affect parenting or coping style.

Using Kruskall Wallis ANOVA there was also a significant difference in the number of children in the families, $p<0.0001$, $\chi^2=2$, DF=2 (ESRF mean =1.45 children, IDDM mean =1.93 children, general population sample mean=2.34). Whilst there were no significant differences in the number of children under the age of five years ($p=0.59$, $\chi^2=1.06$, DF=2), there were however significantly less children over the age of 5 years in the families with a child in ESRF (mean 0.81) compared to families of children with IDDM (mean=1.53) or from the general population sample (mean=2.00), $p<0.0001$ ($\chi^2=28.77$, DF=2).
A possible explanation for this difference is that many of children with ESRF are diagnosed in the first two years of life. This is not the case in IDDM. Parents of children with ESRF have reported that they are sometimes reluctant to have more children, either because the burden of care is already very demanding, or because of fear that any further children may also have ESRF. Parents of children with IDDM may have similar feelings, but many are not diagnosed until after their fifth birthday, by which time younger siblings may have already been born. Also such concerns are likely to be to a lesser degree as the diabetes is neither so demanding, nor so likely to result in early death for the child.

**Chronic illness groups only**

Statistical analysis using Mann Whitney U tests revealed were no significant differences between the families of children with ESRF and those of children with IDDM on the following further socioeconomic factors; the age or sex of the study child, the education level of the parents, the perceived financial status of the family, the number of single parent families, the division of health-related childcare.

**Hypotheses**

It was expected that the parents of children with ESRF would report greater impact of illness, and greater associated stress, as well as greater stress related responses such as anxiety and depression, than any other group of parents. Parents of children with IDDM were hypothesised to have lower stress than parents of ESRF, but higher than the parents from the general population sample. It was hypothesised that within all groups the age of the child may have an influence. It was also hypothesised that the treatment the child was
receiving would be a significant factor in the parents' reports of impact of illness and stress. It was proposed that there would be an association between greater parents' reported information needs and poorer psychological well-being. Mothers were also expected to be affected more by their child's illness as they were reported to deliver more of the illness-related childcare than fathers.
Impact of chronic illness and restrictions in daily life

Introduction

Chronic illnesses which involve a demanding routine of home care often impose considerable restrictions on daily life. Restrictions and treatments usually affect not only the child, but also their parents and other family members. Disruptive treatments and restrictions upon daily activities result in additional work and emotional strain for the parents who are required to administer the treatments and also to justify to the child the restrictions on daily life (Steinhauer et al., 1974). In medical conditions that require frequent hospitalisations, or painful treatments, additional pressures will be brought to bear upon the parents and the child.

Making decisions about lifelong, intrusive but potentially life-saving treatments, yet with no guarantee of life, nor assurance of acceptable quality of life for the child should they live, is probably one of the most onerous burdens that parents are required to carry.

Delivering treatments such as twice daily physiotherapy, or bringing the child to regular specialist clinics or therapists will bring more direct demands upon the time, energy or finance of the parents. Parents of children with cystic fibrosis report that adhering to their child's treatment regime, and living with the uncertainty of what the future may bring were taxing (Gibson, 1988). Parents may need to assist their child with basic activities such as dressing, or they may need to make adjustments to the family routine.
involving food, travel or holidays.

The burden of care that parents bear is not often measured, but it is difficult to assess the burden of care using only simple unidimensional measures such as time or financial cost. How parents perceive the care they are required to deliver will invariably have an influence on how great an impact the illness and treatments are seen to have upon parents and child. The age of a child requiring illness-related care has certain effects upon how parents perceive and administer that care. Mothers may feel more comfortable with the increased dependency imposed by disease upon younger children, since younger children are expected to be dependent (Eiser et al., 1992), whereas with older children a parent may feel that the illness and treatments are having a greater impact both on their life and on that of their child.

Parents delivering care for a child with ESRF

For any parent caring for a chronically ill child there will be extra illness-specific demands, both physical and psychological. Physical demands are commonly related to delivery of treatments. Psychological demands include dealing with the stress of delivering the care and any sequelae of chronic stress such as anxiety or depression. Parents must also manage their concerns about the child's health and future.

The burden of caring for a child with ESRF varies with the type of treatment, as well as the age of the child. A successful transplant is considered to be the best treatment, with better growth, appetite, and social adjustment outcomes. However, unless there is a living-related donor, patients have to wait for a cadaveric donor kidney to become available. Therefore the majority of children will require
alternative renal replacement therapy, either haemodialysis or peritoneal dialysis. Haemodialysis is usually delivered in the hospital setting, and peritoneal dialysis at home.

Home dialysis is considered to be the most suitable for the child's social and psychological adjustment (Brownbridge and Fielding, 1991), and least likely to disrupt education. These benefits are not without their costs though. Parents are required to deliver the care to their children. This care requires significant amounts of time and energy and cannot be undertaken without considerable training taking place first. Increasing expertise in home peritoneal dialysis combined with an emphasis on family-centred care means that parents are taught to undertake more procedures at home (Gartland, 1993)

Home peritoneal dialysis can be of either of the two main types. CAPD, the manual emptying of fluid into the peritoneal cavity or CCPD which involves the child being attached to a peritoneal dialysis machine overnight. Gartland (1993) carried out a survey of the 15 UK paediatric renal centres which revealed that nationally in September 1991 there were 126 children on home peritoneal dialysis. 52% (n=66) were on CCPD of whom 26 were less than five years of age. 48% (n=60) were on CAPD, with only 8 under five years of age.

Whatever method of peritoneal dialysis is carried out there are sterile dressings to be changed around the abdominal Tenckoff catheter (which is positioned into the peritoneal cavity). All the children on home dialysis in this study were on CCPD and an illustration of the demands made upon the parents is outlined below.
Demands on parents delivering CCPD to their children

Nationally 12 of the 15 paediatric renal units follow a structured training programme to enable parents to gain the knowledge and master the skills required to deliver the home dialysis. 13 of the centres considered the demands so great that they trained not one, but both parents to deliver that care (Gartland, 1993).

The demands of CCPD require the parents to set up the dialysis cycling machine each night, first cleaning the machine, then putting the giving set (a sterile set of tubes with valves and connections) correctly on to the machine. Then a bag of the correct strength dialysate fluid is placed on the top warming shelf of the dialysis cycler (this gives enough height to allow fluid to drain into the child's abdomen and also brings the fluid up to body temperature). Sterile techniques are employed by the parents to join the bag to the giving set and break the fluid seal, letting the dialysate fluid run through, and completely fill the tubing.

Parents then close the appropriate valves - taking special care to fasten the valve on the end of the waste bag positioned under the machine, otherwise waste fluid can empty onto the carpet. The dialysis prescription (strength, amount of fluid, dwell times and so forth) is the same each night and the machine would already be programmed with the amount of fluid to be deliver each cycle, the length of time the fluid is to dwell intra-abdominally, and the number of cycles to be delivered.

When the child comes up to their bedroom they are weighed before being settled for the night. The parents then connect the child's peritoneal catheter to the giving set, again employing sterile, aseptic, techniques. The peritoneal catheter is then taped securely to the
child's abdomen ensuring there are no kinks, and the machine is then switched on to deliver the dialysis.

Theoretically the dialysis cycler will then follow the programme overnight, and parents and child will awake to completed therapy. Unfortunately this is not always the case. The dialysis machines are very sophisticated and are able to detect a number of causes of dialysis failure, and emit an appropriate auditory alarm, accompanied by a visual indication of what the problem is.

The most commonly reported problem is that the child has moved, in their sleep, into a position that does not permit the dialysis to take place. This can be because the tube is being lain on and has become kinked, or because the child's peritoneal catheter is "position sensitive", where internally the end of the tube is perhaps positioned against some tissue, thus preventing drainage. Children rarely wake up when the alarm has gone, presumably because they have adapted to it. Parents are then woken, and need to reposition the child to allow free flow of the fluid.

Another cause of an alarm is when insufficient of the fluid that was drained into the peritoneal cavity drains out. This can happen because of the position of the child, or more worryingly in the case of infection in the peritoneal cavity. Parents have to assess which is the cause by moving the child, and by looking for signs of infection such as pyrexia in the child, or clouding of the waste dialysate fluid.

If there are signs of infection then parents need to telephone the on-call renal nurse. In most cases of peritonitis the child will be admitted to the paediatric renal unit for administration of antibiotics into the peritoneal cavity via the dialysate fluid. If the parents have received instruction and teaching about how to add antibiotics to
the dialysate they may, on occasion, be instructed to administer the antibiotics at home. The bag of waste dialysate fluid would be brought to the hospital to be sent for bacterial analysis.

Most infants and young children under five will need dietary supplements delivering via a tube, either a nasogastric tube or a gastrostomy button. Drugs may also be administered by this route. Parents need to clean and dress the area around the button on a regular basis. The majority of the supplementary feed can be administered overnight, with the rest being given as bolus doses through the daytime. To deliver overnight feeds parents first mix the feed formula and place it into a sterile bag. Parents also tend to put medications into the feed for overnight delivery too. Then the parents attach a giving set and connect it to a feeding pump.

The pump will need to be set to deliver the feed at a predetermined rate such as 100mls per hour. Once the child is in bed the giving set is connected to the tube and switched on. Again the machine may alarm if the tube becomes kinked in the night. Another problem can arise if the tubes become disconnected (a risk when toddlers are involved) as the feed, which is usually quite a thick sticky fluid can soon empty onto the floor or bedding instead.

During the daytime, feeding is often one of the biggest problem for parents of children on dialysis. A UK survey of the children on peritoneal dialysis revealed that 30% \( (n=38) \) were also receiving supplementary overnight feeds (Gartland, 1993).

In 1980 Chantler et al reported that generally a year on home dialysis was acceptable to about 80% of the children, and to about 50% of the families. The children Chandler referred to were most often on home haemodialysis, rather than home peritoneal dialysis.
Concerns about parents who have to deliver home peritoneal dialysis for more than a year are also reported (personal correspondence from Dr Watson, Consultant Paediatric Nephrologist, Nottingham).

Restrictions on daily activities in chronic childhood illness

Childhood is traditionally when formal education begins and is a period of great scholastic importance. Childhood is also a period when social development is progressing. Social development takes place not only in the family setting, but is strongly influenced by the child's opportunities to interact with other children. Peer groups form naturally among children who live close to each other or go to school together, and of course many children who attend the same schools live in the same areas. Much of a child's peer interaction can occur either in the school setting or with children from school but outside the school domain. Attendance at school then is not only educationally beneficial but also socially valuable.

Chronic illnesses can have negative affects upon the education and schooling of children. School performance is noted to be poorer in those children on dialysis compared to those who have a successful transplant (Lawry et al., 1994). This was particular significant in the areas of mathematics and written language. In one study approximately one third of parents of children with IDDM reported that their child had experienced problems at school which they believed were related to diabetes (Parker et al., 1994).

A German study identified that children with chronic renal failure were more likely to attend a school providing vocational training than were the general child population, and were also less likely to attend a school which provided qualifications for a university career.
(Rosenkrantz et al., 1992). For parents of children on CAPD, school absenteeism has been reported as a concern (Hulstijn-Dirkmaat and Damhuis, 1994). Nearly two-thirds (61.9%) of parents of school-aged children on CAPD reported that they found school absenteeism either difficult or causing great burden. This was significantly more than parents with preschool children (7.1%). Parents also reported equal or greater concern about their child's educational future, as they did about the absenteeism.

The degree of concern about school and friends was considered in one study of parents caring for children with ESRF (Reynolds et al., 1995). Whilst over half of the parents reported that "school and friends" was a concern, the majority of these only considered it to be a minor, not a major, concern. This pattern was reflected in the concerns of the children themselves. To a degree this abrogates the interpretation of previous studies where low educational attainment in children with ESRF is unconditionally portrayed as a major problem.

The symptoms of ESRF, such as tiredness, or the demands on the child of the necessary renal replacement treatments, commonly restrict the child's daily activities. If the restricted activities include attendance at school or opportunities to socially interact or play with their peer groups, then children can feel isolated or develop low self-esteem (Brook and Benjamini, 1993). Self-esteem is not only important in the development of the child's personality, but also in developing further friendships (Cook et al., 1978).

Social competence allows children to successfully develop and sustain peer relationships and to function adequately in school (Breitmayer et al., 1992). The more an illness interferes with a child's daily life and restricts them from carrying out activities that they
wish to do, then the more negative effect it is likely to have on a child's self esteem.

Usherwood, Scrimgeour and Barber (1990) devised a questionnaire for parents to complete which measured perceived symptoms and disability in children with asthma. They saw a need for quantitative measures of the effects that may be experienced by a person with a chronic disease. The measure assessed general disability (mainly restrictions on daily activities) and also nocturnal and daytime symptoms. Children with asthma displaying active symptoms and requiring more active treatment (inhaled steroids) were compared to children with less severe asthma.

The parents of children with severe asthma reported higher scores on each of the three scales, although this was minimal for nocturnal symptoms (median 6.0 vs 5.5). Unfortunately there were no statistical analyses of this data, but the difference in the median scores was greatest in the general disability scale (9.0 vs 3.0) (Usherwood et al., 1990). These results suggest that looking at general impact of illness is better at discriminating between severe and mild cases than looking at specific symptoms is.

No published studies examining burden of care or general restrictions on life caused by childhood ESRF, could be found. However a study which did examine these aspects of caring for children on home peritoneal dialysis was presented at a European conference (Nüssli et al., 1992). The study showed that parents of children with younger children on RRT spent many more hours carrying out ESRF related care, than did parents of older children. The burden of care was highest when CAPD was prescribed but was reduced when overnight cycling dialysis machines were introduced although still remaining high. A particularly burdensome aspect of
care was considered to be the feeding, especially when the child was young.

Rather than measuring the burden of care, either via observation or self-report, it was decided to assess the impact of the illness on daily life. This was primarily the perceived impact upon the child, but also included some aspects of impact on the family. The aim was to identify the areas of life that the parents considered were disrupted or restricted for their child. By this process it was hoped that support and advice could be directed in more focused ways by the multidisciplinary team.
Method

To assess the impact of illness on daily life two main routes were used. The first was a questionnaire and the second was transcription data from the parent support group. The questionnaire was adapted from that discussed earlier of Usherwood, Scrimgeour and Barber (1990), originally used with parents of children with asthma. The questionnaire was to be sent to the parents four monthly as part of the series of questionnaires. General questions, that is those not specific to the medical condition of asthma, were left in their original state; however those that were disease specific were altered with the advice and assistance of the specialist nurses. This gave the questionnaire relevance to the conditions of ESRF and IDDM. An example of an unaltered general question is "Over the past three months, being tired has limited your child's daily activities", and of a specific question "Over the past three months, dialysis has been more problematic than usual". The full list of questions can be found in Appendix C.

Parents were asked to rate the perceived impact of illness on daily living by estimating how often there were restrictions on different activities of the child or family. Parents were instructed not to count up the number of times, but rather to indicate an alternative that seemed like a reasonable estimate. For each question they chose from the following alternatives. Scores allotted for each alternative are also presented below.

4 = every day
3 = most days
2 = some days
1 = a few days
0 = not at all
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 addressed envelope for its return. The decision to issue the questionnaire over the two years provided the opportunity to follow people's information needs to see if they changed at any identifiable treatment stage.

Plotting the scores from a repeated, objective, quantitative questionnaire over time also allowed the use of an individual's own baseline against which one could measure increases or decreases in impact of illness. There would be no need to compare across individuals.

Replies were received from 43 parents of children with ESRF (mothers=25, fathers=18), and from 41 parents of children with IDDM (mothers=23, fathers=18), as discussed in Chapter 3.

Socioeconomic family details were obtained at the beginning of the study, including age of parents, number and age of all children, occupation of both parents, and any chronic illness in any family member. Age of child at diagnosis was also noted. A front sheet asking about the previous month accompanied each set of questionnaires for parents to complete, noting: any treatment or health changes for the child; the number of admissions or telephone calls to the liaison nurse; number of visits to the GP for the child, themselves or any other family member; and the frequency of outpatient appointments. A section also requested information on major life changes such as housing, finances, support etc. Changes could be for the better or for the worse.

The information from the transcripts of the parent support group provided a qualitative balance to the questionnaire. For the
questionnaire the limitation of the data received was constrained by the information requested. The transcripts on the other hand were taken from support group discussions. The parent support group had been functioning for a year prior to the commencement of this project, and had been established by the social worker and the clinical psychologist to address the issue of social isolation identified by some of the parents. Parents mentioned that those who had never experienced caring for a child with ESRF, going through dialysis and transplantation, could ever understand the burden of care that they had to carry. The need for such empathy and support were identifiable needs that the social worker and clinical psychologist were seeking to address through the parent support group. All groups were tape recorded, and had been since the group began. These tapes were then transcribed.

Hypotheses

It was hypothesized that the impact of the illness on daily living would alter at certain keypoints such as change of treatment modality. (That is to say when a child is about to commence dialysis, or has just received a transplant, or whose transplant has just failed). It was also hypothesised that diabetes would have a lesser impact then end stage renal failure, but that within the end stage renal failure group, it was also hypothesised that being on dialysis would pose more restrictions than having a renal transplant would. The research would also investigate the effects of factors such as age of child, time since diagnosis etc.
Results

The results section will consider

a Impact of illness scores explored along the two year collection of the data, with regard to socioeconomic data available, and to questionnaire data regarding stress, anxiety and depression scores, as well as the impact of illness score.

b The impact of illness score for each activity

c For five individual families the impact of illness results will be discussed in more depth, relating treatment changes and alterations in paediatric renal service.

d Finally, qualitative data, of parents' discussions relating to the impact of ESRF, will be extracted from the transcripts of the parents support group.

Complete ANOVA and regression tables for results discussed in this chapter can be found in Appendix D.

Two year study data

Only the general impact of illness questions were able to be compared, as disease specific questions could not be guaranteed to be of equal weighting or importance across conditions. Whilst parents of children with renal failure scoring on "Being tired has limited your child's daily activities" could be directly compared with parents of children with IDDM, the same could not be said for the specific questions. For example, comparing scores for the question regarding "Steroid treatments have caused some problems" with the question regarding "Your child has had a high blood sugar" would not be acceptable.
Parents were divided into high and low responders (see Chapter 3, p92). Mann-Whitney U tests were carried out on these two groups, first for mothers and then for fathers, to identify whether responders had a bias towards being those reporting particularly high or low impact of illness scores. There were no significant differences for mothers (p=0.67, U=56, W=98) or fathers (p=0.51, U=24, W=57) of children with ESRF, nor for mothers (p=0.42, U=52, W=133) or fathers of children with IDDM (p=0.14, U=13, W=49).

Overall scores

Due to the small number of respondents that replied on every occasion it was not possible to carry out trend analysis. For analysis of the data collected over the two year study it was necessary to calculate mean scores over the study for each subject. It is these mean scores that were used in the Two year Study analysis. Mean general impact of illness scores for mothers and for fathers of children with ESRF, and with IDDM can be seen in the table 4:1 below.

Table 4:1 Mean general impact of illness scores over study

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers of children with ESRF</td>
<td>7.90</td>
<td>5.77</td>
</tr>
<tr>
<td>Fathers of children with ESRF</td>
<td>7.35</td>
<td>5.90</td>
</tr>
<tr>
<td>Mothers of children with IDDM</td>
<td>5.04</td>
<td>5.58</td>
</tr>
<tr>
<td>Fathers of children with IDDM</td>
<td>4.81</td>
<td>4.44</td>
</tr>
</tbody>
</table>

Two way analysis of variance revealed a trend (p=0.06, F(1,79)=3.76) for parents of children with ESRF to report higher general impact of illness scores than parents of children with IDDM. There were no significant differences between mothers and fathers reported.
general impact of illness scores \(p=0.94, F(1,79)=0.005\)

**Time since diagnosis & age of the child**

ANOVA's were carried out to identify whether the time since diagnosis had a significant effect on parents' mean general impact of illness score. A two way ANOVA was carried out with time since diagnosis, and age of child in the analysis.

As the study was longitudinal it was necessary to use time since diagnosis at the centre point of the study (Time 4). As it was expected that any association would not be linear families were divided along quartiles to provide bands. The groups were as follow, those whose child had been diagnosed less than 22 months, those whose child had been diagnosed more than 22 months but less than 52 months, those whose child had been diagnosed more than 52 months but less than 69 months, and those whose child had been diagnosed more than 69 months.

The age of the child was also divided into bands as the literature suggests that certain developmental stages can give rise to differing depression scores (Walker et al., 1987). The age bands consisted of: children under five years: children over five but under 10 years; over 10 but under fourteen years; and over fourteen years old.

There were no significant differences in general impact of illness scores indicated by either time since diagnosis, or age of child for any parent group. Significance of interactions could not be reported as not all carebands contained a child from each ageband. See Appendix E for a graph illustrating this point.
Delivery of care

Three way ANOVA's were carried out to examine whether the division of care for the child had any effect upon general impact of illness scores. Care was either provided by the mother mainly, or the mother and either the father, or the child themselves. The medical condition and the sex of the parent were also in the analysis. There were no significant effects, however a significant interaction was reported between the medical condition and the provision of care upon the general impact of illness scores (p=0.009, F(1,63)=7.335). Figure 4:1 illustrates the nature of the interaction.

Figure 4:1 Interactions between medical condition and care provision upon general impact of illness scores.
For families of children with ESRF the general impact of illness score is higher when the provision of care is by the mother with assistance and lower when provision of care is mainly delivered by the mother alone. However, this is not the case for families of children with IDDM where general impact of illness scores are lower when the provision of care is mainly by the mother with assistance and higher when provision of care is mainly delivered by the mother alone.

Further analysis indicated that there were further treatment related (non-significant, p=0.21, F(2,26)=20.91) interactions within the ESRF group (see table 4:2).

Table 4:2 shows that in families where dialysis or transplant was the constant renal replacement therapy throughout the study period, the mean general impact of illness scores were higher when the mother was the primary care giver, and (slightly) lower in those families where the mother shared the care with another. However when a transplant had taken place during the study period (no families went from transplant back to dialysis during the study), it appears that the mean general impact of illness scores were lower in those families where the mother was the primary care giver, and higher in those families where the care was shared with another.

Following on from this a three way ANOVA was carried out of mean general impact of illness scores of parents of children with ESRF, with main care provision, treatment received by the child, and the sex of the parent replying entered as variables. The only significant effect was by treatment (p=0.01, F(3,35)=4.10).
Table 4:2 Mean general impact of illness scores by main care provision, and treatment received during the study.

<table>
<thead>
<tr>
<th></th>
<th>Mother Only (n=16)</th>
<th>Mother and Other (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All dialysis</td>
<td>Mean 4.33 (n=3)</td>
<td>3.20 (n=5)</td>
</tr>
<tr>
<td></td>
<td>S.E. 0.74</td>
<td>0.37</td>
</tr>
<tr>
<td>All transplant</td>
<td>Mean 2.86 (n=10)</td>
<td>1.43 (n=4)</td>
</tr>
<tr>
<td></td>
<td>S.E. 0.48</td>
<td>0.55</td>
</tr>
<tr>
<td>Both dialysis and transplant</td>
<td>Mean 3.24 (n=3)</td>
<td>7.11 (n=13)</td>
</tr>
<tr>
<td></td>
<td>S.E. 0.47</td>
<td>1.38</td>
</tr>
</tbody>
</table>

One-way analyses of variance with post hoc exploration of these findings showed that parents of children receiving both dialysis and transplant therapies over the study period reported significantly higher general impact of illness scores (mean=6.39) compared to parents of children who were predialysis (mean=1.00), and to parents of children receiving only transplant (mean=2.43), or only dialysis (mean=3.63). Significance of interactions could not be reported as for one of the treatment groups (both dialysis and transplant) the general impact of illness score was the same for both mothers and fathers. See Appendix E for a graph illustrating this.

Health indicators, and life changes

Information was requested at the beginning of each questionnaire asking about events in the previous month (frequency of out-patient appointments, number of in-patient admission, number of outpatient visits to the ward, number of telephone calls to the specialist nurse, number of visits to the GP: for the child; self; or other household member, and any life event changes including housing/
Means for each subject were averaged over the study. As parents of the same child sometimes reported different rates of occurrence for these variables, results were analysed separately for mothers and fathers, each using their own reporting of these variables. Analysis using paired Wilcoxon test identified that differences in reporting between parents were not significant.

Using Kruskal-Wallis one-way ANOVA's, the means of four of these variables were found to be significantly different between the renal and diabetic parents. (As results were so similar only mothers' results will be reported see appendix F for précis of those of the fathers, and Appendix D for the complete tables).

There were significant differences in: frequency of out-patient appointments \( p<0.0001, \text{DF1, } \chi^2=24.85 \), with renal children attending more often; frequency of in-patient admissions \( p=0.0006, \text{DF1, } \chi^2=11.8 \), with renal children being admitted more; the number of calls made to the specialist nurse \( p=0.006, \text{DF1, } \chi^2=7.48 \), with parents of children with ESRF making more calls; and the frequency of parents attending the GP for their own health, with parents of children with ESRF attending their family doctor more often. This was again significant for both parents and significant at approximately the same level, for mothers \( p=0.03 \) (DF1, \( \chi^2=4.74 \)), and for fathers \( p=0.03 \) (DF1, \( \chi^2=4.89 \)).

It was possible to investigate possible associations between the general impact of illness scores and the health indicators and life events. A stepwise multiple linear regression analysis was carried and mothers and fathers were investigated separately.

There were no significant associations for fathers of children with
renal failure. Mothers of children with renal failure had a significant negative association between their general impact of illness scores and length of time between out-patient appointments \((p=0.02, \beta = -0.48, \text{Rsquare}=0.23)\).

Mothers of children with diabetes had a significant negative association between their general impact of illness scores and their reported life changes \((p=0.001, \beta = -0.64, \text{Rsquare}=0.41)\). Fathers of children with diabetes had several variables with significant negative associations with their general impact of illness scores. Reported life changes were entered at step 1 \((p=0.008, \beta = -0.64, \text{Rsquare}=0.41)\), on step 2 length of time between out-patient appointments was entered \((p=0.002, \beta = -0.44, \text{Rsquare}=0.60)\) and number of times that another (not self or the child with diabetes) went to see the GP, was entered on step 3 \((p=0.001, \beta = -0.34, \text{Rsquare}=0.72)\).

**Independent variables associated with variation in the mean general impact of illness scores.**

The age of the child, highest parental education level, finance (poor, fair, good), highest parental occupation, number of children and age of parent were all put in to the regression equation with the mean general impact of illness scores.

There were no variables entered at the 0.05 level for mothers or fathers of children with renal failure nor for fathers of children with diabetes. For mothers of children with IDDM one variable, Finance, was significantly associated with the mean general impact of illness scores \((p=0.05, \beta = .52, \text{Rsquare}=27)\).

**Dependent variables associated with the mean general impact of illness score.**
The mean information needs score, the mean stress score, the mean anxiety and the mean depression scores were not put into a regression equation to explain the mean general impact of illness score, as the impact of the illness was considered to be a cause in these variables rather than being an effect of them.

Discussion of the two year study data

The overall means show that the mothers and the fathers of children with ESRF perceived the illness had a greater impact on daily activities than did parents of children with children with IDDM, although this was not at a statistically significant level. Whilst treatments for both conditions have improved over the last twenty years there are still greater treatment demands for ESRF than for IDDM, especially when the renal replacement therapy is dialysis.

Differences in the demands faced by parents of children with renal failure and those faced by parents of children with diabetes can be partly identified from the results. Parents of children with ESRF reported that their children attended out-patients significantly more often, and that their children were also admitted as in-patients significantly more often. Parents of children with ESRF also made significantly more telephone calls to the specialist nurse than did the parents of children with IDDM. These results suggest a greater degree of surveillance by the parents and health care professionals indicative of a more unstable, less predictable, and perhaps more serious condition.

Within each medical condition mothers and fathers had comparable mean impact of illness scores. Impact of illness scores were not significantly affected by the age band of the child. This was contrary to findings of previous studies. Nor were they affected by the
length of time since diagnosis. However parents of children with ESRF reported significantly greater impact of illness when their child had received both dialysis and transplant therapy during the study as compared to those receiving the same RRT during the study (be it dialysis or transplant). This suggests that times of treatment change and transition are those that result in a greater impact on the life of the child and family.

The provision of the care has significantly different associations with the impact of illness score depending upon the medical condition of the child. In IDDM the mean impact of illness score is lower in those families where the care of the child is shared by the mother and another, than when the mother is the sole main carer. This is the opposite of the results found in the families of children with ESRF, where the mean impact of illness score is higher in those families where the care of the child is shared by the mother and another, than when the mother is the sole main carer. This could be because of the variability of care burden within the ESRF group.

Children on dialysis require much more direct care than do children with transplants. The treatment required by children with IDDM is relatively homogenous compared to that required by children with ESRF. If in ESRF, care is most usually shared when the child is on, say, dialysis when the treatment has a greater impact on the child and family this would explain the difference. Mothers of children with ESRF would then receive help when the impact was greatest, whereas whenever mothers of children with IDDM shared the care they would almost always have their burden reduced, thus reducing the impact. However further analysis identified that it was not the difference between providing dialysis or not that caused this interaction. Instead it seems that the change from dialysis to
transplant is when there are differences in the parents' impact of illness scores for families where the care of the child is shared by the mother compared to when the mother is the sole main carer.

As the impact of the illness was higher in those families where the fathers were more involved in the health-related care of the child, and where there was a change in treatment analysis of variance was carried out to identify this difference was caused by the fathers in those families having higher impact of illness scores. This was not found to be the case.

Both mothers and fathers of children with IDDM report greater impact of illness scores if they have reported more life changes. This could reflect the contextual aspects of impact of illness and burden of care. When other demands are being placed upon the parents the intrusion or restrictions imposed by the illness may be perceived as being greater. This may also explain why fathers of children with IDDM also report higher impact of illness scores to be related to the frequency of another close family member (not self or the child) visiting the GP. If the mother or one of the other children have also been ill then this too may increase demands and the perceived impact of the illness. Mothers of children with ESRF and fathers of children with IDDM also indicate that the more frequent the out-patient appointments then the greater the reported impact of illness score. Increased frequency of out-patient appointments usually reflects increased problems or instability of the illness. Problems or instability are also likely to impact on the child's daily life, hence the association.

A finding that was not anticipated was that mothers of children with IDDM whose finances were perceived to be better, reported the impact of the diabetes as greater than those less financially content.
This explained 27% of the variance for the impact of illness scores (p=0.05). Whilst this may be a Type I inferential error it is difficult to be certain. It is possible that parental expectations of a child's activity level are influenced by their financial situation. Families where money is not limited may be able to offer their child more opportunities to do things (such as horseriding). If this is the case, as it probably is, it is possible that a corollary of this is that parents have greater expectations of what their child should, or could, be achieving.
Results for individual questions

Parents were asked to rate the perceived impact of illness on daily living by estimating how often there were restrictions on different activities of the child or family. To ascertain which aspects of daily living were those most affected by illness-related restrictions, the mean scores for each question over the entire study were calculated. The scoring of the questions gave the answer "every day" a score of 4, "most days" scored 3, "some days" scored 2, "a few days" scored 1, and "not at all" scored zero. Means for each question were calculated for mothers and fathers separately within each group (ESRF or IDDM), to show differences between the impact of illness scores of these groups if any were present. The seven highest scoring questions for the parents of children with ESRF (figure 4:2), and of children with IDDM (figure 4:3) are below. The maximum mean score that could be obtained by a question is 4.0.

Figure 4:2 The seven highest scoring impact of illness questions for the parents of children with ESRF
The daily activities that parents of children with ESRF rated as having been affected most by illness-related restrictions were as follows:

14. Over the past three months, you have had to make adjustments to family life because of your child's renal failure.

8. Over the past three months, during term time, your child's education has suffered due to his or her renal failure.

10. Over the past three months, your child's renal failure has interfered with his or her life.

13. Over the past three months, your child's renal failure has limited your activities.

11. Over the past three months, renal failure has limited your child's activities.

12*. Over the past three months, (P) having treatment has interrupted your child's life (D) dialysis and/or other treatment has interrupted your child's life, (T) renal treatments have interrupted your child's life.

2. Over the past three months, being tired has limited your child's daily activities.

As can be seen the questions that score highest are not the same for parents of children with ESRF and for parents of children with IDDM.
Figure 4.3 The seven highest scoring impact of illness questions for the parents of children with IDDM

The daily activities that parents of children with IDDM rated as having been affected most by illness-related restrictions were as follows:

4*. Over the past three months, your child has had a high blood sugar.

5*. Over the past three months, your child has complained about doing their blood tests.

12*. Over the past three months your child has eaten the wrong foods.

14. Over the past three months, you have had to make adjustments to family life because of your child's diabetes.

1*. Over the past three months, your child has complained of painful injection sites.

2. Over the past three months, being tired has limited your child's daily activities.

10. Over the past three months, your child's diabetes has interfered with his or her life.
A one-way ANOVA showed significant differences in the mean scores of general impact questions by parent grouping $p=0.02$, $F(3, 43)=3.79$. Post hoc exploration revealed that general impact of illness questions were rated higher by mothers of children with ESRF than mothers of children with IDDM, and were also rated higher by fathers of children with ESRF than fathers of children with IDDM.

Using Student's t-test, further analysis of the scores attained by individual question differences identified that it was only on certain general questions that there were significant differences between parents of children with ESRF and of children with IDDM. These findings are in Table 4:3. As there are 20 analyses $p=0.025$ has been taken as the accepted level of significance to reduce the risk of a Type I inferential error occurring. For all questions the level of impact was reported as higher by parents of children with ESRF than by parents of children with IDDM.

Table 4:3 Differences between scores of parents of children with ESRF and those of children with IDDM, for each general question

<table>
<thead>
<tr>
<th>Question No.</th>
<th>Topic</th>
<th>mothers</th>
<th>fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Child tired</td>
<td>$p=0.40$</td>
<td>$p=0.85$</td>
</tr>
<tr>
<td>6</td>
<td>Child stayed indoors</td>
<td>$p=0.66$</td>
<td>$p=0.21$</td>
</tr>
<tr>
<td>7</td>
<td>Child stopped from playing</td>
<td>$p=0.13$</td>
<td>$p=0.03$</td>
</tr>
<tr>
<td>8</td>
<td>Child's education suffered</td>
<td>$p=0.002^*$</td>
<td>$p=0.004^*$</td>
</tr>
<tr>
<td>9</td>
<td>Not doing what normal for age</td>
<td>$p=0.02^*$</td>
<td>$p=0.04$</td>
</tr>
<tr>
<td>10</td>
<td>Interfered with child's life</td>
<td>$p=0.27$</td>
<td>$p=0.58$</td>
</tr>
<tr>
<td>11</td>
<td>Limited child's activities</td>
<td>$p=0.025^*$</td>
<td>$p=0.55$</td>
</tr>
<tr>
<td>13</td>
<td>Limited your activities</td>
<td>$p=0.10$</td>
<td>$p=0.01^*$</td>
</tr>
<tr>
<td>14</td>
<td>Adjustments to family life</td>
<td>$p=0.99$</td>
<td>$p=0.72$</td>
</tr>
<tr>
<td>15</td>
<td>Child lost sleep</td>
<td>$p=0.41$</td>
<td>$p=0.71$</td>
</tr>
</tbody>
</table>

* significant at the $p=0.025$ level
Discussion of the individual question findings

The specific impact of illness questions were not really comparable across the two conditions, especially as the two high scoring specific questions diabetes were mainly addressing compliance, and there were none of these for ESRF. More informative is the comparison across conditions for the general impact of illness questions. It can be seen that the children with ESRF are more likely to have had their education suffer due to illness-related factors, than are those with diabetes. A predictable but important finding.

Questions on family adjustments are highly scored for both sets of parents, as are general interference for child and the child being overly tired. However when the mean scores for the general impact questions are compared across the groups of parents it can be found that whilst, many of the general questions score rank highly for parents of children with either ESRF or IDDM, the mean scores for those questions are significantly higher for parents of children with ESRF. This demonstrates that the general impact of ESRF (as demonstrated through restrictions to daily life), is considerably higher than the general impact of IDDM. This finding is not unexpected considering the nature of the diseases and their treatments.

Mothers and fathers of children with ESRF reported that their child's education had suffered more frequently than was reported by the mothers and fathers of children with IDDM. This was highly significant. Mothers of children with ESRF reported that their child's illness had resulted in the child being more frequently stopped from doing all the things that a child of their age should be doing, and also that the illness had more frequently limited their child's activities. Fathers of children with ESRF however reported
that the illness had limited *their* activities significantly more often than was reported by fathers of children with IDDM.

It can be seen that the main difference between impact of ESRF and IDDM is seen in the effect on the child's education, with that of children with ESRF suffering more. This is a finding consistent with previous studies. Social relationships were not always perceived to be restricted significantly more in ESRF however, with no significant differences in the reporting of whether the child had been stopped from playing with their friends, or had had to remain indoors, because of feeling unwell. Despite the higher burden of care with ESRF there were no significant differences in the number of adjustments that had to be made to family life, however fathers of children with ESRF reported the illness limiting their lives significantly more than was reported by fathers of children with IDDM.

It is probable that parents of chronically ill children adjust their expectations of their child, and that the process of normalisation has an influence on the perceived impact of an illness. This could account for the majority of questions being perceived to affect the child and family life no more significantly in ESRF than IDDM when the treatment demands are clearly more intrusive in ESRF.
Individual families

Plotting the data for individual families over the course of the study illustrates not only how impact of illness varied between individuals, but also for families over time. Five families have been selected.

<table>
<thead>
<tr>
<th></th>
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<td>2</td>
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Family 114, with a young child (aged five years at Time 4) on overnight continuous cycling dialysis. At the beginning of the study the child has been on CCPD for two years and six months. There had been an unsuccessful cadaveric transplant (primary failure) nine months prior to the study. There is an older sibling (aged seven years at Time 4). Father (aged 35 years at Time 4) is in full-time employment. Mother (aged 34 years at Time 4) is currently not employed outside the house. Care is shared by both parents. There are additional care burdens due to supplementary feeds and dressings to the gastrostomy button.

At the beginning of the study the child has been on CCPD for two years and six months. There had been an (immediately) unsuccessful cadaveric transplant nine months prior to the study.

Both mother and father have mean general impact of illness scores within one standard deviation of their group means.

It can be seen that for both of the parents the impact of illness scores were fairly stable over the duration of the study.

The child ceased dialysis between time 6 and time 7 due to repeated infection of the peritoneal drain site, but this appears to have no major effects on the impact of illness score of the mother, although following this treatment change the father's score does reach it's highest point.
Family 103 - Impact of illness

![Diagram showing impact of illness over time for mother and father.]

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<tr>
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Family 103, with an older child (aged 15 years and five months at Time 4) who received a transplant six years prior to the this study, and which was still functioning well. Peritoneal dialysis had been carried out for eight months prior to transplant. There are addition concerns in the family about the health of the child, who had a cerebral vascular accident around the time of transplant. She was taking medications, not only immunosuppression for her renal transplant, but also antihypertensives and thyroxine. There were two younger brothers (aged eight years at Time 4). Father (aged 45 years at Time 4) and mother (aged 43 years at Time 4) are in full-time employment. Mother is responsible for the care, in cooperation with the child herself.

Both parents have quite low mean general impact of illness scores, which are within one standard deviation below their group means.

It is interesting to note that the scores for the mother and the father follow similar variation except at time 4 where the father's score goes up whilst the mothers goes down. Both parents completed their questionnaires around the same date so that does not appear to be the reason for this difference. The father's higher score was obtained by a score of two on many general questions rather than, for example, a score of four on two or three questions. Further examination of data shows that this overall general impact of illness score at time 4 did follow the same pattern (mother down, father up) for the mother's and father's depression score (see chapter five, page 47) which suggests that mood can create a perceptual difference of how the child was being affected.
Family 131 - Impact of illness

|   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
|   |   |   |   |   |   |   |   |
| Time 1 | Time 2 | Time 3 | Time 4 | Time 5 | Time 6 | Time 7 |

- mother - general impact of illness score
- father - general impact of illness score

| 131 |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| mother | mean general impact of illness score | mean | lowest | highest | range |
|       |                                           | 6.80 | 0       | 22       | 22    |
| father | mean general impact of illness score      | 11.17| 7       | 26       | 19    |
Family 131, with a young child (aged two years four months at Time 4) on overnight cycling dialysis. There is an older sibling (aged five years at Time 4). Father (aged 42 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is currently employed part-time outside the house. Care is shared by both parents. A successful transplant was carried out between times 5 and 6. There are addition care burdens due to supplementary feeds and dressings to the gastrostomy button.

Both mother and father have mean general impact of illness scores within one standard deviation of their group means. It can be seen that their individual mean general impact of illness covered a large range over the study period. However the large range occurred mainly as a consequence of an initial high score, with the impact of illness scores settling at a lower range following this.

It can be seen that for both of the parents' their mean general impact of illness scores were high at the beginning of the study, two standard deviations above the group mean for both the father and the mother.

At the beginning of the study their child was receiving hospital dialysis, overnight, twice weekly. This had commenced following an acute episode of Haemolytic Uraemic Syndrome following which the renal function had failed to completely recover. There was initial clinical uncertainty whether this would resolve or would develop into ESRF. Intermittent peritoneal dialysis (IPD) was the treatment of choice for the first few months until long term renal function could be ascertained. Unfortunately renal function never recovered to a degree suitable for life without renal replacement therapy. IPD required the parents to travel to the hospital twice a week and stay overnight with their child.
Between Time 1 and Time 2, home cycling peritoneal dialysis, and supplementary feeds via a gastrostomy button were commenced. Despite this the impact of illness scores dropped considerably, although after a year of this (time 5) the scores appear to be rising again. The successful transplant was carried out between times 5 and 6, and this certainly appears to have reduced the impact of illness for the father.
Family 134 - Impact of illness

![Graph showing the impact of illness over time for mother and father](image)

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<td>mean general impact of illness score</td>
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Family 134, with a child, aged 11 years and four months at Time 4, on overnight cycling dialysis commencing just before time 3. There is a younger sibling, with no health problems. Father (aged 41 years at Time 4) is in full-time employment. Mother (aged 41 years at Time 4) is not employed outside the house. Care is shared by both parents. A successful transplant was carried out between times 6 and 7. There are additional care burdens due to poor appetite and oral supplements, until transplant. There are also developmental and behavioural problems, and a history of epilepsy.

Both mother and father have mean general impact of illness scores over three standard deviations above their group means.

It can be seen that the parents' scores tend to fluctuate considerably, but remain consistently high. There were insufficient questionnaires issued after the transplant to ascertain whether there was a downward trend as a result of this treatment change.

Both parents appear to find the renal replacement therapies to have quite an impact on their daughter's life, and on their own. This may be due to the fact that renal failure was not the only health problem that their daughter had, but there is inadequate information to ascertain whether this was the case or not. It may also have been that the child reacted quite badly (emotionally or behaviourally) to the renal replacement therapy, but again there is inadequate information to ascertain whether this was the case or not.
Family 120 - Impact of Illness

<table>
<thead>
<tr>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
<th>Time 5</th>
<th>Time 6</th>
<th>Time 7</th>
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</table>

- mother - general impact of illness score

<table>
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<tr>
<th>120</th>
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<th>mean</th>
<th>lowest</th>
<th>highest</th>
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<tbody>
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<td>5.3</td>
<td>0</td>
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</table>

135
Family 120, with a child (aged seven years at Time 4) on overnight cycling dialysis, commencing six months prior to the start of the study. There is an younger sibling. Father (aged 44 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is not employed outside the house. Care is mainly delivered by the mother. A successful transplant was carried out between times 1 and 2.

The mother has a mean general impact of illness needs score within one standard deviation of her group mean. The father did not take part in the study.

It can be seen that there are fluctuations of the mother's general impact of illness score during the study, but that these fluctuations are around the mother's own mean.

One year post-transplant it can be seen that the impact of illness score has decreased to zero, for two questionnaires in succession. The mother did not return the next questionnaire. It seems that by this stage in the child's treatment the mother no longer considered the ESRF and treatments to be a significantly restricting factor in her child's, or family's, life.
Qualitative data

Transcripts revealed that there was great exchange of information during the parent support group discussions, often consisting of personal experiences regarding caring for a child in ESRF. There were often direct references to the impact of the illness upon the family and to demands involved in caring for a child with ESRF. Whilst it was apparent that the majority of parents were coping with that burden there were few references which directly addressed how parents coped. These references to impact of illness are transcribed below.

Comments may be included from parents of the families in the individual plots. To better preserve anonymity each family is identified by a single letter, rather than the original number code.

Topics include specific care demands, concerns about the child's future, making decisions about treatment choices, schooling, and coping resources such as social support, normalisation and respite care.

Specific care demands

"the routine is the source of the thing, if we have our evening meal later than a particular time or if we get up in the morning later than a particular time you know you're in for trouble "[father E] (delivering both overnight peritoneal dialysis and overnight feeds)

"he was on so many medicines, it's unbelievable ... he's only on feed, but at one time he was on about ten, wasn't he, trying to get that down a fourteen month child, I mean it was a battle you know" [mother F]
The feeding was often seen as problematic and demoralising.

"We regularly had feeds that went on so long that it was running into the next feed, it was just continuous" [family D]

"I can't think of anything more soul destroying than perhaps having spent an entire hour trying to get about 50mls in and that 50mls to promptly be brought straight back up again" [unidentified]

"I'd have a cup of tea or cup of coffee, then take him off and start feeding him and I would finish feeding him about 2 o'clock in the morning. What then? 5 o'clock the next morning, start again" [mother B]

"at least with the dialysis machine we can judge when to put it on and when we want to get it off, but we've compared notes with other people about using the overnight feed, and it seems to have a mind of it's own and it's very difficult" [father E]

"as she is you know she doesn't feed properly, doesn't drink properly, I mean I tend to panic" [mother E]

Overnight dialysis also caused some problems at times

".....we knew it (peritoneal dialysis machine) wouldn't work, we just couldn't cope, so we took her off, we couldn't cope with getting out all the time" [family D]

"she's tremendous, to what she used be, through the dialysis...it's funny every morning when she used to wake up she used to feel sick you know... we'd bypassed an alarm Friday night and Saturday morning to get away early, she'd only had six cycles, and then last night was her night off, and I tell you for the first time in three months she woke up with this sicky..[ father L]"
"It (peritoneal dialysis machine) used to alarm between 12 and 14 times a night every night" [family B]

- The child's future was an issue of great concern for the parents

"that's something to look at, the state of (child)'s stomach, I used to think he's not going to be able to go around without a tee-shirt and be the big I-am on the beach...but he wouldn't be allowed to anyway...he'd have to keep his clothes on anyway so it doesn't matter" [mother B] (referring first to her son's scarred abdomen, and then to the increased risk of skin cancer for those on immunosuppression therapies)

"(child)'s twelve and we feel now that she's more conscious you know. When's she's going to have a transplant she's going to be on steroids and things and she's going to, her face is going to be changing and she's getting older, she's more conscious of it, as when they're littler they just accept it" [mother L]

"...the apparent lack of liaison between paediatric renal and adult renal ...I'm just making a point that okay it's going to be twelve years before (child) ... maybe has to make this switch...that knowing how long things take to change maybe if we start a little bit of this now, by the time our kids are passing through there might be some change in attitude" [father E]

- The unpredictability of the course of ESRF caused problems for some parents

"but every day when you hear that phone ring at work, you think god is it me or not, you know and my heart's in my mouth every time the phone rings" [mother L] (child on transplant waiting list)
"Other people they get over their problems, they might have polio - yes you are going to be disabled for the rest of your life, we don't know what is going to happen to our children for the rest of their lives" [mother A]

"parents'll admit it's been hard it's hard on the children thinking they've had their transplant, it'll see you through an education, but then it's failed and they've got to start again on dialysis. They've got enough to cope with with education, and exams without having to...." [mother B]

Decision making, especially about renal replacement therapies, was often discussed

"At one stage the transplant was going to be the answer to everything, he was going to grow to be normal, but now transplant is not necessarily going to make him grow all of a sudden, and we are discussing hormone treatment and things like that" [family B]

"(child) looks so well on dialysis that well I think is it really fair putting her through all that..because I am anxious, I'm really worried about the transplant..she is extremely well" [mother E]

"We did it because of (child) being ten now, we've done live donor rather than wait to get him settled before he goes to comprehensive school, to let hopefully go through his education"

> families sometimes reported feeling under pressure to agree with the decisions of the paediatric renal team

"do you feel you couldn't say no then (to putting their child on the transplant waiting list), because in my case, although it's always more difficult to say no than yes or simply to go along with it I feel we could have said no.."[father E]
"...we could have said no but we'd have been hassled until we said yes. He admitted that. I said have we really got a choice then and he said well yes you have, I wouldn't put (child) on without your agreeing, but I'll keep nagging until you do so" [mother B]

Education of the child

This was seen to be a problem primarily because of the teachers' lack of knowledge and understanding or because of potential difficulties with the child's peer relationships.

"I think there were about six of them (members of the paediatric renal team) came up to the school and talked to the headmaster, and his attitude to me, and to (child)'s problem changed, he felt better because they'd been up to talk to him" [mother C]

"I just found two dolls, you know one with a gastrostomy, one with a catheter, went in and tried to explain to the kids (child's classmates) what a kidney does because there's a book "Me and my kidneys", a good book and it's got pictures in..." [mother B]

"even with his drinks he had to have special things he had to have, in first sitting in school because of his diet you know...he wasn't on his own because their was another boy who had to have a special diet, and they used to have all the special diets first round one table, and then they'd bring the rest of the children..." [mother C]

".. he was always pulled out as different but once he got into this other school he was like everybody else, (though) they knew he'd got his problem ...." [mother C]

"there are some activities that as you know the hospital recommend that she doesn't take part in, but the general rough and tumble of the playground, knowing what (child)'s like that's something that
she won't be happy to be excluded from" [mother E]

"did it bother him that you were going up to school at this time (to do lunchtime CAPD bag changes) and not anyone else's mum did? why is my mum the only one that's coming in, you know like you do if you're the only one who's still collected from school" [mother B]

Coping resources

- Support was recognised as being available from both formal and informal sources

"I went to see her (GP), I...made a point of saying I want to come and chat, she came up with this idea you should (look) in a difficult situation for some good that's come out of it, and my initial reaction was this is stupid, I mean it's dreadful, I mean this is absurd, I started thinking about it, and it works...because there are good things that have come out of it it's just for the moment you have to balance them against the big problem" [father E]

"You feel one of a team here it's different...you feel as if you are sort of somebody and you are within a group, where there (different hospital) you were just another person in the queue" [family D]

"we talk about it with (child) we've got photographs and we do talk about it if he wants to... you know talk about it and talk about the transplant still... and he never asks why he has to have it, he just says he's not going back on dialysis" [mother C]

"we've found that talking with the parents or to the adults that's had transplants helped us quite a bit, and helped us to understand more about what was going off" [father C]
The parents' support group was an appreciated source of support.

"at clinic visits we don't really get chance to sit down and talk... and the kiddies are listening, at least they're out of earshot here and you can sort of sit down and talk to other parents about what you really feel about things, because at clinic you're fraught and you're rushed" [mother J]

"and when you're new and you come to a meeting like this you meet a lot of people at once...it's a good introduction I think for new people especially to feel that they belong to something" [mother M]

"when you find out about oh my child's got kidney problems you tend to feel as though you're an odd one out, nobody else knows what I'm going through and I've got all these problems and it's so nice to be able to sit and talk about your problems and realise that there's a lot of other people going through the same problems and be able to talk about your experiences..." [mother C]

"and if you talk to people in the same position, it's a bit, maybe a bit more reassuring you know, transplant's maybe not as horrific as people think" [mother E]

"it's surprising just how the children (at clinic) talk to one another about things and they get to know a lot even though you don't think they know much" [father C]

The process of normalisation of the child and their circumstances was observed in some parents, as was accommodation.

"He's been on it for two and a half years and to him it's his normal way of life...so he's quite used to it, and sort of you putting me on
the dialyser or whatever it is and he quite expects everything to happen, it's a way of life and so it's not caused any problems"
[mother B]

"I mean with a kidney transplant they are leading a normal life"
[mother E]

"I mean if you had a choice obviously you'd do without all of this, but you still see people around you who are worse off. A friend of mine her son's just gone in for a valve replacement ... it's his second one, he's got to have another one later on, you know they're pretty dicey, whereas you know the kidney treatment these days, I mean ... I don't know it's so common that I suppose there's more research going on" [mother M]

"they tried to do peritoneal dialysis but unfortunately it was leaking...she had an incision that was big on her stomach you know it was so bad that they had to put metal clamps to pin it together to stop it leaking. you know the front (looked) ready to pop anyway so she wasn't healing. She was on that for about three months then they switched to haemo, it's amazing how resilient...but some of them I mean it's you know really even though we could see how bad (child) was, you see the others you're basically thinking well you know, we're lucky" [father K]

Respite care was seen as being very important and helpful, although sometimes difficult to arrange

- Holidays were often complicated to organise with a child on dialysis

"would there be an understanding with the hospital (in Kings Lynn) .. would they be aware that we're going to be there (permanent
holiday site in Norfolk) so we could at least go there in the first instance if you had a problem" [mother B]

"while I think about it, you know at the end of the week, you know you've got renal waste, what will you do with ....?" [mother C]

"so Baxters would take your machine, or we might have a machine based at the hospital which is a holiday machine that would go out?" [father E]

Other caring for the child on a short term basis

"if it's the Cubs or whatever, they have to stay the weekend or something I mean how do people feel about taking kids who are potentially, I mean still, ill" [mother E]

"...they are more willing to take (child) now he's had a transplant that what they was before" [mother C]

"We had our first babysitting (from the unit's babysitting service) last night, we actually got out for an evening..." [father E]

"...although ... I was sitting in the theatre thinking oh has she got peritonitis, is there a blockage, and you know feeling, are they going to get in touch us you know......she was okay" [mother E]

"it must be really good to be able to go out and leave them knowing whoever's there can if there's a problem, ... they've only got to pick the phone up and they know who they're talking to at the other end" [mother C] (talking about the Unit's babysitting service)

"if we needed them (close relatives) to look after (child) it was always 'what shall I do ?' you know so I thought if they didn't want to look after him then you know I wouldn't like to make them or have to rely on somebody and look after the machine or (child) if
they were so frightened, I rather I didn't have to " [mother C]

Summary

These comments are just a few selected from approximately 7 hours of discussion tape transcripts. It should be noted that whilst approximately 70% of those parents invited (those on dialysis, or within a year of transplant) attended the parent support group, not all parents attended each group, and some parents contributed to a greater extent than others. However the value of descriptive qualitative data such as this is in lending a more personal insight into the stresses of caring for a child with chronic renal failure.
Discussion

The questions regarding general impact of illness (or disability as considered by Usherwood et al. 1990) were able to be used to make useful comparisons between the perceptions of parents caring for children with ESRF and parents of children with IDDM. The disease or treatment specific were less useful in the context of this study. However if such a questionnaire was to be used by health care professionals directly involved in the care of chronically ill children it would be clinically useful to be able to identify which symptoms or problems with care were reported most frequently. Identification of the problems might lead to greater understanding of what child and parents undergo, as well as helping team members target their resources.

Treatment, or symptoms, of ESRF and IDDM have an impact on children and on the parents caring for them. Results indicate quite strongly that there is greater impact on those children with ESRF than those with IDDM, and that there are increased restrictions in daily life. Within the treatment options for ESRF it had been anticipated that having dialysis therapy would have a significantly greater impact than a successful kidney transplant. Data from the parents did not however confirm this, instead showing that established dialysis and established transplant both have significantly less impact on life than when a treatment change is experienced. This finding helps explain some of the apparently ambivalent comments transcribed from the parent group.

Mother E states that her daughter is so well on dialysis that she is reluctant to let her have a transplant, yet she also states that children with transplants live normal lives. In part this is probably due to concern because of potential surgical dangers and to the knowledge
that not all kidney transplants work. Mother E will undoubtably have also spoken with parents whose child was in the early days of transplant, when uncertainty and fear of rejection are paramount. Also in the first weeks and months following a kidney transplant the child needs to have their immunosuppression therapy monitored very closely which requires weekly clinic visits. There are also increased fears of infection during these early stages when the immunosuppression therapy is considerably more intense.

These factors may combine to place additional restrictions on the child's opportunities for schooling or peer interaction. Parents have also reported dissatisfaction with the lack of control they feel they have when there are concerns about a transplanted kidney, compared to higher rates of perceived control with dialysis, even when it was problematic.

For those families where the child changed from dialysis to transplant therapy during the study there were differences in how the impact of illness score was associated to the division of care provision. The assessment of care provision was carried out at the beginning of the study. In those families where a transplant took place during the study the impact of illness was perceived as being higher by those parents where care was shared by the mother and an other, compared to those families where the mother alone was the carer. This was found for both mothers and for fathers. However as this was not significant (p=0.21), and no explicable cause could be found for this difference in interaction it should be considered that this is not a clinically relevant observation.

Surprisingly the age of the child, either at time 4, or by age band, was not found to be a significant factor in explaining impact of illness scores, which was not what one might have expected from
previous research findings. What did however contribute to explanations of reported impact of illness scores for parents of children with diabetes was reporting of other life changes. This helps set the child and their illness back in the context of the family life, where other internal and external factors may affect how the illness and its treatments are perceived. This is suggesting that at times the subjective experience rather than objective impact is more important in the effect upon the parents. Members of the multidisciplinary team need to be aware of any other life events that are taking place, such as financial difficulties or one of the parents themselves being ill.

The reported differences between general impact of ESRF and general impact of IDDM are most pronounced for the question about the child’s education. Both mothers and fathers of children with ESRF report that education suffers more frequently than is reported by mothers and fathers of children with IDDM. Education is also the second highest rated general impact of illness question in ESRF, compared to the seventh and ninth in IDDM (for mothers and fathers respectively). Considering the importance of school this is an important difference to note between the two conditions. It could also be considered quite a good measure of restrictions of the child’s daily activities, as parents may be more consistent in their inclination to send their child to school when possible, as opposed to a question on playing with friends, where parents may have greatly different ideas about how well a child has to be before they are permitted to play with friends.

The fathers of children with ESRF reported significantly more limitations being placed on their own life, than was reported by fathers of children with IDDM. This probably reflects the increased
illness-related involvement of fathers of ESRF children compared to those of children with IDDM. The number of fathers attending the paediatric nephrology clinic is considerably more than attending the paediatric diabetes clinic (personal observation). Also the paediatric renal team always try to train both the mother and the father prior to the commencement of renal replacement therapies, especially dialysis.

One of the main shortcomings of this aspect of the study was that the impact of illness questionnaire fails to take into account how problematic the parents consider the restrictions to be. This would give a more informative view of the impact of the illness, allowing the parents perceptions and concerns to be considered as factors. Also it may have been useful to actually have carried out an objective assessment of burden of care for each treatment, and for different age ranges. This combination of objective measurement and of weighted parental perceptions could provide a more sophisticated insight into the experience of parents caring for chronically ill children.
Chapter Five

Parental information needs

For individuals to be able to make sense of the world and of events that are occurring information is required, either from their own experience and knowledge, or directly from their environment. Information helps people, not only to comprehend events, but also to build realistic expectations.

In the health setting it is important that patients understand their symptoms and treatments otherwise they may not be able to follow the best course of action for their health. Compliance with treatments starts with the requirement that the patient understands what they have to do and how to do it. Patients then have to be both willing and able to follow the treatment. Information helps in all these areas, a simple example occurs when medications are prescribed. The doctor needs to ensure that the patient understands the reasons for the treatment, and of the consequences if the medication is not taken as prescribed. The doctor or pharmacist has to provide the instructions for dosage and mode of administration. The patient also needs to be able to carry out the administration of the medication. Information is required by the patient throughout the process.

Skipper, Leonard and Rhymes (1968) stated that mothers of hospitalised children can have their levels of stress reduced through the communication of accurate information. To care for a chronically ill child at home parents require information to be able to carry out the practical aspects of care, and would also want to understand why a treatment is of value. Because of the critical
nature that information plays in health care delivery and compliance this area will be explored further.

**Information in Medical Practice**

The significance of the exchange of information in the health care setting is easily identified. Health care professionals require information from the patient to be able to reach the correct diagnostic conclusions, and to be able to select the most suitable treatment for any individual. The patient requires information to better understand their health status and the requirements of treatment. This may in turn alleviate concerns by reducing uncertainty.

Patients generally expect the doctor to be informative, but often perceive them to be insufficiently so (Cassileth et al., 1980; Ley, 1988, p9-10), which can increase patient dissatisfaction, non-compliance and misunderstanding of medical information (Ley, 1988, p53-70). Physicians tend to overestimate the amount of information they have given (Waitzkin, 1985), underestimate the patients desire for information (Strull et al., 1984), and to give varying amounts of information in response to the patient's education, income, sex and age (Waitzkin, 1985; Street, 1991).

Patient's gender has not been found to be consistent in it's effect upon information giving by the doctor. It has been argued that doctors are less informative with female patients than they are with males (West, 1984; Todd, 1989), however in some studies female patients have been found to receive more information than male patients (Hooper et al., 1982; Waitzkin, 1985; Street, 1991). In part this may be caused by the attitude of the physician towards the patient. An alternative possibility for differences in information
giving could be a direct response to the communication style of the patient rather than due to any assumption held by the doctor, for example, patients who ask more questions receive more information (Street, 1992).

Street (1991) identified that college educated patients received more diagnostic and health information than those with less education, but on examining the patients communication style found that these patients were more affectively expressive, thus influencing the doctors information giving. This link between patient expressed affect increasing doctors' information giving may in part be responsible for the reported increase in information-giving to women.

**Why parents of ill children require information**

When adults become ill, treatment decisions are made by that adult with the advice of the doctor. If the patient decides not to take the advice of the doctor that is their responsibility so, if health care professionals recommend a course of treatment the adult has the freedom to chose whether to accept it or not.

In the case of children who develop illness treatment decisions are usually made jointly by the parents and the doctor, the parents being recognised as the legal guardians of the child's rights. This is clearly shown in the use of consent forms in paediatric surgery where they have to be signed by the parents or legal guardians. Since the introduction of the Children's Act 1988, children themselves have gained more rights but until they reach the age of 16 these rights do not usually override the rights of the parents (Department of Health, 1991). Thus the burden of care on parents is both a legal and moral one.
Parents of chronically ill children, whilst not patients themselves, require information about their child's illness and treatment. Parents are the advocates of their children. That is to say they have both a legal and a moral responsibility to ensure that their children's welfare is being considered at all times. It is an assumption of society that parents will care for and seek the best for their children. This is especially the case for mothers, who are generally given the primary caring role for the children within the family (White and Woollett, 1992).

When a child becomes ill the parents require information to make decisions about the treatment. In the case of minor illness whether parents decide to accept the recommended treatment or not is unlikely to have any long term detrimental effects upon the child, and as such is rarely a controversial issue. In the case of severe or chronic illness such a decision is more likely to be problematic.

Ultimately parents must decide whether or not they wish to have their child treated for the illness. Sometimes the decision not to treat may be made in light of the heavy burden on the child, both physically and emotionally. The parents decision not to take the recommended course of treatment may be challenged by the medical profession by applying to make the child a ward of court.

In the case of chronic conditions which rely on parent contribution to daily treatment regimes, such as diabetes or ESRF, forced compliance through the courts is unlikely to be maintained once the child is discharged home. It is therefore imperative that parents feel they can give informed consent to a treatment, though when possible there may be room for some compromise by the medical staff also. and information plays a large part in these processes. Parents must make decisions for their children, and sometimes these
decisions must be made when there is little or no certainty about outcome, even following treatment. At times it is also difficult for parents to fully comprehend the information they are being given.

Medical and nursing professionals may find it difficult to convey the full impact of treatment to parents, and in some cases it may be thought appropriate to incorporate other parents who are already undergoing similar care for their child. The use of such parents is an attempt to convey the information at the correct level and with the weighting of information being decided by the relevance to parents not professionals.

It can be seen that parents require information for many reasons. Not all of which may be fully appreciated by the health care professionals who are relied upon for the provision of information. It has been shown in several research studies that dissatisfaction with communication and information can lead to increased levels of non-compliance. As it is the parents that are responsible for most of the treatment practices in children, then it is their satisfaction with communication and information that must be addressed to increase their likelihood of successfully maintaining treatments.

**Information in childhood End Stage Renal Failure**

In the case of childhood End Stage Renal Failure (ESRF) the decision to treat may be required as early as the first week of life, though this is rarely the case. It is difficult, if not impossible, for the physician involved to be able to give an accurate long-term prognosis for infants as they are the first generation to be treated so young for ESRF. Many of the questions that the parents may ask and require answering may be unanswerable to any detail. If ESRF requires renal replacement therapy later in life then the parents major
decision will be with regard to the modes of treatment available.

The specialized units often have the facilities to be able to offer a choice of treatment. The results of such a decision may have many implications for both the child and the family as a whole, and as such must be actively decided by the parent. For a parent to watch their child undergo rigorous investigations and treatment can obviously be distressing. To counteract this, parents will often require information to be able to justify, to themselves as well as to the child, what the doctors and nurses are doing to their child.

Information may also be needed for the parents to justify the fact that they have given consent for this to happen. Because of the social context within which families live, parents will have obligations to explain both the disease and the treatments to others in the extended family, to the child’s school and also to friends and associates that may be affected by the parents’ increased involvement with their child. Having inadequate information to explain to others may limit the way parents can use the social support that others could be able to provide. Parents must fully be able to understand the disease and treatment themselves before they can explain further to children and others.

Information decisions

It would be unwise to suppose that all parents would like all the information available on the disease that their child has, and on the entire range of treatments available. For some diseases such information could be too technical, may seem to far distant from the actual child, or it may simply be too voluminous. Indeed some individuals may want minimal information, preferring to adopt more avoidant coping styles (Thompson et al., 1988; Steptoe et al.,
Therefore health care professionals cannot make blanket decisions about information provision, and decisions have to be made about which information individual parents are given. To date there has been little attention paid to how these decisions are made and who makes these decisions.

There has been much work on patient satisfaction with communication (Lewis et al., 1991; Steptoe et al., 1991; Sharp et al., 1992), and on their ability to retain information (Ley, 1988, p27-52), but to date there has been very little work to ascertain what information parents consider themselves to require. Part of the reason for this has been the culture within the health system that decreed that the doctor knew best, and carried the responsibility for the treatment. This atmosphere is changing with the increase in parent contribution and participation in the care of their children.

The parent is no longer a bystander with an interest, but is more likely now to be an active and vital part of the treatment regime. Increasing recognition of this shift can be seen in the growing body of literature considering parents as partners in care. As such their perspective on information needs must be given consideration. Such consideration requires the parents to be asked what their information needs are.

In the paediatric literature (both medical and nursing) there are very few articles that actually address the issue of what information parents considered they need. Much greater interest has been shown however in the communication style, the format that information is presented in, and on the effect such information has upon treatment and compliance outcomes. There are a few papers however that do address the issue of what information parents require (Henley and Hill, 1990; Weichler, 1990, 1993; Perlman et al., 1991).
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Information needs

It has been recognised for at least twenty years that parents seek information as part of their adaptive and coping mechanisms (White 1974), but the health care team need to assess what information the parents need or want to know. Whilst individuals are commonly asked if there is anything else they would like to know it is a rare occurrence for parents as a group to be formally asked to identify the information required be able to care for their children effectively.

Weichler (1990) researched the information needs of the mothers of children receiving liver transplants. The study questioned the mothers about the time the children were evaluated and placed on the waiting list, until the time of interview (average 2½ weeks post transplant). Weichler hypothesized that if the information needs of parents are identified and met, then they would have less anxiety and a better understanding. Parents would therefore be better able to assist their children to cope, and to facilitate the adaptation of the child as they re-integrate back into the family.

The study divided the transplant experience into five phases; the evaluation/waiting phase, the intra-operative phase, the Intensive Care Unit (ICU) phase, the post-surgical phase and the discharge phase. The study used descriptive exploratory methods of interviewing using open ended questions. Thirteen mothers were interviewed, when their children were in a medically stable state. All interviews were tape recorded, allowing later transcription and coding. The study found that during each stage of the transplant experience the mothers had specific information needs to that stage.

The information needs changed along the following lines. During
the Evaluation/waiting phase mothers wanted to know specific details of the surgical details and asked for knowledge of all possible post-operative complications. During the intra-operative phase they simply needed to be kept informed of progress.

Once their child was in the ICU mothers became interested in information about the tubes, laboratory values, blood pressure (BP), medications and the child's overall physical wellbeing. During the post-surgical phase needs were concrete and varied, including such as the laboratory values, and results of any investigations, signs and symptoms of any rejection, what they were, how to recognise them, all blood results, what the child could physically do, and what to expect from the child emotionally.

Working up to the discharge phase there were many questions that the mothers were interested in, and which could be split into two broad categories, medical and non-medical. Within the medical information needs mothers wanted to know about medications and their side-effects, signs and symptoms of infection, the parameters of an acceptable blood pressure (BP), the effects of other diseases and the need for immunization, and also the likelihood of the child being able to reproduce in the future.

The non-medical needs included the child's physical activities, information contained within the teaching discharge book, what the follow-up procedures would entail, finding out acceptable values for laboratory tests, the best kind of diet, and the effects of returning to school. There were expressions of concern about whether the children would generally be able to live 'normal' lives.

This study clearly showed that parents quickly identified the laboratory values of great importance, and they sought out many
sources to help them learn the normal values, and acceptable ranges. It was reported that mothers would ask how to read a chart, and to know which values were okay. The prime concern for the mothers was rejection, and how to identify and prevent it. Mothers understood that immunosuppression affected the response to normal childhood disease, and thus the risks of children’s exposure to crowds including school. It was primarily the mothers of adolescents that expressed concern about children’s future reproductive abilities.

The mothers identified the importance of support and suggested that the multi-disciplinary team be available to help. They also attended a support group during the period of hospitalization, which they found helpful and felt necessary. Despite any anxiety mothers expressed a strong need to be prepared for the transplant experience, and that during the evaluation phase and the post surgical recovery were the times that they required most information. This seems to reflect periods of mental adjustment to challenges of changing treatment mode, with changes in the type of information they will be confronted with, with dramatic changes in the health and life-style of the child, and also upon their own participation in caring for their child.

Silverman (1987) concurs that parents have greater demands for information where active intervention is contemplated and when soundly-based knowledge is available. Specifically he reports that parents' questions are greatest when, for example, the child's suspected condition is serious but treatable or when the child has just undergone a complex procedure such as cardiac catheterization (Silverman, 1987).
Weichler completed further research on the information needs of parents following either liver or renal transplants (1993), specifically addressing the question "What are the information needs of primary caretakers of children following organ transplant?". Weichler developed a semi-structured questionnaire based on the findings of her earlier work (Weichler, 1990), and introduced a further sixth stage to the transplant process, that of reintegration of the family unit (post-discharge). Again differing information needs were identified at the various stages, but the most persistent was knowing about rejection of the transplanted organ.

During the post transplant stage the effects of medications were also identified as being of extreme importance. Once back home and into the reintegration phase parents expressed concerns over regaining or achieving a "normal" life, but were generally very pleased with the results that the transplant had had upon their child's life. When asked what would have helped to better prepare them for the transplantation process "the overwhelming response by all the subjects was to be adequately prepared prior to coming for the transplant. They'd like more information such as booklets in advance about the transplant process. With adequate information of events to come, the caretakers felt they could cope better and be better able to support their children." (p138).

A further study took a different approach, instead asking parents of hospitalized sick neonates which information provided during the doctors consultation they had found most useful and helpful (Perlman et al., 1991). The views of the parents were then compared to those expressed by the doctors.

The study found that parents emphasized different categories of information to the doctors, with parents concentrating on current
management and child's prognosis most, whilst the doctors emphasized the diagnosis. 82% of the parents were satisfied with the information provided despite this apparent difference in emphasis, suggesting perhaps that parents' attention to information is not determined solely by the doctors selection of the information.

It is probable that details about the diagnosis are much more meaningful and informative to the doctors, and probably there is a large amount of management information available to the doctor once the diagnosis is known. This would not usually be so for parents, where management information would need to be more explicit and clearly laid out. These discordances may provide meaningful clues to the information required by parents yet less likely to be provided. The medical and nursing professionals involved in communicating information to parents of chronically or severely ill children may be making too many assumptions about the implicit knowledge that they attach to terms and explanations. It may also be that parents want management information because of its tangible, concrete nature during a time of uncertainty and probabilities.

Despite the small amount of research to date, it remains important that parents information needs should be met if compliance is to be increased, and they therefore need to be identified. One of the few studies that has systematically researched the information needs of parents (Henley and Hill, 1990) investigated the information needs of family members where there was a child with cystic fibrosis (CF). The study was undertaken because although health care professionals were to provide information to the patient and the family, there were no published studies on the nature of CF families' information needs.
Henley and Hill approached all families that attended a regional centre in South Africa, sixty one families in all. The parents were asked how much they wanted to know about CF, using global statements such as "I want to know as much information as possible about cystic fibrosis - good or bad". The majority of parents (99%) wanted as much information as possible, and thought it to be their right (98%).

The study looked at specific questions regarding CF and the child's wellbeing and asked respondents to rate whether they had enough information or whether they wanted a little or a great deal more, for each issue. There were selected medical and psychosocial topics about which the respondents were asked. The general trend was for parents to want less information about symptomatology, treatment and genetics, and more information about psychosocial issues and future implications of the disease. This could be, in part, a result of the fact that the parents claimed to have been given more medical than psychosocial information. Although highly sought after, information about the impact of CF on the patient's career, social life and marriage had (reportedly) not been provided for approximately 75% of the parents.

Findings indicated that on over a third of the topics fathers requested significantly more information than mothers, these were primarily regarding medical topics but also included information about diet and sport for the child. Provision of such information could possibly enable the father to participate more in the basic care of the child. A small number of parents claimed they had not been given basic medical advice, which could then lead to accidental non-compliance, due to ignorance regarding correct treatment practices. It was also identified that fathers' social class was a factor in
whether or not they received information about CF. Those fathers from social classes III, IV, or V received significantly less than those fathers from social classes I and II. There was a similar association for mothers, though it was not significant.

Fathers, more than mothers, required information about meals and exercise. The reasoning for this could be that mothers generally have responsibility for meals and child activities, but fathers would like to become more involved if possible. Provision of this information would possibly enable fathers to feel capable of being more actively involved in the patients day to day management.

Thus the research demonstrated that there were a variety of issues that family members considered they had not received enough information about. This was particularly true for information regarding psychosocial issues, and the authors had several suggestions as to why that may have been the case.

First they identified the time constraints placed upon many clinic and hospital consultations, adding that when this was the case then the medical issues may have been favoured as a result of the child’s clinical status. Second the multidisciplinary team was identified as a potential risk factor. If there had been no allocation of clear responsibility as to who should provide what information there was a chance that the information may have been assumed to have been provided by others. Third they claim that doctors often feel ill-equipped to counsel families on sensitive, emotionally charged issues. It is recognised that doctors receive little or no formal training in emotional counselling and that few are actively encouraged to develop the skills necessary (Graham and Jenkins, 1985; Dickson et al., 1989, p4-6).
It is also possible that more psychosocial information had been imparted to the parents than they recall, but that parents failed to retain it due to the upsetting nature of some of this information.

Self-report methodology may not accurately reflect the actual information given, but it does reflect the family members' perceptions. However, this research suggests that family members should be given a great deal more anticipatory guidance about future implications of Cystic Fibrosis whilst employing an individualised approach, as some families do want less information rather than more. Henley and Hill suggest a check list to reflect what information has been given and by whom. The authors also suggest that doctors, as "front-line providers of information to cystic fibrosis families", need to be equipped with communication skills.

Not all of the identified factors will be fully appreciated by the health care professionals who need to provide such information. As it is the parents who are relied on for most of the treatment practices in children, then it is their satisfaction with communication that must be addressed, even if only to increase their likelihood of complying with recommended treatments and practices.

Information needs - this study

Weichler (1990) defined parental information needs as "any deficit of facts or knowledge verbalized by parents about their child's care, including new data or the reinforcement of data". Whilst this definition certainly acknowledges the parents needs as being the measure against which information should be provided, it has its limitations. It decrees that parents must verbalize the knowledge deficit. This would exclude the needs of those parents who are too uncertain to mention their concerns or who do not like to question
health care professionals.

This definition would also exclude information that parents may not realize they need, and may therefore not ask about, for example, if the parents of an immunosuppressed child were not informed that receiving live vaccines is harmful to immunosuppressed children then they would not necessarily ask about the safety of such vaccines as they would not be aware of their need to know that information.

Ultimately it is parents who must have such information as they are considered by many others, GP's included, to be the authority on their child. It is therefore suggested that the definition of information needs be expanded to:

"The cohort of knowledge that is required for effective and comprehensive provision of care, including any deficit of knowledge as seen by the parents. Information needs may be for new data, or for clarification or reinforcement of old data".

Whilst this definition does not provide strict guidelines about which information be provided for parents, this is intentional; rather it should be used to structure information around individual parents or patients. The needs of individual parents vary greatly.

What is important is that parents have sufficient information to be able to carry out the care being demanded of them, and so that they feel confident and comfortable with the knowledge that they have. To provide too much information or in too great a detail may, for some, be almost as detrimental as providing insufficient for others (Thompson et al., 1988; Steptoe et al., 1991).
To overcome the difficulty of varied requirements it is suggested that a first step is to identify the information that parents need, and then to ensure that information is easily available (and known to be available) for those that wish to have it. This must include getting information to those who are reluctant to ask, and also to those who are ignorant of the amount of knowledge they require. This though should not make assumptions about the information that parents may want or need to know.

Initially there must be identification of the information that the parents must have to be able to perform the treatment practices correctly, and then further identification of information that may be beneficial, of value, or interest to parents carrying out such tasks. The imperative must be to provide the information that permits and facilitates treatment, but this is closely followed in importance by the need to provide further information that parents desire. At the beginning of the project it was decided to ask parents at intervals about the type of information that they felt they had enough of, or that they felt they required more of.
Method

To assess information needs two main routes were used. The first was a questionnaire and the second was the transcription data from the parent support group. The questionnaire was adapted from Henley and Hill (1990), originally used with parents of children with cystic fibrosis. The questionnaire was to be sent to the parents four monthly as part of the series of questionnaires.

General questions, that is those not specific to the medical condition of cystic fibrosis, were left in their original state; however those that were disease specific were altered with the advice and assistance of the specialist nurses. This gave the questionnaire relevance to the condition of ESRF. An example of an unaltered general question is "How serious your child's illness is", and of a specific question "Whether your child will need dialysis". The full list of questions can be found in Appendix G.

The benefits to adapting and utilising this questionnaire were twofold. First, it had already been validated. Second it gave a further comparison group for the results of the general questions, so that the results from the parents of children in ESRF could viewed against not only the diabetic comparison group, but also against those of the previous study involving the parents of children with cystic fibrosis. By the time of completion of the project it was also possible to use a one-off assessment of information needs of parents who had a child with nephrotic syndrome (Moore et al., 1994).

Whilst it is difficult to compare the seriousness of medical conditions it would probably be fair to say that severity, using threat to life and intrusion of treatment, increases in severity from diabetes to ESRF to cystic fibrosis. Thus to be able to look at the three
conditions would give a contextual positioning of those results gained from the parents of children with ESRF. If certain question scores bore similarities in diabetes, nephrotic syndrome, ESRF and cystic fibrosis it would be possible to conclude with a degree of reliability that these might be common to chronic illness in childhood generally.

Parents were asked to rate their information needs by estimating how much information they considered they required. For each question they chose from the following alternatives. Scores allotted for each alternative are also presented below.

2 = a great deal of information needed
1 = a little more information needed
0 = 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 addressed envelope for its return. The decision to issue the questionnaire over the two years provided the opportunity to follow people’s information needs to see if they changed at any identifiable treatment stage. Replies were received from 43 parents of children with ESRF (mothers=25, fathers=18), and from 41 parents of children with IDDM (mothers=23, fathers=18), as discussed in Chapter 3.

Plotting the scores from a repeated, objective, quantitative questionnaire over time also allowed the use of an individual’s own baseline against which one could measure increases or decreases in information needs. There would be no need to compare across individuals.
Socioeconomic family details were obtained at the beginning of the study, including age of parents, number and age of all children, occupation of both parents, and any chronic illness in any family member. Age of child at diagnosis was also noted. A front sheet asking about the previous month accompanied each set of questionnaires for parents to complete, noting: any treatment or health changes for the child; the number of admissions or telephone calls to the liaison nurse; number of visits to the GP for the child, themselves or any other family member; and the frequency of outpatient appointments. A section also requested information on major life changes such as housing, finances, support etc. Changes could be for the better or for the worse.

The information from the transcripts of the parent support group provided a qualitative balance to the questionnaire. For the questionnaire the limitation of the data received was constrained by the information requested. The transcripts on the other hand were taken from support group discussions whereby the parents themselves shaped the direction that the conversation went. All groups were tape recorded, and had been since the group began. These tapes were made available for transcription. Many of the support group meetings had a basic theme for part of the discussion, and one of these had been information and communication.

Hypotheses

It was hypothesized that information needs would change, and increase, at certain keypoints such as change of treatment modality. (That is to say when a child is about to commence dialysis, or has just received a transplant, or whose transplant has just failed). it was also hypothesised that parents from lower socioeconomic classes would have higher information needs than those from higher
ones. It was also anticipated that overall, information needs would decline over time, as parents accrued more knowledge. The research would also investigate the effects of factors such as age of child, time since diagnosis etc.
Results

The results section will consider

a Information scores explored along the two year collection of the data, with regard to socioeconomic data available, and to questionnaire data regarding stress, anxiety and depression scores, as well as the reported intrusion score.

b The information needs score for individual questions

c For five individual families their information needs results will be discussed in more depth, relating treatment changes and alterations in paediatric renal service.

d Finally, qualitative data, of parents discussions relating to information needs, will be extracted from the transcripts of the parents support group.

Complete ANOVA and regression tables for results discussed in this chapter can be found in Appendix H.

Two year study data

Due to the small number of respondents that replied on every occasion it was not possible to carry out trend analysis. For analysis of the data collected over the two year study it was necessary to calculate mean scores over the study for each subject. It is these mean scores that were used in the analysis of the two year study data.

Only the general information questions were able to be compared between parents of children with ESRF and parents of children with IDDM, as disease specific questions could not be guaranteed to be of equal weighting or importance across conditions. Whilst parents of
children with renal failure scoring on "How serious your child's illness is" could be directly compared with parents of children with IDDM the same could not be said for the specific questions. For example, one could not compare scores for the question regarding "How to carry out dialysis" and for the question regarding "How to deal with illness, eg. flu or vomiting".

Parents were divided into high and low responders (see chapter 3, p92). Mann-Whitney U tests were carried out on these two groups, first for mothers and then for fathers, to identify whether responders had a bias towards being those reporting particularly high or low information needs scores. There were no significant differences for mothers (p=0.13, U=38, W=116) or fathers (p=0.07, U=13, W=68) of children with ESRF, nor for fathers of children with IDDM (p=0.91, U=25, W=37).

However there was a significant difference in the information needs score of the high and of the low responding mothers of children with IDDM (p=0.035, U=31, W=86). Further analysis identified that mothers who were high responders had lower information needs scores than the low responders.

**Overall scores**

Mean general information scores for mothers and for fathers of children with ESRF, and with IDDM can be seen in table 5:1.

Two way analysis of variance revealed no significant differences between the reported general information needs scores of parents of children with ESRF and of parents of children with IDDM (p=0.69, F(1,79)=0.17) or between mothers and fathers reported general information needs scores (p=0.58, F(1,79)=0.31).
Table 5.1. Mean general information scores over study

<table>
<thead>
<tr>
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<th>Mean</th>
<th>SD</th>
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<tbody>
<tr>
<td>Mothers of children with ESRF</td>
<td>0.77</td>
<td>0.48</td>
</tr>
<tr>
<td>Fathers of children with ESRF</td>
<td>0.71</td>
<td>0.35</td>
</tr>
<tr>
<td>Mothers of children with IDDM</td>
<td>0.72</td>
<td>0.41</td>
</tr>
<tr>
<td>Fathers of children with IDDM</td>
<td>0.68</td>
<td>0.37</td>
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**Time since diagnosis & age of the child**

ANOVA's were carried out to identify whether the time since diagnosis had a significant effect on parents' mean general information needs score. A two way ANOVA was carried out with time since diagnosis, and age of child, in the analysis.

As the study was longitudinal it was necessary to use time since diagnosis at the centre point of the study (Time 4). As it was expected that any association would not be linear families were divided along quartiles to provide bands. The groups were as follow, those whose child had been diagnosed less than 22 months, those whose child had been diagnosed more than 22 months but less than 52 months, those whose child had been diagnosed more than 52 months but less than 69 months, and those whose child had been diagnosed more than 69 months.

The age of the child was also divided into bands as the literature suggests that certain developmental stages can give rise to differing depression scores (Walker et al., 1987). The age bands consisted of: children under five years; children over five but under 10 years; over 10 but under fourteen years; and over fourteen years old. Significance of interactions could not be reported as not all carebands contained a child from each ageband. See Appendix E for
a graph illustrating this point.

There were no significant main effect results for either mothers or fathers of children with ESRF, nor for fathers of children with IDDM.

However the mean general information needs score of the IDDM mothers was significantly different, depending upon time since diagnosis \((F(3, 12)=3.62, p=0.05)\), and upon ageband of child \((F(2, 12)=4.14, p=0.04)\). Post-hoc analysis revealed that mothers whose child had been diagnosed for more than 22 months but less than 52 months had significantly greater information needs (mean question score = 1.05), than both those groups diagnosed longer (mean question score = 0.53, for both bands). Post-hoc analysis also revealed that mothers whose child was aged 10-14 years old had significantly greater information needs (mean question score = 0.99), than those whose children were younger (mean question score=0.47), or those that were older (mean question score = 0.62).

**Delivery of care**

Three way ANOVA's were carried out to examine whether the division of care for the child had any effect upon information needs scores. Care was either provided by the mother mainly, or the mother and either the father, or the child themselves. The medical condition and the sex of the parent were also in the analysis. There were no significant main effects or interactions.

**Health indicators, and life changes**

Information was requested at the beginning of each questionnaire asking about events in the previous month (frequency of out-patient appointments, number of in-patient admission, number of out
patient visits to the ward, number of telephone calls to the specialist nurse, number of visits to the GP: for the child; self; or other household member, and any life event changes including housing/finances/support etc.) Means for each subject were averaged over the study. As parents of the same child sometimes reported different rates of occurrence for these variables, results were analysed separately for mothers and fathers, each using their own reporting of these variables. It was possible to investigate possible associations between the dependent variables and these health indicators and life events. A stepwise multiple linear regression analysis was carried and mothers and fathers were investigated separately.

There were no significant associations for mothers or fathers of children with IDDM or for mothers of children with renal failure.

Fathers of children with renal failure had a significant positive association between their information needs scores and the number of times their child attended the GP (p=0.018, β = -0.56, Rsquare=0.32). However inspecting this association graphically, using a scatterplot there was one outlier. It was identified that this child was attending the GP very frequently throughout the study, but because of a medical complaint unrelated to the successful kidney transplant. When this outlier was removed from the stepwise regression it no longer produced the significant result.

Trend Analysis

It was noted that the group mean general information scores for mothers and fathers of children with ESRF declined over the study, see Figure 5:1.
The initial impression is of information needs falling over the length of the study for both parents of children with ESRF, but not for those of children with IDDM. It was necessary to check whether this was an actual decrease in individuals' information needs or only due to those with low information needs replying at the end of the study, with those with high information needs replying earlier.

As all parents had not replied on all occasions trend analysis was not possible, however statistical analysis using each subject's own mean over the study was possible. The mean for each subject was calculated for: the entire study; over Time 1, 2 and 3; and over Time 5, 6 and 7. For each subject it was calculated as to whether the 'first half of study' mean general information score was more or was less than their overall mean. This was carried out for their 'second half of study' mean information scores also. Using this data a Fishers exact test was carried out for; mothers and fathers of children with ESRF separately and for mothers and fathers of children with IDDM.

Figure 5:1 Group information needs over study
A significant number of mothers of children with ESRF had 'first half of study' mean general information scores higher than their mean and 'second half of study mean general information scores lower than their mean (p=0.01). Fathers of renal children also had this trend, but which was not as great (p=0.06). There was no significant trend for mothers (p=0.21) or fathers (p=0.25) of children with IDDM.

**Independent variables associated with variation in the information needs scores.**

The age of the child, highest parental education level, finance (poor, fair, good), highest parental occupation, number of children and age of parent were all put in to the regression equation with the mean general information needs scores.

There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, nor for fathers of children with renal failure.

For mothers of children with ESRF, and for all fathers, and for all mothers, one variable, Occupation, was significantly associated with the mean general information needs scores (see Table 5.2).

**Table 5.2 Variance of mean general information scores explained by occupation**

<table>
<thead>
<tr>
<th></th>
<th>p=</th>
<th>Rsquare</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers of children with ESRF</td>
<td>0.03</td>
<td>0.22</td>
<td>0.46</td>
</tr>
<tr>
<td>All mothers</td>
<td>0.007</td>
<td>0.19</td>
<td>0.44</td>
</tr>
<tr>
<td>All fathers</td>
<td>0.05</td>
<td>0.15</td>
<td>0.39</td>
</tr>
</tbody>
</table>
Dependent variables associated with the mean general information score.

The mean impact of illness score, the mean stress score, the mean anxiety and the mean depression scores were put in to the regression equation for the mean general information scores. Life event changes were also entered in the analysis.

No variables reached the significance level for mothers or for fathers of children with renal failure.

For mothers of children with IDDM the mean general impact of illness score was positively associated with the mean general information score, \( p=0.04 \) (\( \beta =0.43, \text{Rsquare}=0.18 \)). For fathers with IDDM the depression score was positively associated with the mean general information score (\( p=0.03, \beta = 0.52, \text{Rsquare}=0.27 \)).
Discussion of the two year study data

The overall means show that the parents of children with ESRF had similar information needs to the parents with children with IDDM. Treatments for both conditions are now better than ten, fifteen years ago and so the outcomes are likely to have improved for both, however there is still greater risk of short stature, dependence upon the hospital for treatment, risk of morbidity for ESRF than for IDDM.

Within each medical condition there was no significant difference between the information needs scores of the mothers and of the fathers. This was contrary to the findings of Henley & Hill, (1990) in their study of parents of children with cystic fibrosis, where they found that fathers had significantly higher information needs.

Mothers of children with diabetes who responded more frequently were those with significantly lower information needs scores. Parents of children with renal failure also had a tendency to respond along this trend. When there are subjects who do respond, and others that respond infrequently one has to question whether the responses received can be considered representative of the sample population as a whole.

From these results it is possible to suggest that parents who respond to the questionnaires are not those who have greater needs than those who do not respond. The results garnered from the parents who have responded are more likely to reflect an underestimate of the information needs than an over estimate. However this is only a supposition, suggested but not proven by these results.

It might be expected that information needs scores should gradually reduce for all parents as they find out answers to their questions.
from one source or another. However this might not be the case as information needs may also increase as new situations arise, either medical, or due to the child's development. Parents may also fail to reduce information needs if they cannot access information sources, or if they do not realise they are available.

The significant reduction in the information needs of parents with children with ESRF was not present in the parents of children with IDDM. It is probable that meeting information needs is a much more active process than previously considered, and that specific targeting of efforts may be required. The decrease in the information needs of the parents of children with ESRF may reflect an improvement in the service they received. The increased provision of information is probably a consequence of two main factors.

First ESRF requires more active intervention, especially when the child is undergoing dialysis. Second there are considerably fewer specialised health care professionals employed to provide for those children with IDDM, as direct illness-related parental needs are considered to be less. There is a specialised paediatric renal unit, and the staff were engaged in a concerted effort to improve the information available to the parents.

In 1991 there was one booklet on chronic renal failure in children and three specialised videos produced by the unit. By 1994 there were three booklets setting out treatment options, a set of four parent information leaflets, a set of eight booklets to prepare children for common renal investigations, five videos produced by the unit, and in addition to this there was an increase in the books and videos obtained from outside sources and made available to the families. There was even the provision of a library for the children.
which included books on health, hospitals and coping with difficult situations.

The finding that information needs are related to the highest occupation of the family is of interest, especially as the information needs are greater as the occupation classification is lower. This finding is in line with that of Henley and Hill (1990). Many people might assume that the professionals would have higher information needs, but this is not the case. One explanation for this is that the information needs of professionals are better met, both formally and informally.

Street (1992) found that patients who ask more questions receive more information, but as one generally needs to know what to ask to get the right information, then professionals are better placed to be initiating questions. Street (1991) also found that college educated patients were also more affectively expressive which again had positive effects on the doctor's information giving.

For mothers of children with IDDM those who perceived the diabetes as a greater impact of illness on the life of the child and the family, also had higher information scores. It is possible that these children were less stable diabetics. The concerns associated with diabetes are often focused around unstable blood sugar levels, and possible long-term consequences of this. If diabetes becomes unstable it is generally less easy to manage and becomes more intrusive too. Unfortunately it is not possible to ascertain whether this hypothesis is supported, as data regarding control is not available to this study.

Information needs of mothers with IDDM children aged 10-14 years is also significantly higher than mothers whose children are in
younger or older age groups (5-10 years or >14 years). This probably occurred as a result of increasing independence for these children, especially as they start secondary education and have greater responsibility for their own diet, and are probably administering their own insulin. As mothers primarily deal with these in younger children, this transitional period will probably raise new concerns for them.
Results for individual questions

The scoring of the questions was: the answer "I have enough information" scored 0, "A little more information needed", scored 1, and "A great deal more information needed" scored 2.

To ascertain which questions were those that parents needed more information about, the mean scores for each question over the entire study were calculated. These means were calculated for mothers and fathers separately within each group (ESRF or IDDM), to show differences between the information needs of these groups if any were present. The seven highest scoring questions for the parents of children with ESRF (Fig 5:2), and of children with IDDM (Fig 5:3) are below. The maximum mean score that could be obtained by a question is 2.0.

*Figure 5.2* The seven highest scoring information needs questions for parents of children with ESRF
Figure 5.3 The seven highest scoring information needs questions for parents of children with IDDM

As can be seen from these two figures the same seven questions are present for all groups. The questions are as follows:

9  (P & D) New information about renal failure from other places in the world. (T) New information about kidney transplants from around the world.
(IDDM) Research about diabetes from other places in the world

10 (All) Detailed results of any tests performed on your child when he/she attends clinic

11 (P & D) Possible complications of renal failure. (T) Possible complications of having had a kidney transplant
(IDDM) Possible complications of diabetes

13 (P & D) What to tell your child about renal failure. (T) What to tell your child about kidney transplants
(IDDM) Do you have enough information to answer your child's questions about diabetes

15  (P & D) How renal failure might affect your child's career, social life and marriage. (T) How a kidney transplant might affect your child's career, social life and marriage (IDDM) How diabetes might affect your child's career, social life and marriage

16  (P & D) How renal failure might affect your child's chances of having their own children. (T) How a kidney transplant might affect your child's chances of having their own children (IDDM) How diabetes might affect your child's chances of having their own children

18  (P & D) What to expect if your child's illness gets worse. (T) What to expect if your child's kidney begins to fail (IDDM) What to expect if your child's diabetes becomes unstable

(P) = Pre-dialysis parents, (D) = Dialysis parents, (T) = Transplant parents, (IDDM) = IDDM parents.

Discussion of the individual question findings

Unlike the varied impact of illness questions there was great similarity for the information needs questions between the scores of parents of children with ESRF and of children with IDDM.

The questions which parents reported wanting most information about were not those concerned with daily management of the treatment, which suggests that these issues are being adequately covered in the clinic consultations, and in the training programme that parents undergo prior to their child commencing renal replacement therapy.

The most pragmatic question of the high score topics is concerned with the test results of the child. Parents want to be given more, detailed results of the tests their child undergoes. For parents
whose children have ESRF this could be to justify to themselves the wisdom of allowing the child to undergo the tests, some of which can be distressing, it could also be to justify the decision to treat the ESRF at all. In IDDM results from blood tests are seen as indicators of how well the child and family are able to manage the condition. Certain investigations can indicate the level of blood glucose levels over the previous weeks. Clinicians, it appears, need to be more informative to the parents, perhaps about the meaning of test results.

Concern about the consequences of the disease and of treating it are the major group of questions in the high scoring questions. Parents want to know about possible complications, and what to expect if the condition deteriorates. Questions concerned with the future are responsible for the three highest scores. These questions refer to concerns parents have about future issues for the child (their fertility and also their social, career and marriage prospects) as well as information about new research, reflecting hope for a new improved treatment, maybe even a cure. These three questions were also the highest scoring in the study on parents of children with Cystic Fibrosis (Henley and Hill, 1990), and in the study with parents of children with Nephrotic Syndrome (Moore et al., 1994).

It appears that the information needs of parents of children with chronic illnesses are similar, whatever the medical condition their child has. This interesting finding leads to several observations.

First, parents are very concerned about the future of their children, concerned about how normal their lives will be, whether they can expect the same as other adults later in life.
Second, that long-term consequences of diseases and their treatments are issues that parents recognise and address early on. Even in families where the child was not yet four years old there were worries about the future fertility of their child. Parents will have to explain to the children any consequences of their treatment decisions. For example, parents may be concerned that peritoneal dialysis, with its associated risks of abdominal adhesions and possibly peritonitis, may pose a threat to a daughter's fertility. Parents want to be able to understand the risks they are putting their child through. Parents also scored the question about 'what to tell their child' highly.

Often parents are the translators for their child, acting as an intermediary between the child's own linguistic ability and understanding, and the technical medical information. Members of the paediatric renal unit endeavour to involve and inform the child but, as the majority of the care takes place at home, and as the majority of the child's questions will be directed to the care-givers, it is the parents who need to be able to provide sound and suitable information.

The questions that parents report wanting most information about are those considered more difficult to answer. It is not possible to give definitive information about a child's future prospects, especially when those previously treated underwent different therapies and therefore may have different outcomes. Parents of chronically ill children do however wish to reduce the amount of uncertainty they have about their child's future.

It may also be that to want information about the future of a child is a normal aspect of parenting, though normally more restricted to issues such as education and career, with perhaps hopes about
eventual grandchildren. It is possible that parents may always report wanting more information about these types of issues, and in that case, the renal team can only try to reduce, rather than remove the information deficit as perceived by the parents.
Individual families

Plotting the data for individual families over the course of the study illustrates not only how information needs varied between individuals, but also for individuals over time. The plots for the same five families selected in chapter 4 are presented below.

family 114 - Mean General Information Needs Score

<table>
<thead>
<tr>
<th>114</th>
<th>mean general information score</th>
<th>mean</th>
<th>lowest</th>
<th>highest</th>
<th>range</th>
</tr>
</thead>
<tbody>
<tr>
<td>mother</td>
<td>mean general information score</td>
<td>0.62</td>
<td>0.32</td>
<td>1.16</td>
<td>0.84</td>
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<tr>
<td>father</td>
<td>mean general information score</td>
<td>0.69</td>
<td>0.42</td>
<td>1.37</td>
<td>0.95</td>
</tr>
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</table>
Family 114, with a young child (aged five years at Time 4) on overnight continuous cycling dialysis. At the beginning of the study the child has been on CCPD for two years and six months. There had been an (immediately) unsuccessful cadaveric transplant nine months prior to the study. There is an older sibling (aged seven years at Time 4). Father (aged 35 years at Time 4) is in full-time employment. Mother (aged 34 years at Time 4) is currently not employed outside the house. Care is shared by both parents. There are additional care burdens due to supplementary feeds and dressings to the gastrostomy button.

At the beginning of the study the child has been on CCPD for two years and six months. There had been an (immediately) unsuccessful cadaveric transplant nine months prior to the study.

Both mother and father have mean general information needs scores within one standard deviation of their group means.

It can be seen that for both of the parents there is a downward trend for the information needs scores over the duration of the study. Their scores at the beginning of the study were high, approximately one standard deviation above their group means. Between Time 1 and Time 2 the parents had an additional meeting with their child's consultant paediatric nephrologist. The purpose was for the mother and father to have a longer than usual consultation, out of the clinic setting, specifically to ask their questions and to be able to address many areas of uncertainty with the doctor. The consultation was tape recorded to enable the parents to listen to the tape later, or to play it back to other family members. This meeting was set up at the suggestion of the clinical psychologist and social worker who recognised that the parents were dissatisfied with the amount of knowledge they possessed about treatment and future options for
their child.

It can be seen from the graph that the information needs scores of both parents decreased considerably following this meeting, and remained around or below the group mean for the rest of the study period.

The child ceased dialysis between time 6 and time 7 due to repeated infection of the peritoneal drain site, but this appears to have no major effects on the information needs of the parents.
Family 103 - Mean General Information Needs Score

<table>
<thead>
<tr>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
<th>Time 5</th>
<th>Time 6</th>
<th>Time 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>1.75</td>
<td>1.5</td>
<td>1</td>
<td>1.25</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>1.75</td>
<td>1.5</td>
<td>1</td>
<td>1.25</td>
<td>1</td>
</tr>
</tbody>
</table>

Mother mean general information score: 0.26
Father mean general information score: 0.10

<table>
<thead>
<tr>
<th>103</th>
<th>mean</th>
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<tbody>
<tr>
<td>mother</td>
<td>mean general information score</td>
<td>0.26</td>
<td>0</td>
<td>0.72</td>
</tr>
<tr>
<td>father</td>
<td>mean general information score</td>
<td>0.10</td>
<td>0</td>
<td>0.50</td>
</tr>
</tbody>
</table>
Family 103, with an older child (aged 15 years and five months at Time 4) who received a transplant six years prior to the this study, and which was still functioning well. Peritoneal dialysis had been carried out for eight months prior to transplant. There are addition concerns in the family about the health of the child, who had a cerebral vascular accident around the time of transplant. She was taking medications, not only immunosuppression for her renal transplant, but also antihypertensives and thyroxine. There were two younger brothers (aged eight years at Time 4). Father (aged 45 years at Time 4) and mother (aged 43 years at Time 4) are in full-time employment. Mother is responsible for the care, in cooperation with the child herself.

There is a narrow range of scores reported by the parents, especially the father. Both parents have mean general information needs scores more than one standard deviation below their group means.

It appears that the parents of this family are satisfied with the information they have regarding their child and ESRF. There are probably three main factors contributing to their low mean general information needs scores.

First, their child had been diagnosed as having ESRF over seven years prior to commencement of the study.

Second, their child has a successful transplanted kidney, and had for the six years preceding the study, and for the duration of the study.

Third, there is a more urgent threat to their child’s health from an unrelated medical condition.

The first two points offer an explanation for low information needs scores, that is parents having had a long period of adaptation to the
ESRF, and having had opportunities to request information they require.

The third point leads to an additional possible explanation. It may be that as their child had a relatively recent (currently very intrusive) illness, and as the renal replacement therapy was stable the parents could therefore have re-prioritised their information requirements. This would lead to the parents seeking information about possible causes and outcomes for seizures and headaches, no longer seeking further information regarding the ESRF.
Family 131 - Mean General Information Needs Score

<table>
<thead>
<tr>
<th></th>
<th>mean</th>
<th>lowest</th>
<th>highest</th>
<th>range</th>
</tr>
</thead>
<tbody>
<tr>
<td>mother</td>
<td>0.54</td>
<td>0.26</td>
<td>1.26</td>
<td>1.00</td>
</tr>
<tr>
<td>father</td>
<td>0.66</td>
<td>0.26</td>
<td>1.37</td>
<td>1.11</td>
</tr>
</tbody>
</table>

Chapter Five
Family 131, with a young child (aged two years four months at Time 4) on overnight cycling dialysis. There is an older sibling (aged five years at Time 4). Father (aged 42 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is currently employed part-time outside the house. Care is shared by both parents. A successful transplant was carried out between times 5 and 6. There are addition care burdens due to supplementary feeds and dressings to the gastrostomy button.

Both mother and father have mean general information needs scores within one standard deviation of their group means. It can be seen that their individual mean general information scores covered great ranges over the study period.

It can be seen that for both of the parents' their mean general information needs scores were high at the beginning of the study, one standard deviation above the group mean for the mother, and nearly two standard deviations above his group mean for the father.

At the beginning of the study their child was receiving hospital dialysis, overnight, twice weekly. This had commenced following an acute episode of Haemolytic Uraemic Syndrome following which the renal function had failed to completely recover. There was initial clinical uncertainty whether this would resolve or would develop into ESRF. Intermittent peritoneal dialysis was the treatment of choice for the first few months until long term renal function could be ascertained. Unfortunately renal function never recovered to a degree suitable for life without renal replacement therapy.
The diagnosis of chronic, end-stage renal failure was confirmed between Time 1 and Time 2 and home cycling peritoneal dialysis, and supplementary feeds via a gastrostomy button were commenced. Whilst this was not a diagnosis that the parents were pleased to receive, it did remove the uncertainty that the parents had faced up to this point. It also meant that the members of the paediatric renal team began to provide more information about chronic, rather than acute renal failure. The parents were then in a situation where they could identify more clearly the sort of information that they wanted to hear about. In this family both the mother and the father expressed the opinion that they wanted to know as much as possible about their child's health and treatment. This was their view from the onset of the illness.
Family 134 - Mean General Information Needs Score

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
<th>Time 5</th>
<th>Time 6</th>
<th>Time 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother mean general information score</td>
<td>0.70</td>
<td>0.39</td>
<td>0.89</td>
<td>0.50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father mean general information score</td>
<td>0.64</td>
<td>0.61</td>
<td>0.89</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chapter Five 202
Family 134, with a child, aged 11 years and four months at Time 4, on overnight cycling dialysis commencing just before time 3. There is a younger sibling, with no health problems. Father (aged 41 years at Time 4) is in full-time employment. Mother (aged 41 years at Time 4) is not employed outside the house. Care is shared by both parents. A successful transplant was carried out between times 6 and 7. There are additional care burdens due to poor appetite and oral supplements, until transplant. There are also developmental and behavioural problems, and a history of epilepsy.

Both mother and father have mean general information needs scores within one standard deviation of their group means.

It can be seen that most of the parents' scores tend to fluctuate around their own individual means.

Dialysis was commenced one month prior to time 3, following a slow gradual decrease in kidney function. The parents had been aware of a renal problem since their daughter's first year of life.

This slow gradual decrease in kidney function probably permitted information about ESRF and renal replacement therapies to be accumulated over a considerable time. Hence when dialysis is commenced, and later when there is a successful cadaveric transplant there does not appear to be any major fluctuation in the mean general information needs score.
Family 120 - Mean General Information Needs Score

<table>
<thead>
<tr>
<th>120</th>
<th>mean</th>
<th>lowest</th>
<th>highest</th>
<th>range</th>
</tr>
</thead>
<tbody>
<tr>
<td>mother</td>
<td>mean general information score</td>
<td>0.79</td>
<td>0.39</td>
<td>1.28</td>
</tr>
</tbody>
</table>
Family 120, with a child (aged seven years at Time 4) on overnight cycling dialysis, commencing six months prior to the start of the study. There is an younger sibling. Father (aged 44 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is not employed outside the house. Care is mainly delivered by the mother. A successful transplant was carried out between times 1 and 2.

The mother has a mean general information needs score within one standard deviation of her group mean. The father did not take part in the study.

It can be seen that there are fluctuations of the mother’s general information needs score during the study.

There is a considerable increase in the mean general information score immediately following the transplant. This is probably as a result of new demands and treatment priorities due to the change from dialysis to transplant. Following this initial peak there is steady decrease in the mothers reported general information score.
Qualitative data

Transcripts revealed that there was great exchange of information during the parent support group discussions, often consisting of personal experiences and opinions regarding caring for a child in ESRF. There were also specific references to information of a more formal type. These references to information provision and requirements are transcribed below.

Comments may be included from parents of the families in the individual plots. To better preserve anonymity each family is again identified by the same single letter as in Chapter 4, rather than the original number code.

Topics include why information is needed, where or who information is obtained from, how information is given by health care workers as well as the type of information considered lacking.

Why information is needed

"It's always very comforting if you've been thinking and worrying about something and you see it in print and you suddenly feel somebody else understands" [family E]

- Parents often find themselves in the role of educator for family, friends or people generally.

"One lady said to me, well transplant's fairly straight forward you know compared to what her child had, her child was spastic, and I just sat there, I said oh well, you don't know the half of it" [mother D]
"I went to see the school doctor and she knew nothing about chronic renal failure" [mother J]

"It's still rare, hence the fact not many people, general public understands really what we do" [unidentified]

"What I find difficult is explaining to (child)...not just those questions, other questions and I know how to answer some of the things but the others, others I don't know how to help a child to explain, it's too complex" [mother D]

"We read it (preparation story book) together and I told him...yet it helped (child) because it helped me explain to (child) what he was going to have" [mother C]

Parents acknowledge a need for information to be able to make the 'right' decisions for their children

"Our children are the recipients of decisions made by parents and doctors" [unidentified]

"But how do the statistics bear up of haemo against peritoneal (dialysis)....what advantages or disadvantages does one have against the other...I think we all know as parents that it's useful to have all these questions answered" [father D]

"I think there ought to be a way of sorting out the pros and cons of transplant in general terms that you could perhaps read yourselves...if you could get that sort of thing, and then having read that, then try with the doctors to apply it to your child so that you're a bit more informed" [mother B]
Where or who information is obtained from

"we'd picked up a lot in hospital, we hadn't realised how much we'd learned" [father E]

"Why can't we have information put up on the ward? I mean there's actually a newsletter upon the board...but I mean there's no leaflets I mean I don't know if anybody prints any leaflets or writes any leaflets about renal failure or different types of renal failure or the problems you have with feeding..." [mother A]

- Parents frequently used each other as a source of information

"You could learn a little bit from us through (child) and through having gone through a transplant, and our feelings particularly being in with her" [mother D]

- Other more formal sources are used

"Well I've quite often gone to the University to find out what I want because I don't get it" [mother D]

"..find things out for yourself, but where you shouldn't be looking, because you shouldn't , you just don't need to look in those sort of books" [mother B]

"This booklet sounds like a good idea" [father E]

- Referring to tape recorded consultations was useful

"Oh yes, because they (grandparents) sort of like we were saying side-effects of some of the drugs can cause....and they don't believe you, you know they think you're making it up or getting it out of proportion..you go back to parents or whoever it is and say...there you are yes you can listen to it." [mother B]
"I think another benefit of making those tapes you record, sometimes you ask a question...I know it sounds daft but you're that worried about it you can't always take in all of the answer" [mother J]

"It would have been useful if we'd had (transplant coordinator)'s conversation on tape" [father E]

How information is given

"I think it was the most frank and honest discussion we have ever had with any consultant. He discussed it as a consultant, and then as a father" [father G]

"I think the picture is painted rosier than it really is" [unidentified]

"To us it wasn't, we were told right from square one...he said do you realise there is going to be an awful lot of hard work, there is going to be no end of setbacks" [mother A]

"and we've gone through so much...too much to take in all at once" [mother F]

> Being told important news was something that parents thought should be carried out when they were both present

"...but some clever spark couldn't wait and so (wife) got the news by herself, and so by the time I got there she was in a right old state" (being given the diagnosis alone, not at Nottingham) [father D]

"He (the consultant) told (wife) one thing and he told me a completely different thing when I came in to fetch (wife),...you are sort of getting two stories and if I'm here and he is talking to the pair of us, he seems to direct what he is saying to me...you see she is looking after him most of the day, it's (wife) he should be talking to,
I should be listening in" [father A]

- Information giving about diagnosis remains with the parents for a long time

"...I sort of picked up half of it hearing behind the curtains, you know which was awful...I knew they were talking about me, but I was thinking, no, no, somebody else....some lady came in and said, has anybody told her about this yet....they told me they'd got this black hole where the kidney should be (on the prenatal ultrasound) and they couldn't see the other side so they didn't know whether there was a kidney on the other side, so they said if there isn't a kidney on the other side she'll last 24 hours or so" [mother M - receiving a prenatal diagnosis for her baby]

"we had a very bad experience at (hospital 1), that stopped as soon as we got to (hospital 2) because they told as soon as we were there, they told us what was going on, what was wrong with and what they wanted to do - up to that point we didn't know anything at all" [father K]

**Type of information considered lacking**

"They haven't done kids that long to be able to tell you, so we're like the guinea pigs, you know for two lots of generation's away children..and it's them sort of thing that no-one can answer, because nobody really knows" [mother B]

"We need to know everything we possibly can" [mother B]

"I read a thing in bed, which was in the doctors on their like magazines about a new rejection drug thing that they've found, it grows in some grass in the Himalayas....it's important little updates like that you know this has been found, we're still at clinical trials..."
but there's a possibility..."[mother B]

Information for others was also requested

"Don't you think that (consultant) ought to write to everybody's individual GP and state things like that, that parents do know what they need.....because my GP complains that he has got a terrible lack of information on (child)" [father G]
Discussion

Parents of children with chronic illnesses need information to be able to understand their child's medical condition, to be able to make informed decisions about treatments, and to carry out the therapies for the child. They also consider information essential for other reasons less directly impacting upon the treatment choices and provision.

Parents require information: to explain to others about their child's illness and/or treatments; to act as an effective intermediary between their child and the health care professionals; to feel at ease with the decisions they have taken; to be able to communicate effectively with health care professionals; for a sense of control; and to reduce the amount of uncertainty they have regarding their child's future.

Parents of children with ESRF report similar information needs to those of children with IDDM. This is despite the differences in caring for children with the two conditions. In childhood insulin dependent diabetes the condition is quite homogenous in presentation, and certainly in the treatment. The health of the child relies upon the balance of insulin administration, dietary intake of carbohydrates and the child's metabolic rate (on occasion influenced by exercise and illness). Whilst the balance may alter as the child develops, the treatment remains the same. Parents have few options about the type of treatment available for their children. In ESRF there are a number of treatment options, all of which may have limited duration. Prognosis is more predictable in IDDM too.

Targeting the efforts of health care workers in the provision of information to parents is a practical necessity. First the information
that will enable the parents to make informed decisions and to carry out treatments will need to be given, however once parents have that information they may still want more. The results indicate that parents consistently want information about the future of their child, and how the illness or the treatment might impact upon it. This is an area of uncertainty that all parents face, and one that they may consider difficult to ask health care professionals about, especially if the majority of information exchange is regarding more tangible, management issues. It may be that health care professionals are themselves unlikely to raise such issues if they are unaware that parents have these concerns or if the answer is unclear.

Parents in this study, in that about cystic fibrosis (Henley and Hill, 1990) and in that about nephrotic syndrome (Moore et al., 1994) reported high scores for the question about new information from around the world. All the children in these studies have medical conditions which are currently without a cure. There is going to be a degree of hope that at sometime in the future there may be a cure for their child. There may also be hopes that even if there is no cure, there may be a better treatment developed.

It may be possible for parents to bring in journals or articles they have read and found useful, so that other parents can see them too. Health care professionals can also ensure that information considered to be of potential interest to parents is also made available. As shown in the transcript data parents will go and seek information if it is not provided, and that may cause more confusion if their search is undirected. Conclusions in books and medical journals can be out-of-date, drawn from poor quality research, be based on opinion instead of research findings, and so on. It may be
preferable to provide a selection of reliable research findings, although it might be difficult if the findings are contrary to the philosophy of the unit.

Health care professionals need to target information specifically at those with lower status occupations. Both doctors and nurses recognise that not everyone has the same information requirements, but there may be personal assumptions of health care professionals about which 'type' of people function best with more information, and which with less. What may not be realised is that non-professionals may ask less questions because they may not have the confidence or the words to express their concerns. It may also be the type of language used, both verbally and in written information, that is not clearly understood. Much of the detailed information directly and indirectly available to parents may be provided in the written form, thus placing limits on whom it may be available to if some are not fully literate in English.

Targeting information provision around times of uncertainty or change is also to be recommended. There is some evidence from the individual plots that parents' information needs are greater when dialysis is just beginning or when a transplant takes place soon after commencing renal replacement therapy. Weichler (1990) also identified that at different stages of treatment parents' information needs change.

The information needs of parent varies as shown by the individual plots. It may be that the information provision to some has been greater, or that opportunities for gathering information have been inadequate for others. Intrinsic factors such as personal coping style may also play a part, as some parents may want less information and a decreased sense of control, instead leaving the decisions to the
health care professionals (Thompson et al., 1988). Health care professionals need to ensure is that information is provided that parents need to carry out treatments effectively, and to ensure that all parents receive and understand this information.

Provision of information extra to that required to deliver treatments is not however considered essential by all parents. For those wishing to have the information it is important and should be given due consideration. The information therefore needs to be available to, but not necessarily provided to, all parents. Whilst many parents reported that they wished to know more about possible future complications, and also of the consequences of a deterioration in their child's health, this should be treated with care.

One father did not take part in the study, but his wife wrote a note on her questionnaire explaining "His way to cope is not to think of things too deeply. Cope with problems as they arise. He finds some of the questions too painful. As they are not things he has thought of. And won't unless forced to. We shall continue to enjoy (child's name)'s good health, and worry about her if, and when, necessary." This is a clear example of an individual who functions best with minimal extraneous information, and someone who would probably find extra facts thrust upon them detrimental to their psychological well-being.

Health care professionals need to identify what information they should have available to the parents, and they may be advised not assume that they know what it is parents want. For example, most health care professionals expressed surprise at the high score given to the children's future fertility.
Parents consider their children to be special, yet still want them to be able to live their lives as other children do, and to grow into normal adults. Seeking reassurance that this is what the future holds is a natural thing for a parent to do. However it is sometimes difficult for health care professionals to be able to offer any guarantees about the child's future health or treatments, let alone their psychosocial or physical adaptation.

To ascertain what information needs are of greatest priority to the parents several sources can be useful, such as a written questionnaire (Henley and Hill, 1990), a checklist of concerns (Hulstijn-Dirkmaat and Damhuis, 1994) or a parent support group (Argles et al., 1994). Finally health care workers need to recognise that they may never be able to fully meet all the needs of all the parents. It is possible that wanting information about the future of one's child is an inherent aspect of parenting.
Chapter Six

Parental Stress, Anxiety and Depression

Chronic childhood illness places the child and their parents in an at risk state that may increase their vulnerability to the stressors of daily life, as well as to additional stressors associated with the illness and its treatments (Grey and Thurber, 1991). Illnesses promote, if not demand, changes in a family's established patterns of functioning and this is especially the case in chronic illnesses. Family adaptation to illness is made of many components some of which have implications for the emotional responses of those involved. Parents caring for a chronically ill child often find themselves facing many extra tasks and demands as a result, but these are seldom experienced in isolation from the rest of life. Parents caring for their ill child are not exempt from the normal stresses of life, though their perception of these may change. It is often when the tasks and demands of caring for their child combine with the normal stresses and strains of life that difficulties are experienced.

Individuals respond to the demands of life in varying ways, some of which are emotional. Unpleasant emotional responses can include feeling stressed, anxious or depressed. These emotions are not mutually exclusive. Knowledge about emotions such as happiness or sadness are understood within the framework of one's own experience, but there is also common understanding of the emotions. Individuals know when they are 'depressed' and can convey this to others through accepted terms such as "feeling down".
The response of individuals to demands of life generally, and of illness specifically, can be understood using the concept of stress. The term stress is used regularly in everyday language, but often very imprecisely. One useful way to use the term stress is in the sense that there is a lack of fit between the individual and the environment (Sims and Owens, 1993, p31). Lazarus however argued that stress is not merely an external characteristic within the environment, rather stress is the product of the relationship between the resources available to an individual and the demands they perceive are being made upon them (Lazarus, 1966).

Stress

Psychological stress is a key concept in health psychology, and probably one of the most widely used in the lay media. There is though, no consensus even amongst professionals in the area, upon the precise definition and meaning of 'psychological stress'. There is however broad agreement that events can be considered stressful when they challenge an individual's psychological or physical status quo, and do not permit easy accommodation (Carroll, 1992, p3).

Stress can be approached from different perspectives, and in different contexts the term used in several different ways. It can be used to: describe various unpleasant situations which are considered to be stressful; to describe the individuals response (either psychological, behavioural or physiological) to such an event; to consider any mismatch or incompatibility of the response to an event (Weinman, 1987).

Certain situations and events have been identified as stressful. Lazarus and Cohen (1977) broadly classified stressors into three
groups, each varying in: their magnitude; their duration; and the number of people simultaneously affected. The first group is 'Cataclysmic events', and includes natural disasters such as earthquakes and wars. These stressors affect large numbers of people, are usually (but not always) short lived, and are exceptionally powerful in their impact upon those involved.

The second group is 'Personal stressors' and includes such things as divorce, death of a close relative, loss of a job etc. Unlike cataclysmic events they happen to relatively few people at a time, though they are also often short lived and powerful in their impact.

The third group of stressors are those Lazarus and Cohen identified as 'daily hassles'. Daily hassles, though encountered by most people, are suffered individually. They are chronic (daily) and ongoing and whilst daily hassles are rarely powerful at each impact it is their persistence which can make them serious.

Specifying the characteristics of an event or situation is, though, insufficient to classify it as stressful, as consideration of the individuals' responses to that event need to be taken into account. Any of the above examples of 'stressful' events could take place, yet if people did not react to them in a particular way, the events might no longer be considered stressful. For example if caring for a sick relative entailed giving up a job one hated, was a task one found manageable and which provided a sense of worth and achievement, it might not be considered stressful. Conversely if caring for a sick relative entailed giving up a job one loved, was a task one found difficult and which provided a sense of hopelessness and of a limited life, it probably would be appraised as stressful.

Seyle (1956) argued that a stress response, an inherent physiological
mechanism, comes into play whenever demands are put on the organism. He identified and described a general physiological reaction to all types of stress, referred to as the General Adaptation Syndrome (GAS). The GAS has three stages, the first being 'alarm', the second being 'resistance' (a functional recovery to a level superior to the pre-stress level), and a third being 'exhaustion' which occurs when the stressor continues through the resistance stage for a prolonged time.

Lazarus however argued that stress is not merely an external characteristic within the environment, rather it is within the perception and appraisal of the individual (Lazarus, 1966).

Lazarus (1976) maintains that stress occurs when there are demands on an individual which he or she cannot cope with. Events can be more, or less, stressful depending upon the particular appraisal an individual makes for that event. Thus stress arises when an individual perceives and evaluates an event as threatening. That evaluation is based upon an assessment of the demands of the situation measured against the individual's assessment of their capacity to cope.

Ways in which an individual reacts to events, both psychologically and practically, are referred to as coping. Coping styles can be positive or negative for an individual (see Chapter One, p31-35 for further discussion on coping). Individual differences can also effect how individuals respond to stressors. People may be more vulnerable to the effects of stressors at an individual level such as their coping style, or at a broader social level.

**Stress and the effect on health**

There has been much work on the effects that stress has upon
health, and it has been suggested that effects may be elicited at a number of levels. Most suggest negative effects. Steptoe (1984) suggests three basic routes whereby stress can contribute to ill health. First, through the physiological responses to stress in various biological systems. Stress is recognised as having effects upon the cardiovascular system, the immune processes and also on hormones and enzymes. Second, stress can lead to changes in behaviour, some of which may be considered harmful to health. Such behaviours may include smoking tobacco, drinking alcohol, poor diet, and/or poor sleep patterns (Steptoe, 1984).

Steptoe (1984) identified that the incidence of such unhealthy behaviours increase during times of stress. Finally stress may increase the awareness of, and attention given to, physical symptoms, thus those reporting higher stress at work also report an increase in their subjective complaints of minor illnesses such as colds and skin rashes (House et al., 1979; Tyler et al., 1991).

Factors mediating the response to stress

For any individual the nature of their response to an event may be determined by many factors. Prior experience is an important aspect in human learning, and can affect an individual's responses to stressors in both an overall way and in a more situation specific way.

Early experiences in child development affect the coping style that one develops. Childhood encounters with stressful situations are not necessarily negative experiences as overcoming them can have some positive effects. Exposure to some stressful situations may allow the opportunity for general problem solving strategies to be successfully learnt or employed (Bush, 1987). A more specific effect
is the predictability associated with having been through an experience once already, where some stressful situations become less threatening when next encountered.

Information is provided by experience, but it is also possible to provide people a priori information to facilitate adaptive reactions to stress. For example, it has been demonstrated that preparatory information describing the operation and post-operative pain can help surgical patients during the recovery period (Hayward, 1975; Wallace, 1985).

Individual differences in how people respond to and adapt to stressors make it inadvisable to recommend a set of rigid guidelines about how to best cope with stressful situations. Some people seek as much information and support as possible, while others may prefer to cope through denial. Likewise some may seek to gain control over the situation, while others may wish for the responsibility for decisions to be in the hands of the 'experts'. This may be better understood through a concept known as 'locus of control'. This refers to the degree of control that individuals consider they have over what happens to them. It has been suggested that those who see themselves as having greater control over their environment (internal locus of control), are less likely to be emotionally disrupted by mounting stress (McFarlane et al., 1980).

Perceived control is therefore an important factor in how stressful some individuals find situations, especially those who have an internal locus of control. Lack of control over unpleasant or stressful stimuli has been found, in animal experiments at least, to lead to increased vulnerability to illness (Weiss, 1968). For humans many distressing situations seem to be those where individuals feel
helpless (Suls and Mullen, 1981).

At a social level individuals may be vulnerable to stressors for two reasons. The first is primarily relevant for those problem-focussed coping strategies when one often needs access to practical resources, such as information or equipment. Access to the resources needed to adopt the coping strategies required may be limited by finance or education levels. Secondly, on the social level the amount of support available from others is an important influence on how people can perceive and appraise the events around them. This social support refers to the provision of comfort, caring, esteem, or direct help from other individuals or from groups. Social support has been shown to reduce the effect of stressors (Kulik and Mahler, 1989). Social support appears to be a protective factor which lessens the impact of stressors, although the exact mechanisms remain unclear.

Sources of stress in chronic illness

McCubbin and McCubbin (1993) identified many factors that can contribute to a pileup of demands in a family's adaptation to illness which they placed in six broad categories. There can be many stressors involved in caring for someone with a chronic illness and it is beneficial to use the six categories of McCubbin and McCubbin (1993) to distinguish between them.

1 The illness and related hardships over time. This category includes the specific hardships associated with the illness and which increase or intensify difficulties that families face. Children undergoing renal replacement therapies require daily medication, regular visits to clinic, and the delivery of dialysis therapy if required. These all require the parents to
organise their time, and that of the child, to fit in with the
treatment demands. Caring for a child with a chronic illness
can also create indirect hardships such as an increase in
financial difficulties due to work absenteeism, special diet,
equipment or direct travelling costs to and from the hospital
(Bodkin et al., 1982). These hardships create additional
burdens on the family above and beyond the diagnosis and
therapy (McCubbin and McCubbin, 1993).

2 Normative transitions. This refers to the dynamic nature of
families, in that they are not static unchanging units. Families
go through reasonably predictable transitions as their
children grow and develop, and as the parents also continue
to develop. Problems can occur if difficulties with the chronic
illness or its treatment are exacerbated by life transitions,
such as adolescence (Zeltzer et al., 1980; Pendleton, 1991;
Zirinsky, 1993).

3 Prior family strains accumulated over time. Prior stressors
that have been largely overlooked can surface under the
pressure of new additional demands. McCubbin and
McCubbin, (1993) suggest that awareness of prior strains is of
importance to the health care team for two main reasons.
One, they can mask major hardships of an illness crisis, and
two, they may be masked under the hardships of an illness
crisis.

If parents caring for a child with ESRF disagree about
treatment choices or the division of the care burden it can be
difficult to ascertain the cause of the friction. Friction
between the parents may have been present before their
child's illness became known, and the burden of care has
simply added to that hostility. Conversely what may appear to be marital dissatisfaction may primarily be a symptom of the parents being over burdened by the care regime. Divorce is common in the UK and marital discord can occur regardless of whether there is a chronically sick child within the family unit. It is desirable, but not often easy, to identify the root causes of stress within the family so that the most appropriate support can be offered.

4 Situational demands and contextual difficulties. McCubbin & McCubbin use this category to identify the demands associated with situations specific to the illness and treatment decisions. It also deals with how the functioning of the family might be affected by the demands placed on them by the health care providers and by any major changes in the delivery of health care (such as the transfer from paediatric to adult care).

5 Consequences of family efforts to cope. Behaviours and strategies that individuals and family units employ to help cope with the illness can themselves produce additional burdens. Financial difficulties may arise if a parent reduces their employment outside the house in order to care for their child. This however may lead to increased stress if, for example, there are insufficient finances to provide respite care.

6 Intrafamily and social ambiguity. Any change in demand for family adaptation, as in the case of a chronically ill child, causes uncertainty as the family needs to alter its structure, roles, responsibilities and expectations. There can also be ambiguity in the way that extended family members respond
to the ill child, and their parents and siblings. It is sometimes the social ambiguity and isolation that parents find difficult to handle (Powellcope and Brown, 1992). Baby sitting grandchildren is a common activity when grandparents live close by, however there can be difficulties when a grandchild has a severe chronic illness. Family members may be reluctant to take the responsibility for care or they may be incapable of delivering the treatments required. This can produce negative emotional responses from both the child’s parents and from the relatives, who can not or will not provide the support that would have been available to a healthy child.

The categories identified by McCubbin and McCubbin (1993) distinguish the likely sources of stressors encountered during chronic illness. However they do not consider characteristics that stressors may have which might determine how stressful they are appraised to be by the person experiencing them.

Characteristics of stressors encountered during chronic illness

Lipman-Blumen (1975) developed a classification that characterizes the nature of crisis and the influence it has on a social system. In 1993 this ten dimensional framework was adapted by Danielson, Hamell-Bissell and Winstead-Fry to classify the dimensions of an illness stressor that govern the illness's capability to cause family stress and crisis (Danielson et al., 1993, p99-127). Stressors have varied effects and using the ten categories as adapted by Danielson, Hamell-Bissell and Winstead-Fry (1993) may help to outline the amount of impact a stressor might have upon the family.
1) **Origin of the stressor.** External illness stressors such as an ill friend or a distant extended family member tend to have less effect and the requirement to respond is usually optional. Internal origins such as an immediate family member being ill lead to close family wanting to, or feeling obliged to, meet the demands of the illness. This response is usually very strong in childhood illness. For the extended family however assisting with the treatment regime is optional and whilst support is often forthcoming in the early days after diagnosis, this commonly lessens as the duration of the illness increases and stability is established (Janosik and Green, 1992)

In childhood ESRF it is the parents who have to meet most of the treatment needs, especially in the case of younger children (see Chapter Two for more details). The parents may meet the treatment needs of their child to the extent of donating one of their own kidneys for transplantation. All members in the household will have to accommodate the changes and impact that renal failure and its treatment will bring, for example siblings may have to give their bedroom to make room for all the equipment required for overnight dialysis.

2) **Extent of the stressor's impact.** The more deeply involved and the greater the number of family members then the greater the potential for family stress (Danielson *et al.*, 1993, p104). The demands of illness and treatment can often be spread unevenly whoever the ill family member, but in the case of childhood disability, the burden of care most commonly falls to the mother (Barsch, 1968, p253-258; Allan *et al.*, 1974). The literature suggests that even when caring for a child with as demanding a condition as cystic fibrosis the child care is left entirely with the mother in up to a third of families (Sabbeth and Leventhal, 1984). Inequality in the
distribution of responsibility for illness decisions and treatments can lead to resentment and increase stress.

In childhood ESRF, the impact on the nuclear family is considerable, especially when the child is undergoing home dialysis. For example, except for when using continuous ambulatory dialysis, it is difficult to arrange holidays unless a venue to dialyse can be organised. Even with CAPD or an organised peritoneal cycling dialysis machine there are usually many supplies to take and store. Fixed site haemodialysis centres, willing to take holiday makers, are unusual and in very few locations. Family mealtimes are often disrupted due to special diets, prolonged anorexia of the child, the need for adequate nutrition despite lack of appetite and so forth. Sleeping patterns are often disrupted too, especially with overnight dialysis. There is often the need for the child to be attached to the cycling peritoneal dialysis machine for ten hours a night. This prolonged dialysis session can result in abnormal bedtimes for children, and disruption of sibling sleep patterns if a room is shared. Overnight dialysis can also mean broken nights sleep for the parents as the alarm may go off periodically. Childhood ESRF after transplantation is usually less extensive in its impact, though monitoring of medications, weight etc. continues.

3) **Severity of the stressor.** In childhood ESRF, the potential severity of the illness is extreme. Without treatment ESRF is fatal, and even with treatment there can sometimes still be deaths. Cause of death can range from cardiac failure due to electrolyte imbalance during dialysis, to death from surgical complications during transplant. Whilst death is not an expected outcome for a child on an ESRF treatment programme it can still occur. The severity of the illness is reflected in the impact of the treatments, and there can be many
scars from surgery, short stature due to dietary insufficiencies and the many side-effects of chronic steroid usage.

4) **Duration of the stressor.** Illnesses of a temporary nature do not demand permanent changes in family functioning and rôle change. When the illness is short term the family merely have to adjust to manage the situation, and established patterns can either remain unchanged or be only temporarily adjusted. However, in childhood ESRF, the duration of treatments and of the underlying condition is life-long. ESRF can not yet be cured, though renal transplantation reduces many of the demands required for treatment by dialysis. It is often difficult for both parents to work outside the home, at least during the more demanding phases of treatment, such as when their child is on dialysis or immediately post-transplant. The nature of ESRF can mean that not only is the treatment always ongoing, there can be few guarantees that there will not be a complication (such as infection or rejection) which might require a parent to attend the hospital with their child. This prolonged unpredictability can pose difficulties to a working parent, unless their employer is very understanding.

5) **Onset of the stressor.** With the sudden, threatening onset of illness, the family has little time to investigate or gather information, and it limits the time available to develop coping strategies. On the other hand, gradual onset of an illness usually allows time to gather information, formulate coping strategies and adjust to new roles and tasks. However, a gradual and uncertain prognosis makes it more difficult to establish the need for family support or action. It also allows denial to be maintained by some individuals. Uncertainty about illness with a gradual onset may also produce fearful fantasies, and increased anxiety and apprehension (Hirsch, 1988).
In childhood ESRF, the pattern of onset varies tremendously. Some children are diagnosed in utero yet develop few symptoms until they are six or seven years old, eventually being admitted into a renal replacement treatment programme at nine years old. Others may be diagnosed at a day or so of age and dialysis may need to commenced right away, in the first week of life, or a child may be born with well functioning kidneys with no abnormality, but still develop acute renal failure later too severe to resolve and ESRF is diagnosed. Due to the greatly differing pattern of onset in ESRF the children form a widely heterogenous group, which is less common in some other chronic childhood diseases such as diabetes or cystic fibrosis.

6) Control of the stressor. Stressors that appear unmanageable can impact families negatively, whereas stressors that appear manageable can even contribute positively to the family's sense of control. A direct inverse relationship is commonly suggested between a sense of mastery or control and anxiety and depression (Mercer et al., 1986). Individuals who feel helpless about the health of themself or a close family member will often make considerable attempts to gain control by obtaining information and attempting to find solutions that offer hope, thus fostering a sense of being in control and increased confidence (Kahn, 1990). It is the appraisal of disease characteristics, and of the situations to be faced, that determines the effect upon the family's sense of control.

In childhood ESRF, some aspects of the treatment are more controllable than others. Parents often state that they prefer it when their child is on dialysis, despite the extra burden of care, because they have a greater sense of control when complications arise than they do when a transplanted kidney is causing concern. The
treatments for peritonitis are much more accessible to the parents, indeed they may be the ones adding antibiotics to the bags of dialysate, and the ones monitoring the status of drainage fluid. They also know that peritonitis is nearly always easy to clear providing treatment advice is followed. Rejection of a transplanted kidney is much less predictable, especially if severe. It is difficult for nephrologists to be able predict the length of time the donor kidney will function for, or even the chances of saving the kidney through any one bout of rejection. Chronic rejection is especially difficult to deal with emotionally as the threat of loss is ever present.

7) Cause of the stressor. In stressful situations people cope more effectively when they have explanations for events (Olson et al., 1989), as it adds to their sense of control when more questions are answered. 'Man-made' illnesses can give rise to a great deal of anger or guilt, depending on where 'blame' is being attributed to, and this often needs to be addressed. Illness where the etiology is unknown can give rise to feelings of helplessness and of less control. Knowing what caused an illness can give hope about the treatment even if currently incurable. In childhood ESRF, the causes are varied, though the majority have natural etiologies. Occasionally ESRF may have man-made origins such as a consequence of surgical intervention for other problems, or as a result of drug or chemical toxicity.

8) Predictability of the stressor. Predictable illnesses give rise to less crises as the patient and family can plan for the responsibilities and changes. Most illnesses have some elements that are predictable and some that are not. It is the balance of these elements that increases or decreases the impact of the disease. In childhood ESRF, predictability depends upon many factors, such as the
etiology, the age of the child and the stage of treatment.

Those who have been treated since infancy are the first cohort of patients to be treated from such a small size and young age, and it is not possible to accurately predict the consequences of such early treatment. Whilst the assumption is that early rectification of uraemia has many benefits, it is impossible to foresee all possible consequences of the early intervention. Another aspect of uncertainty is the transplanted organ.

It is impossible to predict how long a child will be on dialysis for if they are on the waiting list for a cadaveric donor kidney as the list operates using a 'best-match' principle rather than a simple queuing system. It is also impossible to predict how any one transplanted organ will function. Only expectations based on averages and general experience can be offered.

9) Resource demands of the stressor. When stress is considered to be the relationship between the resources available to an individual and the demands made upon them (or at least their perception of the resources and the demands) then the importance of family resources is highlighted. In childhood ESRF, the duration of the treatment can put serious demands upon the resources available.

Interventions to increase resources are possible such as: increasing social support by providing respite care and babysitting services to allow contacts to be maintained; or via a parent support group to directly increase positive contact between parents. Financial resources can be increased through ensuring that all benefits are claimed, or via treatment choices that provide least interference with employment. In addition demands can sometimes be reduced, perhaps by ensuring the care is more equally distributed between
both parents, and again by careful selection of treatment options.

10) **Stigma of the stressor.** The greater the stigma attached to an illness the greater its opportunity to negatively influence the family's appraisal and subsequent responses. Some illness labels, such as cancer, can be negative because people are unable to handle their own feelings about the illness or disability, instead creating a barrier to meaningful communication. These behaviours promote feelings of isolation in patients and their families that serves to intensify the stress generated by the illness.

In childhood ESRF the stigma that parents report is akin to that associated with cancers, of people unable to handle their feelings about a serious illness, who fail to maintain or begin contact. Parents sometimes report feeling failures for not producing the healthy children that everyone else can apparently have. Genetic components in the etiology can increase the guilt parents feel which may compound any such feelings of failure.

The characteristics of illness stressors contribute to the variety and complexity of family responses to illness situations. Ultimately it is the appraisal of the stressors, and of the ability to cope with them that governs what aspects are considered stressful and problematic. It can be clearly demonstrated that with childhood ESRF there is a risk of stressors piling-up from the many sources outlined earlier, and along many dimensions.

**Psychological consequences of chronic stress**

Depression and anxiety have been considered as both personality traits and as emotional states. Personality traits are consistent aspects of an individual's personality which allow one to predict aspects of that individual's behaviour and their emotional responses
to events. Traits are considered to have a biological component in their etiology. State on the other hand refers to the short term response an individual has to an event. Emotional states are strongly influenced by the trait the individual has, but may reflect different behaviours and emotional responses to those usually displayed (Spielberger, 1983, p4-6).

In recent years it has been firmly established that life events and long term difficulties can provoke the onset of specific psychiatric illness, most commonly depression and anxiety (Sims and Owens, 1993, p45). Depression and anxiety disorders that occur as the result of environmental factors are not the same as those that 'spontaneously' occur, usually as a result of a biological predisposition, or chemical imbalance in the brain (Snaith and Zigmond, 1986). It is the depression and anxiety disorders that occur as the result of environmental factors are considered to be sequelae of chronic stress.

Paykel and Cooper (1992) reviewed 27 published studies, all of which found more life events reported prior to depressive onset. Depression has also been found to be more likely in the face of chronic difficulties including those associated with bearing the burden of caring for another person and social isolation (Sims and Owens, 1993, p45). Anxiety often co-exists with depression (Champion, 1992), to the extent that some mental health workers regard anxiety and depression as a single illness, arguing that the majority of patients have mixed anxiety depression (see Montgomery, 1990 and Judd & Burrows 1992 for further information).
Depression

The most obvious features of depression are lowering of mood and decrease in energy and activity, usually accompanied by a reduction in the capacity for enjoyment, loss of interest and sleep and appetite disturbance (Sims and Owens, 1993, p37).

Depression in the general community may be milder and different in quality to the depression of those receiving psychiatric care. This milder form of depression is probably closely linked with social stress or support and more understandable to others (Paykel and Cooper, 1992). Low points in mood often occur when an experience threatens, or results in, loss of some valued idea object or person (Champion, 1992).

There may be feelings of loss associated with caring for a chronically ill child (Fraley, 1990), which may include loss of personal freedom as well as loss of the health of the child and loss of an anticipated future for the child. Adaptation to the illness does abrogate many of these feelings of loss but until adaptation has occurred they may persist (Fraley, 1990).

Paykel and Cooper (1992) report that many people undergo considerable distress, but not all develop a clinical depression, and even fewer seek psychiatric help. Factors such as appraisal of the events and availability of resources to cope with them may be strong buffers between stressors and depression for some individuals (Cobb, 1976).

Anxiety

The term anxiety is commonly used in the lay person's vocabulary, as are stress and depression. Anxiety is a common form of reaction
that most people experience to a greater or lesser extent in his or her lifetime. Anxiety can be a normal response or reaction to a challenging situation, but it can also be disruptive. Whether the anxiety is considered normal is dependent upon the extent of its negative impact on thinking and behaviour, and how much it interferes with the person’s daily life (Callanan, 1992).

Anxiety is generally experienced as unpleasant with a subjective feeling of foreboding. It accompanies any situation where an individual feels threatened (Judd and Burrows, 1992). Anxiety can also be experienced in anticipation of a threat (Callanan, 1992), and it can be generalised where there is no specific focus (Callanan, 1992; Judd and Burrows, 1992). Normal anxiety is a usual even necessary (if unpleasant) response to threatening circumstances, and is adaptive and of biological advantage (Judd and Burrows, 1992). Anxiety is considered to be a disorder when the mood state is either: an inappropriate response to the situation; is perceived to be out of control; or when it results in behaviour that reduces normal functioning (Callanan, 1992; Judd and Burrows, 1992).

Prevalence of depression and anxiety

Psychiatry text books refer to anxiety and depression as "associated with clinically important syndromes", and "common in general medical settings" (Goldberg et al., 1994). Formal diagnosis is not a prerequisite for anxiety or depression to be a problem. Mann (1992) suggests that unrecognised psychological illness still takes a toll on the quality of life a person can enjoy. Self-report studies of depression have revealed varying rates, dependent in part on the measures used, and on the population studied.
A review carried out by Frelling and Tylee (1992) reviewed studies using self-reported measures of depression which indicated disorder rates from 12-47%, with morbidity rates over 25% being common. Within this, an excess rate for depression among women of 3:1 or 4:1 was also identified from the literature (Freeling and Tylee, 1992). The possible reasons for this sex difference may include confounding issues such as willingness to admit to symptoms, as well as a possible higher prevalence. It has been suggested that much of the excess depression reported by women can be attributed to their environmental situation rather than down to physical explanations such as hormones or genetics (Freeling and Tylee, 1992).

Anxiety has also been reported to be more prevalent in women (Sims and Owens, 1993, p90). Prevalence of the diagnosis of anxiety state (as opposed to normal anxiety) in the general population is estimated at between 2% and 4% for men and between 3% and 4.5% in women (Goldberg et al., 1994).

**Stress, anxiety and depression in parents caring for children**

Parents experience stress, anxiety or depression at one time or another, whether they have a child with a chronic disease or not. It is considered likely that parents of chronically ill children would be prone to higher levels of one, both or all three emotional responses. Most of the research in this area has focused upon the mothers of chronically ill children, and rarely considers the father. Many
studies also fail to have control or comparison groups. Findings from a few recent studies are reported here.

Depression levels have been measured in mothers attending paediatric outpatients with their child. Fitzgerald (1985) reported there were more mothers with depressive symptoms with children attending the medical outpatients than with children attending the surgical outpatients. Medical outpatients have a higher proportion of children with a chronic illness which may explain this. This higher depression score in the medical mothers attending the paediatric outpatients was not significant, yet depressive symptoms were present for three times as many mothers in the medical sample, where the child was aged 3-4 years, than there was for the surgical sample for the same age group. The percentage of the mothers who were considered to have a deviant depression score ranged from 9% (surgery patients aged 3-4yr olds), 17% (surgery patients aged 7-11yrs), 31% (medical patients aged 3-4 yrs), to 32% (medical patients aged 7-11 yrs) (Fitzgerald, 1985).

In a controlled study, mothers of children with cystic fibrosis (CF) did not report higher levels of stress than control group mothers (Walker et al., 1987). However those mothers of children with CF in two age groups, preschool (4-5yrs) and early adolescence (11-14yrs), scored higher on a measure of depression than did the control mothers with children in the same age groups (p=<0.01 using ANOVA). This study reported a higher correlation of reported stress with the mother's subjective rating of the child's illness severity, than there was with the clinical Schwachman ratings. This indicates the importance of considering the parental appraisal of illness severity rather than just the clinical assessment.
Leonard, Brust and Nelson (1993) investigated parental distress in a group of mothers and fathers caring for medically fragile children at home. Using a standardized self-report questionnaire, the Brief Symptom Inventory (BSI), parents were assessed over nine symptom dimensions, including depression, anxiety and global distress. Results indicated that 59% of the mothers and 67% of the fathers reported distress symptoms above the cut off point which indicates a need for psychiatric intervention. Regressing the score against independent variables Leonard et al identified three significant factors for mothers (increased homemaker hours, employment outside the house, and fathers' increasing care hours), and four for the fathers (mothers' employment outside the house, siblings in the home, increased child dependency, and private health scheme).

Stress levels have also been assessed in mothers of healthy infants and the results indicate that the score was considerably higher than reported for the female general population. Using the PSS14, the scores obtained in the study were an average of 25 with a standard deviation of 8 (n=173) (Walker, 1989). This compares with a 'norm' for women in the general population (which will include many mothers) of 20.2 and a standard deviation of 7.8 (n=1406) (Cohen and Williamson, 1988).

Stress, anxiety and depression levels in parents of children with ESRF

Brownbridge and Fielding (1991) reported on differences in psychosocial adjustment to ESRF in both children and parents. Comparisons were drawn between families where the child was on haemodialysis, CAPD or post transplant. Parental anxiety and depression levels were measured using the earlier version of the
HADS, the Leeds SAD. Results showed that mean depression and anxiety scores were significant lower in the parents whose children were undergoing home dialysis (CAPD or haemodialysis), than those with children undergoing hospital haemodialysis. It is also stated in the report that a related study (unpublished) showed a negative correlation between parental depression scores and age of the child.

The authors acknowledge that psychosocial factors are considered when choosing the type of treatment to be used by a particular family, and this may have had a contributing effect on the relationship with depression and home versus hospital dialysis. For example in poorer household it may be less likely that there would be sufficient space for a haemodialysis room to be established. It could also be difficult to store all of the supplies required for a home peritoneal dialysis programme.

The abstract also stated that "parents undergoing either CAPD or hospital haemodialysis reported similar....psychological stress....", but there was no measure of stress reported in the study so it is uncertain how this conclusion was reached.

In a recent Dutch study Hulstijn-Dirkmaat and Damhuis (1994) asked mothers and fathers of children with ESRF and on CAPD to complete a 37 item standardized questionnaire. Parents completed the questionnaire on three occasions and their scores were then averaged over the three measurements. The authors chose to define family stress as a total of the items on the questionnaires that the parents either found difficult or caused great burden. Items included social isolation, concerns about the future, work absenteeism, peritonitis, drain into the abdomen, and other items based on findings from the literature. There were only items
looking at demands, with none concerned with resources.

Whilst their use of the term stress does not correspond with that used in this thesis the report still addresses some interesting issues. The findings included considerable differences in the stress experienced, ranging from 5.4% to 64.7%. There was no significant differences between mothers and fathers, and there was a high correlation between partners. The only independent variables shown to significantly increase the amount of stress reported were: previous failed transplant, as opposed to none, child being over the age of 5 years; and duration of illness over 5 years. Duration of CAPD treatment was not significant.

At an item level, mothers reported that they felt a greater burden due to the behavioural problems of their children, than was reported by the fathers. Fathers found 'requesting time off work' and 'drain on the abdomen' significantly more difficult. The report concluded that parents are concerned about the psychosocial implications of their child's disease. It also concluded that parents of children of school age and who have had a failed transplantation are particularly at risk (Hulstijn-Dirkmaat and Damhuis, 1994).

Aside from the criticism that the authors failed to consider resources in their questionnaire, the items also failed to cover other possible stressors independent from their child with ESRF. Whilst most of these would be outside the control of the renal team it might still be of important in case increased demands unrelated to the illness were altering the perceptions of the illness related stressors.
Method

To assess psychological well-being two main routes were used. The first was two questionnaires to assess parents' self-report levels of stress, anxiety and depression, and the second was the transcription data from the parent support group.

The questionnaire to assess parental stress levels was the Perceived Stress Scale (Cohen et al., 1983; Cohen and Williamson, 1988), and the questionnaire to assess parental anxiety and depression levels was the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983).

The Perceived Stress Scale (PSS) measures the degree to which situations in one's life are perceived as stressful and was originally a 14 item instrument. In 1988 the authors published data which, following factor analysis, recommended four of the items be removed from the scale, naming the shortened version of the scale as the PSS10 (Cohen and Williamson, 1988).

The perceived stress scale considers not only demands upon an individual, but also the individual's appraisal of how adequately they are coping with the demands. This is in keeping with the concept of stress being a product of demands on an individual which he or she cannot cope with. Rather than being used to measure psychological symptoms, the PSS is recommended for use in assessing a state that places people at risk of clinical psychiatric disorder (Cohen et al., 1983). The authors of the PSS suggest that it "may provide an economic tool for assessing chronic stress level...where monthly administrations of the scale could be summed or averaged, providing a reliable, i.e., based on more samples, measure of chronic stress" (p393-4). The measurement of perceived
stress levels has advantages over more objective measures of stressful events when the primary stressors are of a more 'daily life' nature.

Caring for a chronically ill child may well involve personal events that would be monitored on a life event scale eg. when the diagnosis is made, but daily hassles may not be covered. It is the accumulative effect that has a negative effect upon an individual as daily hassles are rarely powerful at each impact - it is their persistence which can make them serious. The PSS was therefore considered a suitable instrument for use in a longitudinal study to measure stress levels of parents caring for their chronically ill children.

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) is a 14 item instrument designed to provide a screening device for anxiety and depression. It has been shown to be valid in both hospital and community settings (Lewis and Wessely, 1990; Moorey et al., 1991). It provides separate measures of the two constructs, anxiety and depression, and is considered suitable for detecting minor psychiatric disorder (Lewis and Wessely, 1990). The authors recommend the HADS for use in longitudinal studies.

Questionnaires were posted on seven occasions at 4 monthly intervals. Replies were received from 43 parents of children with ESRF (mothers=25, fathers=18), and from 41 parents of children with IDDM (mothers=23, fathers=18), as discussed in Chapter 3.

Plotting the scores from repeated, objective, quantitative questionnaires over time also allowed the use of an individual's own baseline against which one could measure increases or decreases in stress, anxiety or depression levels. There would be no need to
compare across individuals.

Socioeconomic family details were obtained at the beginning of the study, including age of parents, number and age of all children, occupation of both parents, and any chronic illness in any family member. Age of child at diagnosis was also noted. A front sheet asking about the previous month accompanied each set of questionnaires for parents to complete, noting: any treatment or health changes for the child; the number of admissions or telephone calls to the liaison nurse; number of visits to the GP for the child, themselves or any other family member; and the frequency of outpatient appointments. A section also requested information on major life changes such as housing, finances, support etc. Changes could be for the better or for the worse.

The information from the transcripts of the parent support group provided a qualitative balance to the questionnaire. For the questionnaire the limitation of the data received was constrained by the information requested. The transcripts on the other hand were taken from support group discussions whereby the parents themselves shaped the direction that the conversation went. All groups were tape recorded, and had been since the group began. These tapes were made available for transcription.

**Hypotheses**

It was hypothesized that stress, anxiety and depression levels would change, at certain keypoints such as change of treatment modality. It was predicted that their would be a positive association with the impact of illness scores and stress, anxiety and depression, and a negative association with the information needs scores and stress, anxiety and depression.
The research would also investigate the effects of factors such as age of child, time since diagnosis etc. Plotting the scores from a repeated, objective, quantitative questionnaire over time also allowed the use of an individual's own baseline against which one could measure increases or decreases in information needs. There would be no need to compare across individuals.
Results

The measures used to assess stress, anxiety and depression were all self-report, and are discussed in detail in chapter three. The results section will consider

a Stress, anxiety and depression levels relative to 'norm' values or to the general population samples' scores.

b The scores from these measures will then be explored along the two year collection of the data, with regard to socioeconomic data available and to questionnaire data regarding impact of illness measures and information needs.

c With regard to individual families, the results of the questionnaires on stress, anxiety and depression will be discussed in more depth for three specific families, relating treatment changes, family life changes and alterations in the paediatric renal service.

d Finally qualitative data, of parents discussions relating to stress, anxiety or depression will be extracted from the transcripts of the parent support group.

Complete ANOVA and regression tables for results discussed in this chapter can be found in Appendix J.

Normative and general population samples data

Comparative data were not available from other longitudinal studies. It would not be legitimate to compare the overall means of the parents in this study with the means of the general population samples. Instead a more direct comparison could be obtained by analysing the first reply that the study parents returned. Thus first
replies that subjects completed were used to calculate the study group means, for use in all statistical tests comparing them to the general population groups.

**Perceived Stress Scale**

Normative data was available for the PSS10 (Cohen and Williamson, 1988), and included the mean and standard deviation for women and men separately. Comparative means and standard deviations were also sought from the literature, specifically for adults who were also parents. A previous study of mothers was identified, which had used PSS14. It was still possible to draw direct comparisons as PSS14 was administered to the parents in the study. It was only prior to analysis that it was decided to input responses for PSS10. A parental comparison group of mothers (n=64) and fathers (n=59) was also obtained for the purpose of this study (Parslow, 1994).

Table 6.1 shows those means, standard error, and ranges available for PSS10 either specifically for men and women, or for fathers and mothers.

<table>
<thead>
<tr>
<th>PSS10</th>
<th>Norm (Cohen and Williamson, 1988)</th>
<th>Comparison</th>
<th>ESRF</th>
<th>IDDM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>women n=1344</td>
<td>men n=926</td>
<td>mothers n=64</td>
<td>fathers n=59</td>
</tr>
<tr>
<td>mean</td>
<td>13.7</td>
<td>12.1</td>
<td>16.56</td>
<td>14.6</td>
</tr>
<tr>
<td>SE</td>
<td>0.21</td>
<td>0.19</td>
<td>0.92</td>
<td>0.97</td>
</tr>
<tr>
<td>range</td>
<td>0-35</td>
<td>3-36</td>
<td>5-31</td>
<td>3-25</td>
</tr>
</tbody>
</table>
The norm sample included adults aged 18-65+ years of age, unlike the control and study samples which covered a much narrower age range (22-48 years).

Two-way analysis of variance was performed on the control, renal and diabetic data. There were no significant differences either by medical condition (\(F(2,200)=0.59, p=0.56\)) or by sex of the parent (\(F(1,200)=1.27, p=0.26\)).

It was also possible to compare the PSS14 data available from a published study of mothers with healthy infants (number of children in family ranged 1-5) and the control group, with that of the study parents.

Table 6.2 shows that the study parents appear to be no more stressed than the mothers of infants (aged 2-12 months). Analysis of variance was again performed on the control, renal and diabetic data. There remained no significant differences either by medical condition (\(F=(2,200)=0.88, p=0.42\)) or by sex of the parent (\(F(1, 200)=1.50, p=0.22\)).

Table 6.2: PSS14 means and standard errors for first returns of questionnaires

<table>
<thead>
<tr>
<th>PSS14</th>
<th>(Walker, 1989)</th>
<th>Control</th>
<th>Renal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mothers</td>
<td>fathers</td>
<td>mothers</td>
<td>fathers</td>
</tr>
<tr>
<td>n=173</td>
<td>25.00</td>
<td>21.61</td>
<td>24.5</td>
<td>22.8</td>
</tr>
<tr>
<td>n=64</td>
<td>24.30</td>
<td>21.61</td>
<td>24.1</td>
<td></td>
</tr>
<tr>
<td>n=59</td>
<td>24.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=26</td>
<td>24.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=23</td>
<td>22.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=18</td>
<td>20.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>0.61</td>
<td>1.17</td>
<td>1.59</td>
<td>1.53</td>
</tr>
<tr>
<td>SE</td>
<td>1.11</td>
<td>1.65</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chapter Six 248
Hospital Anxiety and Depression Scale

Norm values were included in the literature which accompanied the questionnaires (≤7 = normal, >7 but <11 = borderline, and ≥11 = probable disorder). Comparative means and standard deviations were also sought from the literature, specifically for adults who were also parents. A parental control group of mothers (n=41) and fathers (n=25) was also obtained for the purpose of this study (Louch, 1994). The HADS provides separate constructs of Anxiety and Depression, and they will be discussed as such.

Anxiety means and standard deviations are shown in Table 6.3.

Table 6.3. HADS Anxiety means and standard errors for first returns of questionnaires

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Control</th>
<th>Renal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mothers</td>
<td>fathers</td>
<td>mothers</td>
</tr>
<tr>
<td></td>
<td>n=41</td>
<td>n=25</td>
<td>n=26</td>
</tr>
<tr>
<td>mean</td>
<td>7.44</td>
<td>4.56</td>
<td>9.69</td>
</tr>
<tr>
<td>SE</td>
<td>0.48</td>
<td>0.48</td>
<td>0.79</td>
</tr>
<tr>
<td>%borderline</td>
<td>24</td>
<td>12</td>
<td>19</td>
</tr>
<tr>
<td>%probable disorder</td>
<td>17</td>
<td>0</td>
<td>42</td>
</tr>
</tbody>
</table>

Analysis of variance was performed on the data. There were significant differences both by medical condition (F(2, 144)=3.91, p=0.002) and by sex of the parent (F(1, 144)=19.00, p<0.001). One-way analyses of variance with post hoc exploration of these findings showed that parents of children with ESRF had significantly higher anxiety scores compared to the control parents, and that mothers
had significantly higher anxiety scores than fathers.

Depression means and standard errors are shown in Table 6:4.

Table 6:4. HADS Depression means and standard errors for first returns of questionnaires

<table>
<thead>
<tr>
<th>Depression</th>
<th>Control</th>
<th>Renal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mothers</td>
<td>fathers</td>
<td>mothers</td>
</tr>
<tr>
<td></td>
<td>n=41</td>
<td>n=25</td>
<td>n=26</td>
</tr>
<tr>
<td>mean</td>
<td>3.68</td>
<td>3.24</td>
<td>5.58</td>
</tr>
<tr>
<td>SE</td>
<td>0.38</td>
<td>0.34</td>
<td>0.70</td>
</tr>
<tr>
<td>% borderline</td>
<td>10</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>% probable disorder</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
</tbody>
</table>

Two way analysis of variance was performed on the data. There were significant differences both by medical condition (F(2, 144)=5.33, p=0.006) but not by sex of the parent (F(1,144)=2.52, p=0.11). One-way analyses of variance with post hoc exploration of these findings showed that parents of children with ESRF had significantly higher depression scores compared to the control parents.

Discussion of normative and comparative data

The norm values for the perceived stress scale, obtained from Cohen and Williamson (1988), were considerably lower than those obtained either in the general population sample or in this current study. This could be for reasons such as cultural interpretation of the questions (Cohen's sample was American, the others are British). It could also be because of the much broader sample included in
Cohen and Williamson's study. They included adults of all ages, whereas parents in this study were from a much more narrow, younger, age band.

Cohen and Williamson report that PSS scores do decrease with age (age 18-29 mean PSS10=14.2, age 30-44 mean PSS10=13.0, compared to age 55-64 mean PSS10=11.9 and age 65+ mean PSS10=12.0). They also identify that having children in the household increases PSS10 scores too, and that as the number of children in the household increases so does the PSS score (no children mean PSS10=12.5, one child mean PSS10=13.4, compared to four or more children mean PSS10=15.1). This suggests that parenting increases perceived stress. They also identified lower income as increasing reported stress levels. These findings of Cohen and Williamson certainly go partway to providing an explanation for the difference of their published means for women and men generally, compared to those of the parents in this study.

When comparing the PSS14 values from a sample of mothers selected to test a theoretical model stress (and not due to any medical condition or poor health in the family), and those of the control group, with the study parents the means do not suggest that the self report stress levels of the study parents are any higher than other parents. This suggests that when comparing parents of sick children in any psychological measures it may be wiser to compare them to control parents rather than to an adult comparison.

Parenthood appears to have stresses of its own, regardless of a child being ill. In another study where the stress levels of mothers caring for a child with a chronic illness (cystic fibrosis) were compared to those of control mothers, again no significant difference was found (Walker et al., 1987).
Reported perceived stress levels showed no significant differences compared to the control families, however reporting of two common psychological sequelae of chronic stress, anxiety and depression, were found to be significantly higher for the parents with a child in renal failure. For the HADS, parents of children with renal failure were significantly more likely to report higher levels of both anxiety and depression. The overall increase in both anxiety and depression, not only above reported norms and cut-off points, but also against control parents is an important finding.

This suggests that there is possibly some increase in chronic stress levels but accompanied by a cognitive shift in the way stressors are appraised. This may occur as a defence mechanism in the parents of children with ESRF, and may involve a degree of denial regarding the pressures parents may feel they are under. It is also possible that they 'talk themselves' up as a coping strategy, focusing on the amount of time they can overcome stresses, rather than on the amount of times they encounter them. Strategies such as these can have beneficial results, especially in a situation where one has to cope, where there is no option to 'opt out' when the stress becomes too much. However these chronic stresses may still surface in less cognitive aspects of mental health, such as affect.

The higher report of stress, anxiety and depression levels for mothers over fathers within each medical condition is consistent with previous findings, although only anxiety reached significance. The HADS has the same cut-off point for both males and females, and so the significantly greater number of mothers who obtained either borderline or probable disorder scores is also unsurprising.
The two year study data

Due to the small number of respondents that replied on every occasion it was not possible to carry out trend analysis or any other longitudinal data analysis. For analysis of the data collected over the two year study it was necessary to calculate mean scores over the study for each subject. It is these mean scores that were used in the two year data analysis.

Parents were divided into high and low responders (see chapter 3, p92). Mann-Whitney U tests were carried out on these two groups, first for mothers and then for fathers using the mean scores over the study, to identify whether responders had a bias towards being those reporting a particular stress / anxiety / or depression state (either high or low). There were no significant differences.

Overall scores

Mean PSS10 scores for mothers and for fathers of children with ESRF, and with IDDM can be seen in table 6:5 below.

Table 6:5 Mean PSS10 scores over study

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers of children with ESRF</td>
<td>17.73</td>
<td>4.49</td>
</tr>
<tr>
<td>Fathers of children with ESRF</td>
<td>16.03</td>
<td>4.27</td>
</tr>
<tr>
<td>Mothers of children with IDDM</td>
<td>16.66</td>
<td>6.39</td>
</tr>
<tr>
<td>Fathers of children with IDDM</td>
<td>15.66</td>
<td>5.32</td>
</tr>
</tbody>
</table>

Two way analysis of variance revealed no significant differences between the PSS10 scores of parents of children with ESRF and of parents of children with IDDM (p=0.54, F(1,79)=0.38) or between mothers and fathers reported PSS10 scores (p=0.25, F(1,79)=1.36).
Mean HADS Anxiety scores for mothers and for fathers of children with ESRF, and with IDDM can be seen in table 6:6 below.

Table 6:6 Mean HADS Anxiety scores over study

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<thead>
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<td>Fathers of children with IDDM</td>
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Two way analysis of variance revealed significant differences between mothers and fathers anxiety scores (p=0.008, F(1,79)=7.42). There were no significant differences between the anxiety scores of parents of children with ESRF and of parents of children with IDDM (p=0.50, F(1,79)=0.46).

Mean HADS Depression scores for mothers and for fathers of children with ESRF, and with IDDM can be seen in table 6:7 below.

Table 6:7 Mean HADS Depression scores over study

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<td>Fathers of children with IDDM</td>
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Two way analysis of variance revealed no significant differences between the PSS10 scores of parents of children with ESRF and of parents of children with IDDM (p=0.49, F(1,79)=0.49) or between
mothers and fathers reported general information needs scores (p=0.31, F(1,79)=1.05).

**Time since diagnosis & age of child**

ANOVA's were carried out to identify whether the time since diagnosis had a significant effect on parents. A two way ANOVA was carried out with time since diagnosis, and age of child as factors. These were applied to first the mean stress scores over the study, then the mean anxiety scores and finally to the mean depression scores.

As the study was longitudinal it was necessary to use time since diagnosis at the centre point of the study (Time 4). As it was expected that any association would not be linear families were divided along quartiles to provide bands. The groups were as follow, those whose child had been diagnosed less than 22 months, those whose child had been diagnosed more than 22 months but less than 52 months, those whose child had been diagnosed more than 52 months but less than 69 months, and those whose child had been diagnosed more than 69 months.

The age of the child was also divided into bands as the literature suggests that certain developmental stages can give rise to differing depression scores (Walker et al., 1987). The age bands consisted of: children under five years; children over five but under 10 years; over 10 but under fourteen years; and over fourteen years old.

Significance of interactions could not be reported as not all carebands contained a child from each ageband. See Appendix E for a graph illustrating this point. Only one main effects was significant.
The mean depression scores of the renal mothers was significantly different dependent upon time since diagnosis ($F(3, 31)=5.70$, $p=0.007$). One-way analyses of variance with post-hoc exploration revealed that mothers whose child had been diagnosed for more than 22 months but less than 52 months were significantly more depressed (mean = 8.1), than those diagnosed less than 22 months (mean=4.4) or more than 69 months (mean = 3.7). There were no other significant results.

**Delivery of care**

Three way ANOVA's were carried out to examine whether the division of care for the child had any effect. Care was either provided by the mother mainly, or the mother and either the father, or the child themselves. The medical condition and the sex of the parent were also in the analysis. These were applied to first the stress scores, then the anxiety scores and finally to the depression scores. There were no significant interactions.

The only significant result was that anxiety scores were significantly different dependent upon who delivered the care ($F(1, 63)=4.46$, $p=0.04$), and upon the sex of the parent ($F(1, 63)=7.38$, $p=0.008$). Mothers had significantly higher anxiety scores, as in the normative sample. In those families where the mother was the main care giver then anxiety scores were higher - this was for both mothers and fathers in those families.

**Health indicators, and life changes**

Information was requested at the beginning of each questionnaire asking about events in the previous month. These included frequency of out-patient appointments, number of in-patient admission, number of out patient visits to the ward, number of
telephone calls to the specialist nurse, number of visits to the GP: for the child; self; or other household member, and any life event changes including housing/finances/support etc. Means for each subject were averaged over the study. As parents of the same child sometimes reported different rates of occurrence for these variables, results were analysed separately for mothers and fathers, each using their own reporting of these variables.

It was possible to investigate possible associations between the dependent variables and these health indicators and life events. A stepwise multiple linear regression analysis was carried out first for stress scores, then anxiety scores and then the depression scores. Mothers and fathers were investigated separately.

**Stress** - There were no significant associations for mothers or fathers of children with diabetes, or for fathers of children with renal failure nor all fathers combined.

**Mothers** of children with renal failure had a significant positive association between their stress scores and the number of times they went to the GP about their own health ($p=0.03$, $\beta=0.43$, $R^2=0.18$). This remained significant for all mothers combined ($p=0.03$, $\beta=0.32$, $R^2=0.10$).

**Anxiety** - There were no significant associations for mothers or fathers of children with diabetes.

**Mothers of children** with renal failure had a significant positive association between their anxiety scores and the number of times they went to the GP about their own health ($p=0.01$, $\beta=0.49$, $R^2=0.24$). However, when a partial correlation was carried out controlling for the stress scores, this association became non significant. Fathers of children with renal failure had a significant
positive association between their anxiety scores and the number of telephone calls to the specialist nurse \( (p=0.02, \beta=0.57, \text{R}^2=0.32) \). The were two variables with positive associations for all fathers combined, on step one \( (\text{R}^2=0.178) \) the number of telephone calls to the specialist nurse \( (p=0.01, \beta=0.68) \), and on step two (additional \( \text{R}^2=0.11) \) the number of times the child goes to the GP \( (p=0.04, \beta=-0.43) \).

**Depression** - There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, for mothers or fathers of children with renal failure, nor for all mothers or fathers combined.

**Independent variables associated with stress, anxiety or depression.**

The age of the child, highest parental education level, finance (poor, fair, good), highest parental occupation, number of children and age of parent were all put in to the regression equation, first for the stress scores, then the anxiety scores and finally to the depression scores.

**Stress** - There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, nor for mothers or fathers of children with renal failure. There were no significant variables for all mothers combined, however for all fathers combined there were two variables that were significantly associated with the self-report stress score. After step 2, \( \text{R}^2=0.41 \), and the two variables, Finance \( (p=0.009, \beta=-0.47) \) and Number of children \( (p=0.004, \beta=-0.52) \) had been entered. Better finances were associated with lower stress levels, as was having more children.
Anxiety - There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, for mothers or fathers of children with renal failure, nor for all mothers or fathers combined.

Depression - There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, nor for fathers of children with renal failure. However for mothers with renal failure, finance was significantly associated with the self-report depression score, $p=0.01$ ($\beta = -0.52$, $R^2 = 0.41$, $F(1, 23)=7.32$) Better finances were associated with lower depression levels. There were no significant variables for all fathers combined, however for all mothers combined finance remained significantly associated with the self-report stress score, $p=0.04$ ($\beta = -0.35$, $R^2 = 0.12$, $F(1, 35)=7.97$) Better finances remained associated with lower depression levels.

Dependent variables associated with the stress, anxiety and depression.

Stress - The mean general information score and the mean impact of illness score were put in to the regression equation for the stress scores. Life event changes were also entered in the analysis.

There were no variables entered at the 0.05 level for mothers or fathers of children with diabetes, for mothers or fathers of children with renal failure, nor for all mothers or fathers combined.

Anxiety - The mean general information score, the mean impact of illness score, the mean stress score, and the mean depression scores were put in to the regression equation for the stress scores. Life event changes were also entered in the analysis.
For mothers of children with renal failure the anxiety score was positively associated with the stress score, \( p=0.001 (\beta =0.62, R\text{ squared}=0.38, F(1, 23)=14.03) \). For fathers of children with renal failure the anxiety score was positively associated with the stress score, \( p=0.001 (\beta =0.72, R\text{ squared}=0.52, F(1, 15)=16.35) \). For mothers of children with diabetes the anxiety score was positively associated with two variables, on step one (\( R\text{ squared}=0.46 \)) the depression score (\( p=0.0004, \beta =0.68, F(1,21)=17.63 \)), and on step two (additional \( R\text{ squared}=0.124 \)) the stress score (\( p=0.02, \beta = 0.40, F(2, 20) \)). For fathers of children with diabetes the anxiety score was positively associated with the stress score, \( p=0.01 (\beta =0.61, R\text{ squared}=0.37, F(1, 14)=8.39) \).

**Depression** - The mean general information score, the mean impact of illness score, the mean stress score, and the mean anxiety scores were put in to the regression equation for the stress scores. Life event changes were also entered in the analysis.

For mothers with renal failure the depression score was positively associated with the stress score, \( p=0.006 (\beta =0.54, R\text{ squared}=0.29, F(1, 23)=9.23) \). For fathers with renal failure the depression score was positively associated with two variables, on step one (\( R\text{ squared}=0.59 \)) the stress score (\( p=0.0004, \beta =0.77, F(1, 15)=21.32 \)), and on step two (additional \( R\text{ squared}=0.12 \)) the life changes score (\( p=0.03, \beta = 0.35, F(2, 14)=17.10 \)). For mothers with diabetes the depression score was positively associated with the anxiety score, \( p=0.0004 (\beta =0.68, R\text{ squared}=0.46, F(1, 21)=17.63) \). For fathers with diabetes the depression score was positively associated with two variables, on step one (\( R\text{ squared}=0.38 \)) the stress score (\( p=0.0001, \beta =0.62, F(1, 14)=6.90 \)), and on step two (additional \( R\text{ squared}=0.11 \)) the mean information need score (\( p=0.02, \beta = 0.33, F(2, 13)=9.63 \)).
Discussion of two year study data

There were no significant differences in the mean reported stress, anxiety and depression levels between high and low responders. This suggests that stress, anxiety and depression levels were not significant factors in self selection of responders. Obviously it is not possible to make conclusive statements about the stress, anxiety or depression levels of non-responders.

Reasons for non return of questionnaires on one, more or all occasions could be due; to high levels of these measures, leading to someone feeling unable to carry out these extra tasks; or it could be because the parents feel perfectly at ease and cannot see the point in such research; or it could be due to a busy life. Without asking non-responders in detail it is difficult to say, and probably unwise to speculate.

Analysis of the means for stress, anxiety and depression over the two year study confirm the findings from the first return questionnaires, that is, there are no significant differences between the scores of the parents of children with ESRF and of the parents of children with IDDM. Anxiety scores also remain significantly higher for mothers than for fathers.

Differences in the practise of care-provision appear to have an impact on psychological well-being. In those families where the mother was reported as being the sole main care-provider, the anxiety levels of both mothers and fathers were reported to be significantly higher than in those families where the care was shared by mother and either the father, or the child themselves. This difference may occur for several reasons, some of which are influenced more by external factors than by the condition itself.
It could be that families where the father is required to work long, possibly unpredictable, hours find that it is difficult for the father to contribute equally. The work hours could also lead to increased anxiety. Mothers who have the sole care for the child may be more likely to become exhausted, and may display anxious behaviours. This may cause anxiety in the fathers, especially those not involved in care because they may either; not understand the burden being undertaken by their partner; be unable to deal with their partners’ anxious behaviour; feel helpless in the face of their partners’ difficulties, be unsure of the long- or short-term health status of their offspring.

If the division of care is due to external factors then the specialist health care team is unlikely to be able to make direct changes, however they may be able to increase resources available to sole-caring mothers, or to reduce the demands. They can also try to ensure the father is sufficiently informed about treatment and prognosis issues in the care of their child.

The results suggest that for the parents in this study several factors appear to influence, or be influenced by, levels of stress, anxiety or depression.

Stepwise regression revealed that stress levels were significantly positively associated with the number of times that mothers of children with ESRF attended their GP, for themselves. Renal parents were also found to be significantly more likely to visit the GP for themselves. As renal parents face greater demands than diabetic parents, and as mothers generally bear a greater share of the care (either as sole-carer, at best with shared care), it is probable that there are negative effects on the health of the renal mothers due to stress.
Whilst renal mothers do not report *significantly* higher stress levels, they do report higher levels than any other group investigated in this study. As discussed earlier there may be a cognitive shift away from acknowledging all the demands that parents have to face, but consequences of stress, such as poorer health (Carroll, 1992, p33-42) may still be experienced.

There was considerable evidence to support the argument that anxiety and depression can be sequelae of chronic stress. There was less evidence for the co-existence of anxiety and depression. The stepwise regression of the dependent variables demonstrated that the stress scores explained a significant amount of the variance in the anxiety levels of mothers (38%) and of fathers (52%) of children with renal failure, and of mothers (46%) and of fathers (37%) of children with IDDM.

Stepwise regression of the dependent variables also demonstrated that the stress scores could explain a significant amount of the variance in the depression levels of mothers (29%) and of fathers (58%) of children with renal failure, and of fathers (33%) of children with IDDM. This regular finding of significant amount of the variance in anxiety and depression scores being explained by the stress levels supports the suggestion that anxiety and depression are commonly found as consequences of chronic stress.

Anxiety and depression are possibly less susceptible to cognitive shift than self-report stress levels might be. So, despite the fact that stress, anxiety and depression scores are commonly correlated it may still be useful to measure all three of these responses, rather than just one.
Apart from the stress score, which explains 59% of the variance of the depression score of fathers of children with renal failure, the life event change score also explains a further, significant, 12% of the variance. This suggests that fathers of children with ESRF are vulnerable to the psychological effects of personal stressors when combined with the additional 'daily hassle' stressors associated with having a child with ESRF.

Stepwise regression demonstrated that the anxiety scores could explain a significant amount of the variance of the depression scores but only for the mothers of children with IDDM. These mothers did not have a significant association between depression and stress.

Stepwise regression also showed that the depression scores could explain a significant amount of the variance of the anxiety scores, again only for the mothers of children with IDDM. This evidence for co-existence of anxiety and depression is strengthened if simple bivariate correlations of the two measures are carried out, however this is statistically weak when so many variables need to be considered.

Separate stepwise regression using the independent variables demonstrated that perceived poor finance was the only other variable to explain a significant amount (12%) of the variance in the depression scores of the mothers of children with ESRF. This is not surprising as a poor financial situation, either in real terms or as an appraised resource, has been found to have a negative influence on mental as well as physical health (ref).

Other variables which explained significant amounts of variance in anxiety scores included number of visits to the GP for self, for the mothers of children with ESRF. However, as partial correlation
controlling for the stress scores negates any significant association, it should be considered that it is the relationship that both anxiety and self-referral to GP have to stress levels that causes this result.

The number of telephone calls to the specialist nurse is the only other variable to explain a significant amount of the variance in the anxiety scores of the fathers of children with ESRF. This is possibly due to the number of telephone calls increasing as the parents find themselves in situations where they are uncertain or concerned about the treatment or health of their child. That is, as parents become more anxious about the health of their child they are increasingly likely to call the renal nurse for advice or reassurance. It is probably the underlying health status of the child that therefore explains how the number of calls to the specialist nurse account for a significant amount of the renal fathers' anxiety score.

Apart from the stress score, which explains 33% of the variance of the depression score of fathers of children with IDDM, the mean general information need score also explains a further, significant, 27% of the variance. This could suggest that fathers of children with ESRF are vulnerable to the psychological effects of uncertainty and poor knowledge regarding their child's treatment, health status, and likely future consequences. Fathers of children with IDDM are not commonly seen attending the out-patient clinic with their child, and so it is probable that they receive most of their information second-hand, if at all. The long-term effect of this could be a feeling of low-esteem and a lack of confidence about their child's care and health.

Champion (1992) reports that low points in mood often occur when an experience threatens, or results in, loss of some valued idea object or person. Alternatively it may be that if the fathers of children with IDDM become depressed, that it is only at this point that they
may begin to acknowledge concerns and worries about the future for their child.
Individual families

Although statistical trend analysis was not able to be carried out on the two year data, it was possible to look at an individual's scores over the study. Plotting the data for individual families over the course of the study illustrates not only how information needs varied between individuals, but also for individuals over time. The plots for the same five families selected in chapter 4 are presented below.

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Family 114, with a young child (aged five years at Time 4) on overnight continuous cycling dialysis. At the beginning of the study the child has been on CCPD for two years and six months. There had been an (immediately) unsuccessful cadaveric transplant nine months prior to the study. There is an older sibling (aged seven years at Time 4). Father (aged 35 years at Time 4) is in full-time employment. Mother (aged 34 years at Time 4) is currently not employed outside the house. Care is shared by both parents. There are additional care burdens due to supplementary feeds and dressings to the gastrostomy button.

The mother has a 'normal' mean anxiety score, a 'borderline' depression score and a stress score which is within one standard deviation of the group mean. The father has low mean anxiety and mean depression scores, a stress score which is within one standard deviation of the group mean.

It can be seen that most of the parents' scores tend to oscillate around their mean, with the exception of an increase in maternal stress at time 3, and paternal anxiety at time 2. Whilst there is nothing in the child's renal history occurring around that time to cause such changes there are several things happening.

The family moved house (to a new area of town) between time 2 and time 3, and the child also had tonsillitis prior to time 2, and a severe ear infection around time 3. The mother's stress level continued to be high at time 4, and the only thing of note at that point was that the child had just recovered from the chickenpox.

It can be suggested that the house move increased the demands whilst reducing resources (it was noted that finances were worse) thus increasing stress for the mother. At this time there were also
rumours of redundancies at the fathers workplace which, though later turning out to be unfounded, are likely to have increased the fathers anxiety. These factors combined with repeated infection in the child with renal failure could be expected to increase anxiety and stress.

The child ceased dialysis between time 6 and time 7 due to repeated infection of the peritoneal drain site, but this appears to have no major psychological effects detected by the self-report measures.
Family 103

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Family 103, with an older child (aged 15 years and five months at Time 4) who received a transplant six years prior to the this study, and which was still functioning well. Peritoneal dialysis had been carried out for eight months prior to transplant. There are addition concerns in the family about the health of the child, who had a cerebral vascular accident around the time of transplant. She was taking medications, not only immunosuppression for her renal transplant, but also antihypertensives and thyroxine. There were two younger brothers (aged eight years at Time 4). Father (aged 45 years at Time 4) and mother (aged 43 years at Time 4) are in full-time employment. Mother is responsible for the care, in cooperation with the child herself.

There is a broad range of scores reported by the parents, especially the father. His anxiety score warrants 'probable disorder', but his depression score is 'normal'. His stress score is more than one standard deviation above the mean. The mother's anxiety score is within the 'borderline' range, but the depression score is low. The mean stress score is approximately one standard deviation above the group mean.

Around the beginning of the study the child had begun have seizures, and to suffer from headaches, and had to be admitted on one occasion. Throughout the study the fits and headaches were referred to by the parents (in the section of the questionnaires left for comments regarding their child's health). Between times 6 and 7 the child was diagnosed as having epilepsy, and commenced on anticonvulsants. At time 7 the mother reported that her daughter was much improved once on this therapy. At time 7 though, there are no decreased self-report scores to indicate, for example, relief. The father comments instead that the daughter was suffering from a
constant urine infection, usually considered as a possible threat to renal function when a graft kidney is *insitu*.

On 5 of the 7 questionnaires there were phone calls to the renal team noted, ranging from 2 calls to "a lot" (at time 7). The child was also a frequent visitor to the GP. Out-patient visits to the renal team were usually three monthly.

At time 3, in the life event section of the questionnaire, the mother reported that the health of her self, her partner and of the grandparents was worse, and she added that this was due to stress. At time 6, in the life event section of the questionnaire, the father reported that the health of his self, his partner and of the grandparents was worse, and he added that this was due to worry.
Family 131

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Family 131, with a young child (aged two years four months at Time 4) on overnight cycling dialysis. There is an older sibling (aged five years at Time 4). Father (aged 42 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is currently employed part-time outside the house. Care is shared by both parents. A successful transplant was carried out between times 5 and 6. There are additional care burdens due to supplementary feeds and dressings to the gastrostomy button.

The mother has a 'probable disorder' mean anxiety score, never reporting a 'normal' score, a 'normal' depression score and a stress score which is more than one standard deviation above the group mean. The father has 'probable disorder' mean anxiety, a 'normal' mean depression score, and a mean stress score which is more than two standard deviations higher than the group mean.

It can be seen that most of the parents' scores tend to fluctuate quite considerably, especially in the father's case.

At the beginning of the study their child was receiving hospital dialysis, overnight, twice weekly. This had commenced following an acute episode of Haemolytic Uraemic Syndrome following which the renal function had failed to completely recover. There was initial clinical uncertainty whether this would resolve or would develop into ESRF. Intermittent peritoneal dialysis was the treatment of choice for the first few months until long-term renal function could be ascertained. Unfortunately renal function never recovered to a degree suitable for life without renal replacement therapy.

Home cycling peritoneal dialysis, and supplementary feeds via a gastrostomy button were commenced between times 1 and 2.
father's stress levels decreased following this, possibly due to the cessation of previous uncertainty and to a greater degree of control now being restored to the family. Whilst home dialysis is disruptive, hospital overnight dialysis can disrupt the family even more so, especially when another child is at home requiring one parent to be there whilst the other attends the hospital. Vacations abroad, prior to times 3 and 6 appear to have a beneficial effect.

Around time 4 the father was under tremendous pressure at work. There was a major reorganisation of workload and expectations, which resulted in the father reporting a large increase in stress, anxiety and depression levels. Speaking to him at this time it was obvious that work was the major contributor to these feelings, yet the care of his daughter also demanded his energies, despite the mother trying to take on more of the care at this time. Once this critical period had passed at work his stress, anxiety and depression returned to previous levels.

A successful cadaveric transplant was carried out between times 5 and 6. At time 7 though, there are no decreased scores indicating, for example, relief.
Chapter Six

### Table

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<tr>
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<td>mother stress</td>
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<td>22</td>
<td>42</td>
<td>20</td>
</tr>
<tr>
<td>anxiety</td>
<td>9.60</td>
<td>3</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>depression</td>
<td>7.40</td>
<td>3</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>father stress</td>
<td>24.50</td>
<td>19</td>
<td>28</td>
<td>9</td>
</tr>
<tr>
<td>anxiety</td>
<td>5.25</td>
<td>4</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>depression</td>
<td>3.50</td>
<td>1</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>
Family 134, with a child, aged 11 years and four months at Time 4, on overnight cycling dialysis commencing just before time 3. There is a younger sibling, with no health problems. Father (aged 41 years at Time 4) is in full-time employment. Mother (aged 41 years at Time 4) is not employed outside the house. Care is shared by both parents. A successful transplant was carried out between times 6 and 7. There are additional care burdens due to poor appetite and oral supplements, until transplant. There are also developmental and behavioural problems, and a history of epilepsy.

The mother has a 'probable disorder' mean anxiety score, reporting a wide range of scores over the study, a 'borderline' depression score and a stress score which is more than two standard deviations above the group mean. The father has 'normal' mean anxiety, a 'normal' mean depression score, and a mean stress score which is more than one standard deviation higher than the group mean. It can be seen that most of the parents' scores tend to fluctuate quite considerably.

Dialysis was commenced one month prior to time 3, following a slow gradual decrease in kidney function. The parents had been aware of a renal problem since their daughter's first year of life. The mother reported poor health for herself at time 3, due to stress, the father reported poor health due to flu. There was no indication of a renal problem that might have caused the father's depression and anxiety scores to rise at time 4. It is probable that the mother was adjusting and learning to cope with dialysis by time 4. The daughter was reported as suffering from increased frequency of seizures around time 5.

A successful cadaveric transplant was carried out between times 6 and 7. The parents reported this as having transformed their daughter's health, and increased her appetite.
Family 120

120 | mean | lowest | highest | range
---|------|--------|---------|------
mother stress | 24.83 | 14 | 32 | 18
anxiety | 6.67 | 3 | 10 | 8
depression | 0.67 | 0 | 3 | 3
Family 120, with a child (aged seven years at Time 4) on overnight cycling dialysis, commencing six months prior to the start of the study. There is a younger sibling. Father (aged 44 years at Time 4) is in full-time employment. Mother (aged 35 years at Time 4) is not employed outside the house. Care is mainly delivered by the mother. A successful transplant was carried out between times 1 and 2.

The mother has a 'normal' mean anxiety score, a low depression score and a stress score which is more than one standard deviation above the group mean. The father did not take part in the study.

It can be seen that there are fluctuations around the mother's own mean anxiety and stress scores during the study.

There are quite large changes in the anxiety scores following the transplant, though it is impossible to say whether there is any connection. There were a few minor rejection episodes in the early stages, which are very common. Times 2 and especially 5 show decreases in the reported stress levels which may reflect the fact that most families had their annual summer vacation prior to this.
Qualitative data

Transcripts revealed that it was uncommon for discussion during the parents support group to become focused on emotional aspects of coping with the child’s illness. The majority of the meetings did however highlight stressors that parents were encountering in their daily lives, especially those associated with the chronic renal failure.

Analysing the transcripts showed that the parents identification of stressors contained a high degree of consonance. The stressors also fitted the categories identified by McCubbin and McCubbin (1993). Quotes from the transcripts will be arranged using their six categories.

Comments may be included from parents of the families in the individual plots. To better preserve anonymity each family is again identified by the same single letter as in Chapter 4, rather than the original number code.

The illness and related hardships over time.

".. doing blood tests which she (the child), which causes her and us more distress than anything else I can think of" [familyE]

> Mechanical difficulties often occurred, with both dialysis machines, and feeding pumps and generally overnight.

"It broke down just before the end. 29 nights out of 40 and after that 40 nights on and 5 nights off I think it worked 3 nights. It used to alarm between 12 and 14 times a night, every night. Nothing wrong with the patient at all, it was the machine"[family B]
The difficulties and stress involved in trying to feed anorexic children, especially younger ones, was a repeated theme.

"You know you are putting them through that distress, why should you force feed them 840 mls a day if they don't want it" [family A]

"It doesn't matter how you do it you get it in, and they we were force feeding in every way possible" [family D talking of several years earlier]

"You can cut the stress with a knife when you walk in the door. Terrible. It's stressful for the parents, it's stressful for the child" [unidentified]

"She (mother) didn't really have to feed him for lunch then and then when I came home she used to say 'He's yours' and she would walk out of the room" [father G]

"If he doesn't do it (vomit) in the cot you just get him nicely dressed and just before you go out then that's it" [family A]

> Having to carry out daily care or dealing with an acute illness episode could cause employment problems

"Did it [CAPD] mean you couldn't work during the day?" "Yes I couldn't have a job, but I worked part-time in a restaurant and I only did night times" [mother C]

"..when I get back to work...long time off I daren't have any more when I get back you see...she says if it don't work this time you'll have to pack it up, ..that's easier said than done, packing work up, got bills coming in and all that" [family F]

"Unless you've got an exceptionally good employer they don't understand" [family D]
As well as threat to earnings there are expenses to be met

"I remember being very surprised when we totted up how much we'd spent, to realise we're talking about hundreds of pounds" [familyE, regarding travel costs]

the child's reaction to the treatment has its own effect upon the parents too

"...but some of the questions she (the child) throws at me now nearly scares the pants off me... it just scares me at times, I don't know how to start answering...and she's asking how long it's (successfully transplanted kidney) going to last and will I have another one, and you say you've just had the transplant" [family D]

"...and the fear of the first time (child) says something like 'why are other kids different?'; 'why hasn't my best friend got a machine in her room?' that..." [family E]

"...she doesn't want to be different to other kids you know..she says 'I just want to be normal mum' " [family L]

Schooling, and ensuring the child received as good and normal an education as possible was an issue that parents became very concerned about

"We had a headmistress in the infants, and she was the nursery, and if she'd had her own way (child) would have been put in a special school" [family C]

"...and I had to pay for the school doctor to see if he could go to the nursery...it annoys me because over and over again you have to have (child) assessed..why, just because he's smaller and he's got these problems, why do we have to keep battling all of the time?"
"..because the heat had gone, you know all the other children were there, but (child)'d got poorly kidneys as she (the headmistress) used to say so he can't possibly come because the schools's too cold and he was always pulled out as different." [family C]

"and she is behind, so we're having problems with schooling in that way" [family D]

"I mean we're going to meet this before long, because we want (child) to go to nursery and so on, in the way (older sibling) did" [family E]

> Siblings can have difficulties adapting sometimes

"..he's (the sibling) kind of reacting now..he's very awkward, you could see it because of the effect of...for I say the first three or four years of her life...cos he missed out, he was only two when she was born, that's the age they need a lot of (indistinguishable)" [family K]

"..because they're attention seeking, this is the one thing we've come up with (sibling)..possibly, its a way of, well look I can be ill too sort of thing, and they lay it on a bit thick" [family B]

Normative transitions.

Most of the developmental changes of childhood bring their own challenges, but parents reported it was especially so with toddlers and early adolescents.

"..he's getting to the stage where, like (another child) he's pulling things, and you know he's pulling the feed off and allsorts" [family A]
"...she's got to an age where body image is really important" [family L]

Prior family strains accumulated over time.

Most of the parents support group discussion sessions focused on illness-related issues, rather than on a broader look at life. However, over lunch, or during coffee at clinic visits other family issues were often discussed. The families had many of the same life stressors as other families. During this study several families moved home, had a family member change job, had a further child, and so forth.

"with the wife being, the wife's disabled, severely disabled as well, and it's very awkward"

"I was actually in the processes of changing my job...so we had nowhere to live...and there I was trying to get some work, living at the mother-in-laws..horrendous" [familyK]

Situational demands and contextual difficulties.

"At that point we didn't know if we were doing the right thing or whether we should just let him die" [family A, reflecting on when their child had been a sick neonate with no kidney function]

"What we found quite difficult was waiting a year to know when she would be going on dialysis" [family D]

"He nearly died within the first day.......nobody to discuss it with.......should he live or should he die?.......So we decided to go back to the other hospital and let him die, but he didn't" [familyG]

"...because I am anxious, I'm really worried about the transplant..there's no guarantees in a transplant what is going to
happen" [family B, concerned about going on the transplant list]

"...the apparent lack of liaison between paediatric renal and adult renal...we've heard such horror stories to be honest with you about the atmosphere in the adult wing" [family E, concerned about the future transfer of their child]

Consequences of family efforts to cope.

- Trying to give the best care and support to a child who is in hospital often caused both emotional and practical difficulties, especially when other children are still at home.

"...when I want to go home to the others it really upsets me, I have to split myself like you do, to back to them, particularly the age they are now. Some of them (the nursing staff) just do not understand that" [family D]

"I don't think they (the nursing staff) seem to appreciate that there is also a family at home that are calling for attention" [family D]

"...and we hadn't been able to come in, for one reason or another, so I rang in and said 'we're not coming in - how is he?' 'Well he hasn't seen you all day I think you ought to come in and see him'.....I don't know who they think they are...I felt quite guilty about it" [family B]

"I felt really guilty...perhaps they don't realise that made us feel very guilty" [unidentified]

"(wife) was off work, we're both working, and lived here at the hospital with (child), when I was at home carried on with my job and looking after (other child) who's just turned five, then we sort of came to our senses about christmas time and we both moved in here" [family E]
"the length of time that you're on it (dialysis) and you don't know when it's going to end" [family B]

"the way I deal with stress...I needed to get out (of the hospital) cos (husband) wasn't there, I suppose some of the time and I find to get out of the hospital but when I came back to the comments I got off the staff...more stressed when I came back than when I'd gone out feeling!" [family D]

Intrafamily and social ambiguity.

"I think this is the problem though, ignorance of those who don't know" [unidentified, referring to parents of children with less serious conditions]

"I find it quite distressing at school...it's not as if they (teachers) don't accept it, they don't understand it" [family D]

"It's just hard I mean, like I say, he's not on dialysis at home but you think nobody likes, to leave him with anybody you know what I mean?" [family F]

"..This isn't just since dialysis, this is from birth. I've got one sister that won't take him, I've another one that is she's had him for an hour she'll bring him back you know" [family C]

"well, even your own family shuts off" [family H]

"well we haven't even close friends up to (child)'s bedroom and you can talk about dialysis and feeding and you explain why she doesn't eat, but unless they actually see the use of the machine and so on, I don't see how people can possibly understand what it actually means" [family E]

"..they (family) are more willing to take (child) now he's had a transplant, than what they was before" [family B].
Discussion

Renal parents report higher stress levels than do the comparison groups. The parents from the community sample also had results higher than would be expected from the norm values (Cohen and Williamson, 1988). Comparison with other parents' PSS scores were also of similar levels to those found in this study. This suggests either that the PSS is more sensitive to the particular demands that parents may be under, compared to other non-parenting adults, or that parents are subjected to more stress than other adults. It would therefore be prudent to try and gather parental control groups, or obtain parents' norms when drawing conclusions from standardised questionnaire results of parents caring for a chronically ill child.

The parents' self report levels of anxiety and depression did however highlight significantly higher levels of anxiety and depression in parents of children with renal failure compared to the levels reported by those parents obtained as a comparison group from the community. From these results one can conclude that it is probably the caring for the sick child that is responsible for the increased anxiety and depression levels.

Depression and anxiety can be considered to be sequelae of chronic stress. This argument is supported by the finding that stress scores of parents are responsible for a significant amount of the variance in both their mean depression and mean anxiety levels. Whilst the measures are highly correlated they do not measure the same construct, and so it is the differences between them that may need to be examined.

Stress, anxiety and depression all have a cognitive aspect to them, but in anxiety and depression this is less so, with affect being the
prime component. Chronic stress may become the norm for an individual and so demands may be appraised as manageable at a conscious level, with perhaps a recognition of the true burden at a deeper, less cognitively demanding level. It may also be that parents consciously take a more positive view of the demands upon them, choosing to concentrate on how much they have achieved, rather than on how much there is left to achieve.

Emotional responses such as depression and anxiety may seem less threatening or may be less under the control of individuals. This might explain why parents of children with ESRF report stress levels which, though higher, are not significantly greater than those of a comparison group of parents drawn from the community, yet report significantly higher anxiety and depression levels than those of a comparison group of parents drawn from the community.

For all groups studied, the stress, anxiety and depression levels were higher for the mothers than for the fathers. This is consistent with findings in the literature. Whether this is as a result of mothers actually experiencing more stress, anxiety and depression or whether it is a result of women being more willing to admit to the symptoms is debateable. The gender differences are present in the norm values for PSS, but the HADS fails to distinguish between 'normal' scores for men and for women. It is however a point to consider when drawing comparisons between groups of people.

If conclusions wish to be drawn about whether, for example, mothers of chronically ill children have higher anxiety and depression scores than would be expected otherwise, then women should be compare to other women (preferably other mothers), not to men, or to a mixed group of adults.
The reported stress, anxiety and depression levels for parents of children with IDDM were not significantly different from either the comparison group of parents drawn from the community, or from the parents of children with ESRF. Their mean scores tended to fall between the two other groups.

In terms of demands it could be argued that caring for a child with diabetes is more demanding than caring for a child with no illness at all, yet less demanding than caring for a child with ESRF. Certainly the results discussed in Chapter Four indicate that children with ESRF attended out-patients significantly more often, and were also admitted as in-patients significantly more often. Parents of children with ESRF also made significantly more telephone calls to the specialist nurse than did the parents of children with IDDM. These results would be consistent with the hypothesis that caring for a child with ESRF is more demanding on the parents.

An increase in demands might be expected to affect stress, and/or anxiety and depression levels, and when care is delivered primarily by only one parent it could be predicted that the individuals would be negatively affected. This was the case for anxiety levels of mothers when they are primarily the sole care-givers, but what also emerged was that the fathers in these families also had significantly higher anxiety levels. From the information available to the study there was little to indicate possible causes of this.

It may be that mothers tend primarily to be the sole care-givers only when fathers are already overburdened by other factors, such as a stressful job. It may be that 'anxious couples' prefer to organise their domestic workload along more strict divisions than other 'less anxious couples'. Whatever the cause it may be useful to health care professionals to pay extra attention to the psychological well-being
of parents where the mother is primarily the sole care-giver. Close liaison with the family doctor can also be a useful tool in identifying parents who are feeling stressed or anxious.

Whilst not lending themselves to inferential statistics, the individual plots demonstrate the great range of self-report scores both between and within individuals. They also show that it can be difficult to identify a specific emotional response to treatment changes, even when as dramatic as the change from dialysis to transplant. There is no simple model of a relationship between stress, anxiety or depression with life events or treatment changes, that can explain all the results to be seen on the individual plots. However when individuals are monitored over time, large fluctuations away from their own mean may help health care workers who know the family circumstances to be more aware of the psychological status of the parents.

Whilst the individual family plots illustrate the large fluctuations in reported stress, anxiety and depression levels that parents experienced, a cause could not always be directly attributed. On occasions there could be a definite contributing factor identified (but not always), and these included outside influences such as pressures of employment outside the home, or moving home.

The individual family plots, combined with the qualitative data from the parents support group transcripts, illustrate very clearly that parents of children with ESRF are subjected to many stressors. Stressors came both from what Lazarus and Cohen (1977) called 'daily hassles' and from 'personal stressors'. Many daily hassles were identified as being involved in the care of their child, hassles considered to be above and beyond those experienced by parents of healthy children.
Finally the qualitative data available from the transcripts of the parents support group provides a valuable insight into the stresses facing the parents caring for a child with ESRF. It is hoped that the parents' comments and statements contribute an additional dimension to the understanding of their concerns and of the burden of care that they are required to shoulder.
Chapter Seven

Discussion

The findings of the study

As identified in previous literature and discussed in Chapters One and Two the process of caring for a child with a chronic illness creates extra demands on the parents. These extra demands may be expected to have a greater effect as the severity of the illness increases (Westbom, 1992). The results of this study support this hypothesis.

Basic measures such as increased frequency of out-patient appointment, number of in-patient admissions and number of telephone calls to the specialist nurses indicate that there are higher demands faced by parents of children with renal failure than faced by parents of children with diabetes. These findings suggest a greater degree of surveillance is required by the parents, something usually associated with a more unstable, less predictable, and perhaps more serious condition. Indeed the impact of illness score is significantly associated with the frequency of out patient appointments.

Further evidence suggests that not only are there increased demands in ESRF, but that the restrictions on the life of the child and the family are perceived to be greater by parents of children with ESRF than by those of children with IDDM.

When the daily life of a child is restricted this has direct effects upon the parents. If a child is too unwell to attend school, or needs to attend an out-patient appointment, then a parent (or other adult)
will be required to be with the child. When these occurrences become more and more frequent the parents may need to make alterations to their schedules. This in turn places limitations on the organisation of their own time as well as having implications for the parents' employment opportunities.

Mothers of children with ESRF note greater restrictions on their child's activities, and age appropriate behaviours than do mothers of children with IDDM, whilst the fathers of children with ESRF note greater restrictions on their own activities than do fathers of children with IDDM. This last finding is not unexpected when one considers the greater care burden on the parents, and how fathers are formally and actively recommended to be involved in the care of children with ESRF.

The results indicate no significant difference in how mothers and fathers report the impact of illness within each condition. Both parents appear to rate the restrictions on the child and family life to a similar degree. However there are differences between medical conditions, with both mothers and fathers of children with ESRF noting increased interference with education of the child.

The impact on the education of the child is perceived to be much greater by the parents of children with ESRF and this finding is important for several reasons. Restrictions on daily activities such as school indicate the limitations that disease symptoms and treatments can impose. As discussed in Chapter Four (p102-104) education is important not only for formal education but also for the establishing and maintaining of peer relationships. Previously school performance has been noted to be poorer in children with ESRF (Rosenkrantz et al., 1992; Hulstijn-Dirkmaat and Damhuis, 1994; Lawry et al., 1994) and this will continue to be a problem.
whilst there is such a high level of interference with the education of these children.

Problems with education, especially enforced absenteeism, can create feelings of isolation and low-esteem. Low-esteem is already reported to be a problem for some adult survivors of ESRF, and is often attributed to the short stature of these adults, however it may be that the effect of illness on education is also partly responsible.

The treatment delivered to the child in ESRF is reported to have an effect on parental demands and psychological well-being. It is common for dialysis therapy to be reported as more stressful than a successful transplant. What this longitudinal study has been able to show is that there is most impact when there is a treatment change from dialysis to transplant. What this reveals is that whilst transplant therapy may have less impact and restrictions than dialysis this may only be the case once it is established. It appears that rather than reducing the limitations on the child and family it may be that in many cases a new transplant is actually more limiting in the early stages.

Members of the paediatric renal team might need to forewarn parents of this change, as many parents may not realise that although a successful transplant does provide the child with a much more 'normal' life with less restrictions than does dialysis, this benefit may not be immediate.

Theories of stress by Lazarus suggest that as demands rise so does the need for resources to deal with those demands (Lazarus, 1966, 1976; Lazarus and Folkman, 1984). A finding of this study that lends support to this argument is the positive association between reported information needs and impact of illness. Seeking
information is a recognised coping strategy for parents caring for chronically ill children (Shapiro, 1983; Jennings, 1992).

It would be expected that as parents of children with ESRF appear to have greater demands upon them then their information needs would be higher. This was not found to be the case. However a trend was identified whereby the information needs of parents gradually declined over the study. It is probable that this was caused by the active programme of parent information provision that was being followed by the paediatric renal team. This suggests that such an association may not be as strong in parents whose children are cared for by units where a concerted programme of information provision is established.

It is probable that once information has been received about management of treatments, parents will continue to ask questions and want information about their child's future. The discussions from the parents' support group indicate that parents continually seek information to help reassure themselves about their decisions regarding the child's treatment, about the best education options for their child, and about their child's future.

Many of the questions that parents reported they needed most information about were those to which there is no definitive answer. Instead they are questions for which advice may be given and different opinions and hopes expressed. The same three questions were the highest scoring by parents of children with four different medical conditions (see page 186). This is support for the argument that suggests the issues that need to be dealt with by parents of chronically ill children are often very similar regardless of the medical condition (Stein and Jones Jessop, 1989; Shute and Paton, 1992; Canam, 1993).
Whilst there are similarities between the information needs of parents of children with differing medical conditions, there are also some differences within the study groups that are important to mention. Contrary to the findings of Henley and Hill (1990) this study did not find that the information needs of fathers were higher than those of mothers. However this study was in accordance with the findings of Henley and Hill that parents in occupations which are classified as lower socioeconomic status reported higher information needs than parents with higher rated occupations.

These two findings may reflect several different aspects of information provision. One could suggest that perhaps all parents are given the same amount and type of information, but that those with lower socioeconomic status have higher needs. There is no evidence available in this study to either support or argue against this. Another possible explanation is that there is disparity in the amount and type of information provided to different groups of parents. Again there is no evidence available in the study to either support or argue against this.

Multiple factors are involved in information provision, many of which have no yet been subjected to objective scrutiny. Previous research on communication suggests that health care professionals, even when following a checklist of information to be given, will be inconsistent in the amount and type of information provided.

Factors which influence doctor-patient communication have been examined in detail elsewhere (Hooper et al., 1982; Pantell et al., 1982; Waitzkin, 1985; Street, 1991, 1992). The findings suggest that the characteristics of the person the doctor is communicating with can have significant influence upon the doctor's communication style. As communication style includes the amount or type of information
provided this is highly indicative that there will be discrepancies in
the information provision between some groups of parents. The
second explanation suggested for the findings of unequal
information needs therefore seems most likely ie. that there is
disparity in the amount and type of information provided to
different groups of parents.

Considering the demands shown to be on the parents caring for
children with ESRF, the perceived impact of the illness on the child's
and family's lives, and the level of further information that parents
report they require, it is not surprising that psychological well-being
of these parents is reported to be poorer than that of other parents.
Stress is thought to occur when the demands rise above the
resources available to deal with those demands (Lazarus, 1966,

The measuring of not only stress but also anxiety and depression
permitted an opportunity to investigate the psychological well-
being more extensively than one measure alone would allow.

In this study mothers reported scores indicative of poorer
psychological well-being than did fathers. Mothers had scores
which indicated they were significantly more depressed and
anxious than were fathers. They also had higher stress scores,
though not significantly so. These findings are consistent with
previous studies using such self-report measures where females are
consistently found to have scores indicative of poorer psychological
well-being. There are two possible explanations given for this
finding, the first is that women actually do have higher levels of
stress, anxiety and depression. The second is that women are more
willing to admit to symptoms indicative of stress, anxiety and
depression, their actual levels of stress, anxiety and depression are
not necessarily worse than those of men.

Because the literature indicates that females *consistently* have scores indicative of poorer psychological well-being than those of men, it is possible to conclude that the finding in this study is not a specific effect of caring for chronically ill children. More telling however are the results indicating that parents caring for children with ESRF have poorer psychological well-being than other parents.

Parents of children with ESRF have significantly higher self report levels of anxiety and depression than the general sample population sample of parents. They also had higher levels of stress although these were not significantly different when statistical analysis was carried out.

Parents of children with IDDM had lower levels of stress, anxiety and depression than parents of ESRF, but higher levels than the general sample population sample of parents. This suggests once more that the severity of the illness is an important factor to consider when looking at the effects of parenting a child with a chronic illness. In the context of this study severity of illness is not assessed but it is the opinion of the author that ESRF is more severe than IDDM.

End stage renal failure may be considered to be more severe primarily because there is increased likelihood of premature death, there is greater need for risky procedures such as surgery, the medications used have more severe side-effects, parents may be required to carry out several hours of specific illness-related care daily if on dialysis therapy and it is possible for renal replacement therapies to become nonviable, in which case death will follow. For all these reasons plus many others, such as the child’s anorexia and
possible growth failure, ESRF might be defined as more severe than IDDM.

Stress levels are not reported to be significantly different between the groups of parents assessed, but anxiety and depression levels are. However stress scores account for a considerable amount of the variance for both the anxiety and depression scores. It is not advisable to dismiss the fact that stress scores of parents of children with ESRF are higher than those of other parents simply because the differences do reach a statistically significant level. The stress scores explaining a considerable amount of the variance for both the anxiety and the depression scores is consistent with previous studies which identify anxiety and depression as psychological sequelae to chronic stress.

It may be that in order to cope with the ongoing nature of the stress parents need to employ cognitive strategies which enable them to perceive the demands differently. Parents have many difficulties to face and tasks to carry out when caring for a child with ESRF. For parents that are managing to deliver the care there is a corollary to that statement, which is these parents are achieving something both challenging and worth while. Parents may develop a cognitive shift in order to concentrate on positive aspects of their situation, such as their achievements and their rôle of capable parent.

Cognitive strategies can be effective as methods of reducing perceptions of stress, yet the demands may still take their toll. Emotional responses to chronic stress such as depression and anxiety may still develop. These emotional responses are less open to cognitive restructuring than is stress, and this is a possible reason for the increased significance in the differences in anxiety and depression reported between parent groups.
**Study design**

The suitability of the methods and tools used in this study are reviewed, in particular the approach which resulted in a two year study of both mothers and fathers and use of both qualitative and quantitative data.

**Methods of data collection used in the study**

The combination of quantitative and qualitative data has permitted a comprehensive investigation into the effects on parents when caring for a child with ESRF. The quantitative data alone cannot convey the personal experiences of the parents, even when used to plot the scores of individuals over time. It is the qualitative data that permits an insight into what the parents have to cope with, and also some of the techniques that parents employed to make that coping possible. The transcripts are rich in information, and have been used to illustrate and expand upon the quantitative data. The qualitative data is intended to assist the reader to reconstruct the numerical analysis from questionnaire sources into meaningful knowledge.

The self-report measures used to gain the quantitative data were found to be effective in some ways, although not perfect. Once data analysis had begun it became apparent that measures could have been more effectively designed. For the PSS and the HADS the measures were used exactly as published, and these measures were not problematic. This however had not been the case for the impact of illness questionnaire and for the information needs questionnaire. In their original form these two measures were disease specific.

It had been decided to adapt the impact of illness questionnaire and the information needs questionnaire to fit ESRF and to IDDM. This
adaptation had included exchanging disease specific questions for other disease specific questions. In analysis though these questions were not able to be usefully analysed as they were conspicuously not comparable. In a comparative study it might have been more prudent to include only general questions that could be asked of all participating parents.

The impact of illness questionnaire and the information needs questionnaire also had other shortcomings. For the impact of illness questions it would have been useful to also assess how problematic the restrictions were perceived to be. This would have given greater meaning to the impact of illness data. For the information needs questionnaire it would have been useful to measure if parents thought they were getting too much information on any topics. It might also have been more telling if the questionnaire had asked about how important considered the information to be. This would indicate the priorities regarding which information parents thought should be given, rather than that they simply would like to be given.

Collecting data from both parents

Fathers are involved in health-related care of their children. Previous studies have shown that when both parents are included in studies their responses are often different to each other. To solely approach mothers for this study would have added to the body of health research that disregards the important rôle that fathers have within the family. Fathers did not respond as frequently as mothers yet 58% (n=36) of fathers did complete and return a questionnaire during the study.

Several important differences were identified such as fathers of children with ESRF having significantly higher anxiety and
depression scores than fathers in the general population sample. Without their inclusion in the study it would only have been possible to identify how mothers were affected.

The response rate

The self-report method of data collection proved practical, however it was possibly not the most effective way to reduce attrition. Postal questionnaires tend not to produce high response rates, as subjects are able to discard them or forget to complete them with less misgivings than they may have about refusing an interview that had been arranged. The low response rate does invite concern regarding whether those who did respond were representative of the sample as a whole. It is difficult to be assess this, however it is possible to look at the high and low respondents to see how they compare.

Fathers responded less frequently than mothers. No socioeconomic information showed significant differences between high and low responders (see Appendix K). Fathers who were classified as high responders were attending their GP significantly more frequently than those fathers who were classified as low responders. Fathers who were classified as high responders also had a study child who was attending their GP significantly more frequently than those children of fathers who were classified as low responders.

Few other factors could be identified which were significantly different for high and low responders. Mean impact of illness score was not significantly different between high and low responders, nor were stress, anxiety or depression scores. Mean information need score was not significantly different between high and low responders for mothers or fathers of children with ESRF, nor for fathers of children with IDDM. It was however significant for
mothers of children with IDDM. Those mothers classified as high responders had significantly lower information scores.

This result might indicate that information needs are underestimated in this study. One possible explanation for this is that mothers who are more proactive about the issues surrounding the care of their child are more likely to respond to the questionnaires, and they are also more likely to have sought out the information they require. If this is the case these mothers may be more likely to ask the health care professionals about their concerns, and thus have lower information needs.

Overall it can be considered that there are few important differences between the high and low responders. This still does not allow conclusions to be drawn about the non-responders, nor however does it support concerns regarding the nonresponders.

**A longitudinal study**

Whilst the ideal would have been 100% response from all parents this was not expected, and predictably was not obtained. The response rates over the study were too poor to make longitudinal data analysis from the panel design study possible.

This was a loss to the study, however it was still beneficial to carry out the two year study. More parents responded than would have done had the questionnaires only been sent out once. Also the individual plots illustrate the range of scores that an individual can produce, dependent upon not only illness related factors but also to other external ones.

It was possible to identify that treatment change increases the reported impact of illness. The information needs of parents of
children with ESRF could also be shown to decrease over the two year study. This was encouraging to the health care professionals involved in the provision of the active attempt to provide the information that the parents required.
Clinical implications

There may be clinical implications from some of the results, and these are outlined below.

☐ Times of treatment change are likely to be those which cause the greatest impact on the child and family. The health care team can use this finding to continue to target their support resources at this time.

☐ If parents are employing cognitive strategies to reconstruct their situation in order to reduce unpleasant feelings of stress then parents may not always be best placed to identify when burn-out is a risk. It may only be when the emotional consequences become so severe that parents recognise the burden of care is more than they can manage. This has implications for the clinical team, who need to be monitoring the health status, both mental and physical, of the parents. Such monitoring may not be of a formal nature, but rather via regular contacts with the parents even when care is stable and not requiring frequent visits to the hospital.

☐ It has been seen that parents undergoing higher levels of stress are attending their GP's more often. Close links between the specialist renal team and the family doctor are to be encouraged, and not only for communication of information about the child's health and treatment. GP's are ideally placed to help identify those parents exhibiting more stress-related illnesses, and to help the specialist team recognise potential signs of 'burn-out'.
School absence should be reduced whenever possible as ESRF symptoms and treatments are reported to be causing the education of the children to suffer. As discussed earlier schooling is of great educational and social benefit. Treatments are already organised so that school is affected less than it might be if the children were on hospital dialysis however it remains a problem.

Parents want to know about the possibilities in their children's future. Some questions may not be easily answered, others more so. For example for parents of children with IDDM the future fertility of the child is an issue that can be discussed with a degree of confidence, as when most are young adults there will be at no greater risk of infertility than for other young adults. However this is not necessarily true for children with ERSF.

Information can be provided to address some of the issues revealed by the information needs questionnaire and the parents support group transcripts. Following this study the researcher drafted simple leaflets addressing issues such as children's future fertility. These leaflets were then handed to the multidisciplinary team for completion and expansion. These leaflets are now available locally in clinic and nationally from the British Kidney Patient Association (see Appendix L).

Information may need to be actively targeted at parents with lower socioeconomic status. It may be that these parents need active encouragement to ask questions, and to participate in the consultation more.
Further research

There needs to be more research on the information provided to parents caring for chronically ill children. Specific issues to be addressed include by whom, and by what processes the type and amount of information provision is decided.

Also as this study supports the finding of Henley and Hill (1990) that there are discrepancies in the information needs between some groups of parents, research could identify possible causes of those discrepancies. It is unfortunate that there is so little research on the assessment of parental information needs, especially into effect of education and socioeconomic class. Research could be directed towards health care professionals' ratings of parents information needs compared to those of the parents themselves. It could explore how health workers arrive at their assessment of parents' information needs, and how they decide what type and amount of information to provide.

Assessing severity of illness is not a simple task but if managed effectively would give rise to a useful tool for use in comparative studies. There is a use for a global measure of severity of childhood illness if one were to be developed. Such a tool would need to take into account many factors such as the treatment burden, life expectancy, restrictions on daily living.

Long term outcome studies are needed which examine psychological well-being of chronically ill children in relation to their education record, paying attention not only to qualifications but also attendance records. The effects of missing the social aspects of school need to be evaluated.
It is unclear how clinically useful some of the findings of this study may be in practical terms, to the paediatric renal team. It may be that further pragmatic questions need to be asked of parents. The article on stress by Hulstijn-Dirkmaat and Damhuis (1994) addressed concerns of parents and combined both information needs (concerns about the future), and impact of illness (school absenteeism). This simple checklist (see Appendix M) might be a quick method by which health care professionals can identify which aspects of care concern parents most, especially if it was adapted to give a weighted system of rating level of concern, rather than simple presence of concern. This could again help the targeting of resources.
Conclusion

The findings of this study indicate that caring for children with ESRF can result in increased demands and be detrimental to psychological well-being. Parents who are required to carry out such care are in need of increased resources to help them cope with the demands. Provision of information is one such resource.

Inclusion of fathers in the study was worthwhile despite their lower response rates. To study the family one needs to look at both parents, not just the mother, and this study revealed that fathers too are subject to the demands and detrimental effects on psychological well-being that mothers are.

The use of comparative groups of parents is an important part of the study which allows more confident interpretation of findings and helps to identify those findings specific to the care of the child with ESRF. It seems clear from this study that results of psychological tests of parents should be compared with norms or comparisons of other parents, not just other adults. Parenting seems to have specific demands and needs.

Use of qualitative data also allows more confident interpretation of findings, and provides the reader with a more enriched view of the lives of parents caring for a child with ESRF. For the researcher, being part of the team permitted much greater insight than would otherwise have been possible.

Prospective panel design studies with good response rates are an ideal way to look not only at associations but also at the direction of the associations. Unfortunately it was not possible to carry this out in this study. Despite the high rate of attrition over the two years, the two year study allowed extra information to be gathered,
through the individual plots and because a group of parents had children who underwent a treatment change during the study period.

In summary, by studying the parents of children with ESRF over two years and with comparison groups of other parents it has been shown that: the care has a significant impact on the life of the child and family; that parents require more information; that the need for information can be reduced by a concerted and active programme of information provision; and that the psychological well-being of the parents is affected detrimentally when caring for a child in ESRF, as they are more anxious and more depressed than other parents in the study.
References

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References
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References 315


Hayward, J. (1975) "Information: A prescription against pain". Royal College of Nursing, London.


Leonard, A. (1994) "Right from the start: Looking at diagnosis and disclosure - Parents describe how they found out about their child's disability". Spastics Society, London.


West, C. (1984) "Routine complications: Troubles with the talk between doctors and patients". University of Indiana Press, Bloomington IL.


Appendices

Appendix

A  Questionnaires used in the study. ......................... A 1

A(i) Complete ANOVA tables for results discussed in 
    Chapter Three. ............................................. A 14

B  Mean scores and response rates for parents of (abandoned) 
    two year control group. ................................. A 17

C  Impact of illness questions. .............................. A 18

D  Complete ANOVA and regression tables for results discussed 
    in Chapter Four ............................................. A 20

E  Graphs illustrating when interactions have not been 
    able to be reported......................................... A 26

F  Précis of Health Indicator results for fathers ........ A 31

G  Information Needs questions. ............................ A 32

H  Complete ANOVA and regression tables for results discussed 
    in Chapter Five. ............................................ A 35

J  Complete ANOVA and regression tables for results discussed 
    in Chapter Six. ............................................. A 40

K  Mann-Whitney U test of socioeconomic data for 
    high and low response groups. ........................ A 47

L  Leaflets developed to address some of the information 
    needs identified during this study ...................... A 52

M  Checklist to identify parents' concerns ................. A 61
Appendix A

Questionnaires used in the study.

All questionnaires have been reduced for binding.

Appendix A contains

- A sample front sheet - used to gather subject details, health indicators and life changes.
- PSS14
- PSS10
- HADS
- Impact of illness questionnaire
  - for parents of children pre-dialysis
  - parents of children on dialysis
  - parents of children post-transplant
  - parents of children with IDDM
- Information Needs questionnaire
  - for parents of children pre-dialysis
  - parents of children on dialysis
  - parents of children post-transplant
  - parents of children with IDDM
A sample front sheet

Family Information

Name: _______________________
Date: _______________________

Insulin
Type: _______________________
Amount: _______________________
How many times daily? ________

Diet
Carbohydrate allowances per day __________

Any comments on the treatment or health of your child over the last month

Contact with the Hospital

Frequency of out-patient clinic appointments: every _____ months
Number of in-patient admissions: ______ time(s) in the last month
Occasions requiring a phone call to the diabetic sister: ______ time(s) in the last month

Contact with your GP

Episodes requiring the child to be seen by the family GP: ______ time(s) in the last month
Episodes requiring you to be seen by the family GP: ______ time(s) in the last month
Episodes requiring any other family member to be seen by the family GP: ______ time(s) in the last month

Family Circumstances

Have there been any major changes in the following areas of family life?
If so please indicate below.

<table>
<thead>
<tr>
<th></th>
<th>For the better / Neither better nor worse / For the worse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finances</td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td></td>
</tr>
<tr>
<td>Health of self</td>
<td></td>
</tr>
<tr>
<td>Health of partner</td>
<td></td>
</tr>
<tr>
<td>Health of other children</td>
<td></td>
</tr>
<tr>
<td>Health of other family or grandparent</td>
<td></td>
</tr>
<tr>
<td>Transport</td>
<td></td>
</tr>
<tr>
<td>Practical support</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
</tr>
</tbody>
</table>

Comments or further details

Appendix A, page 2 of 13
The questions in this section ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

<table>
<thead>
<tr>
<th>Question</th>
<th>Alternatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the last month, how often have you been upset because of something that happened unexpectedly?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>2. In the last month, how often have you felt that you were unable to control the important things in your life?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>3. In the last month, how often have you felt nervous and stressed?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>4. In the last month, how often have you dealt successfully with irritating life hassles?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>6. In the last month, how often have you felt confident about your ability to handle your personal problems?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>7. In the last month, how often have you felt that things were going your way?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>8. In the last month, how often have you found that you could not cope with all the things that you had to do?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>9. In the last month, how often have you been able to control irritations in your life?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>10. In the last month, how often have you felt that you were on top of things?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>11. In the last month, how often have you been angered because of things that happened that were outside of your control?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>12. In the last month, how often have you found yourself thinking of things that you have to accomplish?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>13. In the last month, how often have you been able to control the way you spend your time?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
<tr>
<td>14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?</td>
<td>0. never, 1. almost never, 2. sometimes, 3. fairly often, 4. very often</td>
</tr>
</tbody>
</table>
The questions in this section ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

1. In the last month, how often have you been upset because of something that happened unexpectedly?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

3. In the last month, how often have you felt nervous and stressed?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

4. In the last month, how often have you found that you could not cope with all the things that you had to do?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

5. In the last month, how often have you been able to control irritations in your life?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

6. In the last month, how often have you felt confident about your ability to handle your personal problems?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

7. In the last month, how often have you felt that things were going your way?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

8. In the last month, how often have you been angry because of things that happened that were outside of your control?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

9. In the last month, how often have you been skilled at maintaining an even temper?
   - 0. never
   - 1. almost never
   - 2. sometimes
   - 3. fairly often
   - 4. very often

10. In the last month, how often have you felt that you were on top of things?
    - 0. never
    - 1. almost never
    - 2. sometimes
    - 3. fairly often
    - 4. very often

11. In the last month, how often have you been angered because of things that happened that were outside of your control?
    - 0. never
    - 1. almost never
    - 2. sometimes
    - 3. fairly often
    - 4. very often

12. In the last month, how often have you felt that you were often in control of your life?
    - 0. never
    - 1. almost never
    - 2. sometimes
    - 3. fairly often
    - 4. very often

13. In the last month, how often have you felt that you could not exercise control over your life?
    - 0. never
    - 1. almost never
    - 2. sometimes
    - 3. fairly often
    - 4. very often

14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
    - 0. never
    - 1. almost never
    - 2. sometimes
    - 3. fairly often
    - 4. very often
This questionnaire will help us know how you are. Read each item and indicate the response which comes closest to how you have felt in the last few days. Don't take too long over your replies, your immediate reaction will probably be more accurate than a long thought out response.

<table>
<thead>
<tr>
<th>I feel tense or 'wound up'</th>
<th>I feel as if I am slowed down</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>From time to time, occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I still enjoy the things I used to enjoy</th>
<th>I get a sort of frightened feeling like 'butterflies' in the stomach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Only a little</td>
<td>Quite often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling as if something awful is about to happen</th>
<th>I have lost interest in my appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>Definitely</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>I don't take so much care as I should</td>
</tr>
<tr>
<td>A little, but it doesn't worry me</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things</th>
<th>I feel restless as if I have to be on the move</th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind</th>
<th>I look forward with enjoyment to things</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
<td>As much as I ever did</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>From time to time but not too often</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful</th>
<th>I get sudden feelings of panic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very often</td>
</tr>
<tr>
<td>Not often</td>
<td>Quite often</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Not very often</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can sit at ease and feel relaxed.</th>
<th>I can enjoy a good book or radio or TV programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>Often</td>
</tr>
<tr>
<td>Usually</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
<td>Not often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
Impact of illness questionnaire for parents of children pre-dialysis

The questions in this section ask you about your child's health during the last three months. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times, but rather indicate the alternative that seems like a reasonable estimate.

1. Over the past three months, your child has complained of abdominal discomfort
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

2. Over the past three months, being tired has limited your child's daily activities
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

3. Over the past three months, your child has been more swollen and puffy than usual
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

4. Over the past three months, medication has caused some problems
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

5. Over the past three months, your child has complained of nausea
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

6. Over the past three months, your child has stayed indoors because of feeling unwell
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

7. Over the past three months, his/her renal failure has stopped your child playing with their friends
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

8. Over the past three months, during term time, your child's education has suffered due to his/her renal failure
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

9. Over the past three months, renal failure has stopped your child from doing all the things that a boy or girl should at his or her age
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

10. Over the past three months, your child's renal failure has interfered with his or her life
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

11. Over the past three months, renal failure has limited your child's activities
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

12. Over the past three months, having treatment has interrupted your child's life
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

13. Over the past three months, your child's renal failure has limited your activities
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

14. Over the past three months, you have had to make adjustments to family life because of your child's renal failure
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

15. Over the past three months, your child has lost sleep because of their renal failure
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

Appendix A, page 6 of 13
The questions in this section ask you about your child's health during the last three months. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times, but rather indicate the alternative that seems like a reasonable estimate.

1. Over the past three months, your child has complained of abdominal discomfort
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

2. Over the past three months, being tired has limited your child's daily activities
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

3. Over the past three months, your child has been more swollen and puffy than usual
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

4. Over the past three months, dialysis has been more problematic than usual
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

5. Over the past three months, your child has complained of nausea
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

6. Over the past three months, your child has stayed indoors because of feeling unwell
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

7. Over the past three months, his/her renal failure has stopped your child playing with their friends
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

8. Over the past three months, during term time, your child's education has suffered due to his or her renal failure
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

9. Over the past three months, renal failure has stopped your child from doing all the things that a boy or girl should at his or her age
   0. every day
   1. most days
   2. some days
   3. a few days
   4. not at all

10. Over the past three months, your child's renal failure has interfered with his or her life
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

11. Over the past three months, renal failure has limited your child's activities
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

12. Over the past three months, dialysis and/or other treatment has interrupted your child's life
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

13. Over the past three months, your child's renal failure has limited your activities
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

14. Over the past three months, you have had to make adjustments to family life because of your child's renal failure
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all

15. Over the past three months, your child has lost sleep because of their renal failure
    0. every day
    1. most days
    2. some days
    3. a few days
    4. not at all
1. Over the past three months, your child has complained of abdominal discomfort.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

2. Over the past three months, being tired has limited your child's daily activities.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

3. Over the past three months, your child has been more swollen and puffy than usual.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

4. Over the past three months, steroid treatments have caused some problems.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

5. Over the past three months, your child has complained of nausea.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

6. Over the past three months, your child has stayed indoors because of feeling unwell.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

7. Over the past three months, his/her kidney transplant has stopped your child playing with their friends.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

8. Over the past three months, during term time, your child's education has suffered due to his or her kidney transplant.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

9. Over the past three months, having a transplanted kidney has stopped your child from doing all the things that a boy or girl should at his or her age.
   0. everyday
   1. most days
   2. some days
   3. a few days
   4. not at all

10. Over the past three months, your child's kidney transplant has interfered with his or her life.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

11. Over the past three months, having a transplanted kidney has limited your child's activities.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

12. Over the past three months, renal treatments have interrupted your child's life.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

13. Over the past three months, your child's kidney transplant has limited your activities.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

14. Over the past three months, you have had to make adjustments to family life because of your child's kidney transplant.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

15. Over the past three months, your child has lost sleep because of their kidney transplant.
    0. everyday
    1. most days
    2. some days
    3. a few days
    4. not at all

Appendix A, page 8 of 13
The questions in this section ask you about your child's health during the last three months. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times, but rather indicate the alternative that seems like a reasonable estimate.

1. Over the past three months, your child has complained of painful injection sites
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

2. Over the past three months, being tired has limited your child's daily activities
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

3. Over the past three months, your child has had a hypo
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

4. Over the past three months, your child has had a high blood sugar
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

5. Over the past three months, your child has complained about doing their blood tests
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

6. Over the past three months, your child has stayed indoors because of feeling unwell
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

7. Over the past three months, his/her diabetes has stopped your child playing with their friends
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

8. Over the past three months, during term time, your child's education has suffered due to his/her diabetes
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

9. Over the past three months, diabetes has stopped your child from doing all the things that a boy or girl should at his or her age
   - 0. every day
   - 1. most days
   - 2. some days
   - 3. a few days
   - 4. not at all

10. Over the past three months, your child's diabetes has interfered with his or her life
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

11. Over the past three months, diabetes has limited your child's activities
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

12. Over the past three months, your child has eaten the wrong foods
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

13. Over the past three months, your child's diabetes has limited your activities
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

14. Over the past three months, you have had to make adjustments to family life because of your child's diabetes
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

15. Over the past three months, your child has lost sleep because of their diabetes
    - 0. every day
    - 1. most days
    - 2. some days
    - 3. a few days
    - 4. not at all

Appendix A, page 9 of 13
The best approach is...

The questions in this section ask you about information that you may have or require about your child's condition. The best approach is to answer each question fairly quickly, and select which alternative best expresses how you perceive your information needs to have been met.

For each question choose from the following alternatives:

1. How the human body works
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

2. Symptoms of renal failure
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

3. Whether renal failure can be inherited
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

4. Whether your child will need dialysis
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

5. The effects of medications used in treatment
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

6. How diet effects your child's renal failure
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

7. Forms of exercise and sport that are suitable for children with renal failure
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

8. Healthy meals for children with renal failure
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

9. New information about renal failure from other places in the world
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

10. Detailed results of any tests performed on your child
    when he/she attends clinic
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

11. Possible complications of renal failure
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

12. How to deal with your child's feelings about having renal failure
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

13. What to tell your child about renal failure
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

14. What to tell your other children about renal failure
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

15. How renal failure might affect your child's career, 
    social life, and marriage
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

16. How renal failure might affect your child's chances 
    of having their own children
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

17. How serious your child's illness is
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

18. What to expect if your child's illness gets worse
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

19. How to answer your child's questions about whether 
    he/she might die of renal failure
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information
Information Needs questionnaire for parents of children on dialysis

The questions in this section ask you about information that you may have or require about your child's condition. The best approach is to answer each question fairly quickly, and select which alternative best expresses how you perceive your information needs to have been met.

For each question choose from the following alternatives:

0. a great deal more information needed
1. a little more information needed
2. I have enough information

1. How the human body works
0. a great deal more information needed
1. a little more information needed
2. I have enough information

2. Symptoms of renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

3. Whether renal failure can be inherited
0. a great deal more information needed
1. a little more information needed
2. I have enough information

4. How dialysis works
0. a great deal more information needed
1. a little more information needed
2. I have enough information

5. The effects of medications used in treatment
0. a great deal more information needed
1. a little more information needed
2. I have enough information

6. How to use a gastrostomy tube
0. a great deal more information needed
1. a little more information needed
2. I have enough information

7. Forms of exercise and sport that are suitable for children with renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

8. Healthy meals for children with renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

9. New information about renal failure from other places in the world
0. a great deal more information needed
1. a little more information needed
2. I have enough information

10. Detailed results of any tests performed on your child when he/she attends clinic
0. a great deal more information needed
1. a little more information needed
2. I have enough information

11. Possible complications of renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

12. How to deal with your child's feelings about having renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

13. What to tell your child about renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

14. What to tell your other children about renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

15. How renal failure might affect your child's career, social life, and marriage
0. a great deal more information needed
1. a little more information needed
2. I have enough information

16. How renal failure might affect your child's chances of having their own children
0. a great deal more information needed
1. a little more information needed
2. I have enough information

17. How serious your child's illness is
0. a great deal more information needed
1. a little more information needed
2. I have enough information

18. What to expect if your child's illness gets worse
0. a great deal more information needed
1. a little more information needed
2. I have enough information

19. How to answer your child's questions about whether he/she might die of renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

Appendix A, page 11 of 13
Information Needs questionnaire for parents of children post-transplant

The questions in this section ask you about information that you may have or require about your child’s condition. The best approach is to answer each question fairly quickly, and select which alternative best expresses how you perceive your information needs to have been met.

For each question choose from the following alternatives:

0. a great deal more information needed
1. a little more information needed
2. I have enough information

1. How the human body works
0. a great deal more information needed
1. a little more information needed
2. I have enough information

2. Symptoms of renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information

3. Whether renal failure can be inherited
0. a great deal more information needed
1. a little more information needed
2. I have enough information

4. The effects of medications used in treatment
0. a great deal more information needed
1. a little more information needed
2. I have enough information

5. Signs, symptoms and causes of rejection
0. a great deal more information needed
1. a little more information needed
2. I have enough information

6. Forms of exercise and sport that are suitable for children with a kidney transplant
0. a great deal more information needed
1. a little more information needed
2. I have enough information

7. Healthy meals for children with a kidney transplant
0. a great deal more information needed
1. a little more information needed
2. I have enough information

8. New information about kidney transplants from other places in the world
0. a great deal more information needed
1. a little more information needed
2. I have enough information

9. Detailed results of any tests performed on your child when he/she attends clinic.
0. a great deal more information needed
1. a little more information needed
2. I have enough information

10. Possible complications of having had a kidney transplant
0. a great deal more information needed
1. a little more information needed
2. I have enough information

11. How to deal with your child’s feelings about having a transplanted kidney
0. a great deal more information needed
1. a little more information needed
2. I have enough information

12. What to tell your child about kidney transplants
0. a great deal more information needed
1. a little more information needed
2. I have enough information

13. What to tell your other children about kidney transplants
0. a great deal more information needed
1. a little more information needed
2. I have enough information

14. How a kidney transplant might affect your child’s career, social life, and marriage
0. a great deal more information needed
1. a little more information needed
2. I have enough information

15. How a kidney transplant might affect your child’s chances of having their own children
0. a great deal more information needed
1. a little more information needed
2. I have enough information

16. How serious your child’s illness is
0. a great deal more information needed
1. a little more information needed
2. I have enough information

17. What to expect if your child’s kidney begins to show signs of failing
0. a great deal more information needed
1. a little more information needed
2. I have enough information

18. How to answer your child’s questions about whether he/she might die of renal failure
0. a great deal more information needed
1. a little more information needed
2. I have enough information
The questions in this section ask you about information that you may have or require about your child's condition. The best approach is to answer each question fairly quickly, and select which alternative best expresses how you perceive your information needs to have been met.

For each question choose from the following alternatives:

0. a great deal more information needed
1. a little more information needed
2. I have enough information

1. What diabetes actually is
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

2. How to deal with hypo's
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

3. Whether diabetes can be inherited
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

4. How to deal with illness eg. flu or vomiting
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

5. How insulin works
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

6. Knowledge of carbohydrate values
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

7. Effects of exercise and sport on children with diabetes
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

8. Healthy meals for children with diabetes
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

9. Research about diabetes from other places in the world
   0. a great deal more information needed
   1. a little more information needed
   2. I have enough information

10. Care of injection sites
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

11. Results of any tests performed on your child when he/she attends clinic
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

12. Possible complications of diabetes
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

13. How to deal with your child's feelings about having diabetes
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

14. Do you have enough information to answer your child's questions about diabetes?
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

15. What to tell your other children about diabetes
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

16. How diabetes might affect your child's career, social life, and marriage
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

17. How diabetes might affect your child's chances of having their own children
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

18. How serious your child's illness is
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

19. What to expect if your child's diabetes becomes unstable
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

20. How to answer your child's questions about complications of diabetes
    0. a great deal more information needed
    1. a little more information needed
    2. I have enough information

Appendix A, page 13 of 13
Appendix A (i)

Complete ANOVA tables for results discussed in Chapter Three. Each table is preceded by the number of the page where the results were reported.
### Occupation of highest employed parent by group

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th>Group</th>
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<tr>
<td>56.52</td>
<td>24</td>
<td>Renal</td>
</tr>
<tr>
<td>58.88</td>
<td>16</td>
<td>Diabetic</td>
</tr>
<tr>
<td>47.65</td>
<td>62</td>
<td>Control</td>
</tr>
<tr>
<td></td>
<td>102</td>
<td>Total</td>
</tr>
</tbody>
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**Corrected for Ties**

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<th>DF</th>
<th>Significance</th>
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### Total number of children by group

<table>
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<th>Group</th>
</tr>
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<tr>
<td>46.23</td>
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<tr>
<td>59.63</td>
<td>67</td>
<td>Control</td>
</tr>
<tr>
<td></td>
<td>102</td>
<td>Total</td>
</tr>
</tbody>
</table>

**Corrected for Ties**

<table>
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### Number of children older than 5 yrs at June 1992 by group

<table>
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<th>Cases</th>
<th>Group</th>
</tr>
</thead>
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<tr>
<td>29.87</td>
<td>26</td>
<td>Renal</td>
</tr>
<tr>
<td>50.88</td>
<td>17</td>
<td>Diabetic</td>
</tr>
<tr>
<td>65.96</td>
<td>66</td>
<td>Control</td>
</tr>
<tr>
<td></td>
<td>109</td>
<td>Total</td>
</tr>
</tbody>
</table>

**Corrected for Ties**

<table>
<thead>
<tr>
<th>Chi-square</th>
<th>DF</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>24.67</td>
<td>2</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

### Number of children younger than 5 yrs at June 1992 by group

<table>
<thead>
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<th>Mean Rank</th>
<th>Cases</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>58.27</td>
<td>26</td>
<td>Renal</td>
</tr>
<tr>
<td>50.50</td>
<td>17</td>
<td>Diabetic</td>
</tr>
<tr>
<td>55.69</td>
<td>67</td>
<td>Control</td>
</tr>
<tr>
<td></td>
<td>110</td>
<td>Total</td>
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**Corrected for Ties**

<table>
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<tr>
<th>Chi-square</th>
<th>DF</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.62</td>
<td>2</td>
<td>0.73</td>
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### Age of mother by group

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<th>F Ratio</th>
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<td>94.16</td>
<td>3.81</td>
<td>0.03</td>
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<tr>
<td>Within groups</td>
<td>104</td>
<td>2571.59</td>
<td>24.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>106</td>
<td>2759.91</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Post hoc test**

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

\[
\text{MEAN}(j) - \text{MEAN}(i) \geq 3.5162 \times \text{RANGE} \times \sqrt{1/N(i) + 1/N(j)}
\]

(*) indicates significant differences which are shown in the lower triangle.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Group</th>
<th>Renal</th>
<th>Diabetic</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>35.17</td>
<td>Renal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38.86</td>
<td>Diabetic</td>
<td>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38.15</td>
<td>Control</td>
<td>*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Age of father by group

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of squares</th>
<th>Mean Squares</th>
<th>F Ratio</th>
<th>F Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>382.37</td>
<td>191.19</td>
<td>6.50</td>
<td>0.002</td>
</tr>
<tr>
<td>Within groups</td>
<td>103</td>
<td>3030.55</td>
<td>29.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>105</td>
<td>3412.92</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Post hoc test**

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

\[
\text{MEAN}(j) - \text{MEAN}(i) \geq 3.5162 \times \text{RANGE} \times \sqrt{1/N(i) + 1/N(j)}
\]

(*) indicates significant differences which are shown in the lower triangle.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Group</th>
<th>Renal</th>
<th>Diabetic</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>35.17</td>
<td>Renal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38.86</td>
<td>Diabetic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38.15</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix B

Mean scores and response rates for parents of healthy children who were approached to be assessed over the two years. This control group was abandoned after Time 2.

<table>
<thead>
<tr>
<th></th>
<th>Control mothers</th>
<th>Control Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response rate</td>
<td>26.67%</td>
<td>20.00%</td>
</tr>
<tr>
<td>Mean PSS14 score</td>
<td>24.5</td>
<td>28</td>
</tr>
<tr>
<td>Mean Anxiety score</td>
<td>10</td>
<td>10.7</td>
</tr>
<tr>
<td>Mean Depression score</td>
<td>4.5</td>
<td>9.33</td>
</tr>
</tbody>
</table>
Some disease specific questions (*) needed to be different depending on whether the child was pre-dialysis (P), receiving dialysis (D), or post-transplant (T).

<table>
<thead>
<tr>
<th>Renal parents</th>
<th>Diabetic Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1* Over the past three months, your child has complained of abdominal discomfort</td>
<td>Over the past three months, your child has complained of painful injection sites</td>
</tr>
<tr>
<td>2 Over the past three months, being tired has limited your child's daily activities</td>
<td>Over the past three months, being tired has limited your child's daily activities</td>
</tr>
<tr>
<td>3* Over the past three months, your child has been more swollen and puffy than usual</td>
<td>Over the past three months, your child has had a hypo</td>
</tr>
<tr>
<td>4* (P) Over the past three months, medication has caused some problems</td>
<td>Over the past three months, your child has had a high blood sugar</td>
</tr>
<tr>
<td>(D) Over the past three months, dialysis has been more problematic than usual</td>
<td></td>
</tr>
<tr>
<td>(T) Over the past three months, steroid treatments have caused some problems</td>
<td></td>
</tr>
<tr>
<td>5* Over the past three months, your child has complained of nausea</td>
<td>Over the past three months, your child has complained about doing their blood tests</td>
</tr>
<tr>
<td>6 Over the past three months, your child has stayed indoors because of feeling unwell</td>
<td>Over the past three months, your child has stayed indoors because of feeling unwell</td>
</tr>
<tr>
<td>7 Over the past three months, his/her renal failure has stopped your child playing with their friends</td>
<td>Over the past three months, his/her diabetes has stopped your child playing with their friends</td>
</tr>
<tr>
<td>8</td>
<td>Over the past three months, during term time, your child's education has suffered due to his or her renal failure</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>9</td>
<td>Over the past three months, renal failure has stopped your child from doing all the things that a boy or girl should at his or her age</td>
</tr>
<tr>
<td>10</td>
<td>Over the past three months, your child's renal failure has interfered with his or her life</td>
</tr>
<tr>
<td>11</td>
<td>Over the past three months, renal failure has limited your child's activities</td>
</tr>
<tr>
<td>12*</td>
<td>(P) Over the past three months, having treatment has interrupted your child's life (D) Over the past three months, dialysis and/or other treatment has interrupted your child's life (T) Over the past three months, renal treatments have interrupted your child's life</td>
</tr>
<tr>
<td>13</td>
<td>Over the past three months, your child's renal failure has limited your activities</td>
</tr>
<tr>
<td>14</td>
<td>Over the past three months, you have had to make adjustments to family life because of your child's renal failure</td>
</tr>
<tr>
<td>15</td>
<td>Over the past three months, your child has lost sleep because of their renal failure</td>
</tr>
</tbody>
</table>

Appendix C, page 2 of 2
Appendix D

Complete ANOVA tables for results discussed in Chapter Four. Tables are arranged in the order of the results section and each is preceded by the number of the page where the results were reported.
### Analysis of Variance

#### Mean impact of illness score (over study) - All parents

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>46.63</td>
<td>2</td>
<td>23.13</td>
<td>1.9</td>
<td>0.16</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>0.06</td>
<td>1</td>
<td>0.06</td>
<td>0.005</td>
<td>0.94</td>
</tr>
<tr>
<td>Group</td>
<td>46.39</td>
<td>1</td>
<td>46.39</td>
<td>3.76</td>
<td>0.06</td>
</tr>
<tr>
<td>2-way interaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of parent Group</td>
<td>1.90</td>
<td>1</td>
<td>1.90</td>
<td>0.15</td>
<td>0.70</td>
</tr>
<tr>
<td>Explained</td>
<td>46.73</td>
<td>3</td>
<td>15.58</td>
<td>1.26</td>
<td>0.29</td>
</tr>
<tr>
<td>Residual</td>
<td>973.86</td>
<td>79</td>
<td>12.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1020.59</td>
<td>82</td>
<td>12.45</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed, 15 cases (15.3%) were missing

---

### Analysis of Variance

#### Mean impact of illness score (over study) - All mothers

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>75.86</td>
<td>5</td>
<td>15.17</td>
<td>0.46</td>
<td>0.80</td>
</tr>
<tr>
<td>Age band of child</td>
<td>53.53</td>
<td>2</td>
<td>26.77</td>
<td>0.82</td>
<td>0.45</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>36.41</td>
<td>3</td>
<td>12.14</td>
<td>0.37</td>
<td>0.77</td>
</tr>
<tr>
<td>Explained</td>
<td>75.86</td>
<td>5</td>
<td>15.17</td>
<td>0.46</td>
<td>0.80</td>
</tr>
<tr>
<td>Residual</td>
<td>1046.74</td>
<td>32</td>
<td>32.71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1122.60</td>
<td>17</td>
<td>30.34</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

49 cases were processed, 11 cases (22.4%) were missing

Due to empty cells or a singular matrix
higher order interactions have been suppressed
### Analysis of Variance

Mean impact of illness score (over study) - Renal mothers

by Age band of child

Time since diagnosis band

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>129.49</td>
<td>5</td>
<td>25.90</td>
<td>1.03</td>
<td>0.44</td>
</tr>
<tr>
<td>Age band of child</td>
<td>117.53</td>
<td>2</td>
<td>58.77</td>
<td>2.43</td>
<td>0.13</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>6.46</td>
<td>3</td>
<td>2.15</td>
<td>0.09</td>
<td>0.97</td>
</tr>
<tr>
<td>Explained</td>
<td>129.49</td>
<td>5</td>
<td>25.90</td>
<td>1.03</td>
<td>0.44</td>
</tr>
<tr>
<td>Residual</td>
<td>351.13</td>
<td>14</td>
<td>25.08</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total                      | 622.66         | 17 | 36.63       |       |          |

Due to empty cells or a singular matrix, higher order interactions have been suppressed

### Analysis of Variance

Mean impact of illness score (over study) - Diabetic mothers

by Age band of child

Time since diagnosis band

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>110.46</td>
<td>5</td>
<td>22.09</td>
<td>0.52</td>
<td>0.76</td>
</tr>
<tr>
<td>Age band of child</td>
<td>10.87</td>
<td>2</td>
<td>5.44</td>
<td>0.13</td>
<td>0.88</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>101.32</td>
<td>3</td>
<td>33.77</td>
<td>0.79</td>
<td>0.52</td>
</tr>
<tr>
<td>Explained</td>
<td>110.46</td>
<td>5</td>
<td>22.09</td>
<td>0.52</td>
<td>0.76</td>
</tr>
<tr>
<td>Residual</td>
<td>512.20</td>
<td>12</td>
<td>42.68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>622.66</td>
<td>17</td>
<td>36.63</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23 cases were processed, 5 cases (21.7%) were missing

Due to empty cells or a singular matrix, higher order interactions have been suppressed
### Analysis of Variance

#### Mean impact of illness score (over study) - All Fathers

by **Age band of child**

by **Time since diagnosis band**

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>114.33</td>
<td>6</td>
<td>19.06</td>
<td>1.02</td>
<td>0.44</td>
</tr>
<tr>
<td>Age band of child</td>
<td>87.76</td>
<td>3</td>
<td>29.25</td>
<td>1.57</td>
<td>0.23</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>30.86</td>
<td>3</td>
<td>10.29</td>
<td>0.55</td>
<td>0.65</td>
</tr>
<tr>
<td>Explained</td>
<td>114.33</td>
<td>6</td>
<td>19.06</td>
<td>1.02</td>
<td>0.44</td>
</tr>
<tr>
<td>Residual</td>
<td>410.51</td>
<td>22</td>
<td>18.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>524.84</td>
<td>28</td>
<td>18.74</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

49 cases were processed, 20 cases (40.8%) were missing

Due to empty cells or a singular matrix higher order interactions have been suppressed

---

### Analysis of variance

#### Mean impact of illness score (over study) - Renal fathers

by **Age band of child**

by **Time since diagnosis band**

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>94.94</td>
<td>6</td>
<td>15.82</td>
<td>1.14</td>
<td>0.41</td>
</tr>
<tr>
<td>Age band of child</td>
<td>90.05</td>
<td>3</td>
<td>30.02</td>
<td>2.17</td>
<td>0.16</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>5.59</td>
<td>3</td>
<td>1.86</td>
<td>.13</td>
<td>0.94</td>
</tr>
<tr>
<td>Explained</td>
<td>94.94</td>
<td>6</td>
<td>15.82</td>
<td>1.14</td>
<td>0.41</td>
</tr>
<tr>
<td>Residual</td>
<td>124.74</td>
<td>9</td>
<td>13.86</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>219.69</td>
<td>15</td>
<td>14.65</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

26 cases were processed, 10 cases (38.5%) were missing

Due to empty cells or a singular matrix higher order interactions have been suppressed
### Analysis of Variance

Mean impact of illness score (over study) - Diabetic fathers by Age band of child Time since diagnosis band

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age band of child</td>
<td>31.74</td>
<td>2</td>
<td>15.87</td>
<td>.483</td>
<td>.636</td>
</tr>
<tr>
<td>Time since diag. band</td>
<td>37.49</td>
<td>3</td>
<td>12.50</td>
<td>.380</td>
<td>.771</td>
</tr>
<tr>
<td>Explained</td>
<td>70.72</td>
<td>5</td>
<td>14.14</td>
<td>.430</td>
<td>.815</td>
</tr>
<tr>
<td>Residual</td>
<td>230.07</td>
<td>7</td>
<td>32.87</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>300.79</td>
<td>12</td>
<td>25.07</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

13 cases were processed, 10 cases (43.5%) were missing
Due to empty cells or a singular matrix
higher order interactions have been suppressed

### Analysis of Variance

Mean general impact of illness over study by Sex of Parent GRP Group Careband

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of Parent</td>
<td>.371</td>
<td>1</td>
<td>.371</td>
<td>.031</td>
<td>.86</td>
</tr>
<tr>
<td>Group</td>
<td>20.98</td>
<td>1</td>
<td>20.98</td>
<td>1.73</td>
<td>.19</td>
</tr>
<tr>
<td>Careband</td>
<td>13.89</td>
<td>1</td>
<td>13.89</td>
<td>1.14</td>
<td>.30</td>
</tr>
<tr>
<td>2-way Interactions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of parent / GRP</td>
<td>2.26</td>
<td>1</td>
<td>2.26</td>
<td>0.185</td>
<td>.67</td>
</tr>
<tr>
<td>Sex of parent / careband</td>
<td>0.008</td>
<td>1</td>
<td>0.008</td>
<td>0.001</td>
<td>.98</td>
</tr>
<tr>
<td>Group / careband</td>
<td>89.06</td>
<td>1</td>
<td>89.06</td>
<td>7.34</td>
<td>.009</td>
</tr>
<tr>
<td>3-way Interactions</td>
<td>.247</td>
<td>1</td>
<td>.247</td>
<td>.020</td>
<td>.89</td>
</tr>
<tr>
<td>Sex of parent GRP</td>
<td>.247</td>
<td>1</td>
<td>.247</td>
<td>.020</td>
<td>.89</td>
</tr>
<tr>
<td>Careband</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explained</td>
<td>141.96</td>
<td>7</td>
<td>20.29</td>
<td>1.67</td>
<td>.133</td>
</tr>
<tr>
<td>Residual</td>
<td>764.92</td>
<td>63</td>
<td>12.14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>906.92</td>
<td>70</td>
<td>12.962</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed, 27 cases (27.6%) were missing
Due to empty cells or a singular matrix
higher order interactions have been suppressed
Analysis of Variance

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>60.05</td>
<td>4</td>
<td>15.01</td>
<td>1.19</td>
<td>0.34</td>
</tr>
<tr>
<td>Careband</td>
<td>0.92</td>
<td>1</td>
<td>0.92</td>
<td>0.73</td>
<td>0.79</td>
</tr>
<tr>
<td>Treat</td>
<td>43.82</td>
<td>2</td>
<td>21.91</td>
<td>1.73</td>
<td>0.20</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>0.03</td>
<td>1</td>
<td>0.03</td>
<td>0.01</td>
<td>0.96</td>
</tr>
<tr>
<td>2-way interactions</td>
<td>43.69</td>
<td>5</td>
<td>8.73</td>
<td>0.69</td>
<td>0.64</td>
</tr>
<tr>
<td>Careband treat</td>
<td>41.84</td>
<td>2</td>
<td>20.91</td>
<td>1.66</td>
<td>0.21</td>
</tr>
<tr>
<td>Careband sex of parent</td>
<td>0.52</td>
<td>1</td>
<td>0.52</td>
<td>0.04</td>
<td>0.84</td>
</tr>
<tr>
<td>Treat sex of parent</td>
<td>1.29</td>
<td>2</td>
<td>0.65</td>
<td>0.05</td>
<td>0.95</td>
</tr>
<tr>
<td>3-way Interactions</td>
<td>0.28</td>
<td>2</td>
<td>0.14</td>
<td>0.01</td>
<td>0.99</td>
</tr>
<tr>
<td>Careband treat sex of parent</td>
<td>0.28</td>
<td>2</td>
<td>0.14</td>
<td>0.01</td>
<td>0.99</td>
</tr>
<tr>
<td>Explained</td>
<td>167.70</td>
<td>11</td>
<td>15.25</td>
<td>1.21</td>
<td>0.33</td>
</tr>
<tr>
<td>Residual</td>
<td>328.66</td>
<td>26</td>
<td>12.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>496.36</td>
<td>37</td>
<td>13.42</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

52 cases were processed, 14 cases (26.9%) were missing

Due to empty cells or a singular matrix higher order interactions have been suppressed

One Way Analysis Of Variance

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Squares</th>
<th>F Ratio</th>
<th>F Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>0.61</td>
<td>3</td>
<td>.20</td>
<td>3.79</td>
<td>0.02</td>
</tr>
<tr>
<td>Within groups</td>
<td>2.15</td>
<td>40</td>
<td>.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2.76</td>
<td>43</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Post hoc test

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

$\text{MEAN}(i) - \text{MEAN}(j) \geq 3.5162 \times \text{RANGE} \times \sqrt{1/N(i) + 1/N(j)}$

(*) indicates significant differences which are shown in the lower triangle
Appendix E

Graphs illustrating when interactions have not been able to be reported. Graphs are arranged in the order they are referred to in the thesis and each is preceded by the number of the page where the graph is reported.
Mean general impact over study (fathers)
by child ageband and time since diagnosis

\begin{center}
\begin{tikzpicture}
\begin{axis}[
    xlabel=AGEBAND,
    ylabel=time since diagnosis,
    legend style={at={(0.5,-0.2)},
      anchor=north,legend columns=-1},
    ymajorgrids=true,
    grid style=dashed,
]

% Data points
% ... (data points for each ageband and time since diagnosis)

\legend{Missing, \leq 22 months since diag, >22 \& \leq 52 months since diag, >52 \& \leq 69 months since diag, >69 months since diag}
\end{axis}
\end{tikzpicture}
\end{center}
Mean general impact over study ESRF by sex of parent and treatment type

SEX OF PARENT

Appendix E, page 3 of 5
Mean mean general information score over study by time since diagnosis and child's ageband

Mothers of IDDM children

Appendix E, page 4 of 5
Mean anxiety score over study
by time since diagnosis and child's ageband

Mothers scores

![Graph showing mean anxiety scores over study by time since diagnosis and child's ageband.](image-url)
Appendix F

Fathers significant differences in: frequency of out-patient appointments ($p<0.0001$, DF1, $\chi^2 = 18.15$), with renal children attending more often; frequency of in-patient admissions ($p=0.0047$, DF1, $\chi^2 = 8.00$), with renal children being admitted more; the number of calls made to the specialist nurse ($p=0.0214$, DF1, $\chi^2 = 5.29$), with parents of children with ESRF making more calls.
Appendix G

The disease specific questions (*) needed to be different depending on whether the child was pre-dialysis (P), receiving dialysis (D), or post-transplant (T).

<table>
<thead>
<tr>
<th>Renal parents</th>
<th>Diabetic Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1* How the human body works</td>
<td>What diabetes really is</td>
</tr>
<tr>
<td>2* Symptoms of renal failure</td>
<td>How to deal with hypos</td>
</tr>
<tr>
<td>3 Whether renal failure can be inherited</td>
<td>Whether diabetes can be inherited</td>
</tr>
<tr>
<td>4* (P) Whether your child will need dialysis</td>
<td>How to deal with illness, eg. flu or vomiting</td>
</tr>
<tr>
<td></td>
<td>(D) How to carry out dialysis</td>
</tr>
<tr>
<td></td>
<td>(T) ----</td>
</tr>
<tr>
<td>5* The effects of medications used in treatment</td>
<td>How insulin works</td>
</tr>
<tr>
<td>6* (P) How diet affects your child's renal failure</td>
<td>Knowledge of carbohydrate values</td>
</tr>
<tr>
<td></td>
<td>(D) How to use a gastrostomy tube</td>
</tr>
<tr>
<td></td>
<td>(T) Signs, symptoms and causes of rejection</td>
</tr>
<tr>
<td>7 (P &amp; D) Forms of exercise and sport that are suitable for children with renal failure</td>
<td>Effects of exercise and sport on children with diabetes</td>
</tr>
<tr>
<td></td>
<td>(T) Forms of exercise and sport that are suitable for children with a kidney transplant</td>
</tr>
<tr>
<td>8</td>
<td>(P &amp; D) Healthy meals for children with renal failure</td>
</tr>
<tr>
<td>----</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>(T) Healthy meals for children with a kidney transplant</td>
</tr>
<tr>
<td>9</td>
<td>(P &amp; D) New information about renal failure from other places in the world</td>
</tr>
<tr>
<td></td>
<td>(T) New information about kidney transplants from around the world</td>
</tr>
<tr>
<td>10</td>
<td>Detailed results of any tests performed on your child when he/she attends clinic</td>
</tr>
<tr>
<td>11</td>
<td>(P &amp; D) Possible complications of renal failure</td>
</tr>
<tr>
<td></td>
<td>(T) Possible complications of having had a kidney transplant</td>
</tr>
<tr>
<td>12</td>
<td>(P &amp; D) How to deal with your child's feelings about having renal failure</td>
</tr>
<tr>
<td></td>
<td>(T) How to deal with your child's feelings about having a transplanted kidney</td>
</tr>
<tr>
<td>13</td>
<td>(P &amp; D) What to tell your child about renal failure</td>
</tr>
<tr>
<td></td>
<td>(T) What to tell your child about kidney transplants</td>
</tr>
<tr>
<td>14</td>
<td>(P &amp; D) What to tell your other children about renal failure</td>
</tr>
<tr>
<td></td>
<td>(T) What to tell your other children about kidney transplants</td>
</tr>
<tr>
<td></td>
<td>(P &amp; D) How renal failure might affect your child's career, social life and marriage</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>(T) How a kidney transplant might affect your child's career, social life and marriage</td>
</tr>
<tr>
<td>15</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>(P &amp; D) How renal failure might affect your child's chances of having their own children</th>
<th>How diabetes might affect your child's chances of having their own children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(T) How a kidney transplant might affect your child's chances of having their own children</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>How serious your child's illness is</th>
<th>How serious your child's illness is</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>(P &amp; D) What to expect if your child's illness gets worse</th>
<th>What to expect if your child's diabetes becomes unstable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(T) What to expect if your child's kidney begins to fail</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>How to answer your child's questions about whether he/she might die of renal failure.</th>
<th>How to answer your child's questions about complications of diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Care of injection sites.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Each question was rated by the parents depending upon the perceived information needs.
Appendix H

Complete ANOVA tables for results discussed in Chapter Five. Tables are arranged in the order of the results section and each is preceded by the number of the page where the results were reported.
### Analysis of Variance

#### by Mean Mean general information over study by Sex of parent Group

**Unique sums of squares. All effects entered simultaneously**

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>0.084</td>
<td>2</td>
<td>0.042</td>
<td>0.25</td>
<td>0.78</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>0.053</td>
<td>1</td>
<td>0.053</td>
<td>0.31</td>
<td>0.58</td>
</tr>
<tr>
<td>Group</td>
<td>0.028</td>
<td>1</td>
<td>0.028</td>
<td>0.17</td>
<td>0.69</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>0.002</td>
<td>1</td>
<td>0.002</td>
<td>0.01</td>
<td>0.92</td>
</tr>
<tr>
<td>Sex of parent Group</td>
<td>0.002</td>
<td>1</td>
<td>0.002</td>
<td>0.01</td>
<td>0.92</td>
</tr>
<tr>
<td>Explained</td>
<td>0.09</td>
<td>3</td>
<td>0.03</td>
<td>0.17</td>
<td>0.91</td>
</tr>
<tr>
<td>Residual</td>
<td>13.42</td>
<td>79</td>
<td>0.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>13.51</td>
<td>82</td>
<td>0.17</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed 15 cases (15.3%) were missing

---

### Analysis of Variance

#### by Mean Mean General information over study- IDDM father by Time since diagnosis Ageband

**Unique sums of squares. All effects entered simultaneously**

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>0.67</td>
<td>5</td>
<td>0.13</td>
<td>3.36</td>
<td>0.07</td>
</tr>
<tr>
<td>time since diagnosis</td>
<td>0.46</td>
<td>3</td>
<td>0.15</td>
<td>3.83</td>
<td>0.07</td>
</tr>
<tr>
<td>Ageband</td>
<td>0.23</td>
<td>2</td>
<td>0.12</td>
<td>2.95</td>
<td>0.12</td>
</tr>
<tr>
<td>Explained</td>
<td>0.67</td>
<td>5</td>
<td>0.13</td>
<td>3.36</td>
<td>0.07</td>
</tr>
<tr>
<td>Residual</td>
<td>0.28</td>
<td>7</td>
<td>0.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>0.94</td>
<td>12</td>
<td>0.08</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23 cases were processed 10 cases (43.5%) were missing

---

Appendix H, page 2 of 5
### Analysis of Variance

Mean mean general information over study - ESRF father

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>0.63</td>
<td>5</td>
<td>0.13</td>
<td>0.7</td>
<td>0.63</td>
</tr>
<tr>
<td>time since diagnosis band</td>
<td>0.52</td>
<td>3</td>
<td>0.17</td>
<td>0.98</td>
<td>0.45</td>
</tr>
<tr>
<td>age band</td>
<td>0.31</td>
<td>2</td>
<td>0.15</td>
<td>0.87</td>
<td>0.46</td>
</tr>
<tr>
<td>Explained</td>
<td>0.63</td>
<td>5</td>
<td>0.13</td>
<td>0.71</td>
<td>0.63</td>
</tr>
<tr>
<td>Residual</td>
<td>1.24</td>
<td>7</td>
<td>0.18</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1.87</strong></td>
<td><strong>12</strong></td>
<td><strong>0.16</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

26 cases were processed 13 cases (50.0%) were missing

### Analysis of Variance

Mean mean general information over study - ESRF mother

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>1.40</td>
<td>5</td>
<td>0.28</td>
<td>1.21</td>
<td>0.36</td>
</tr>
<tr>
<td>time since diagnosis band</td>
<td>1.17</td>
<td>3</td>
<td>0.39</td>
<td>1.67</td>
<td>0.22</td>
</tr>
<tr>
<td>age band</td>
<td>0.7</td>
<td>2</td>
<td>0.35</td>
<td>1.50</td>
<td>0.26</td>
</tr>
<tr>
<td>Explained</td>
<td>1.40</td>
<td>5</td>
<td>0.28</td>
<td>1.21</td>
<td>0.36</td>
</tr>
<tr>
<td>Residual</td>
<td>3.25</td>
<td>14</td>
<td>0.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>4.65</strong></td>
<td><strong>19</strong></td>
<td><strong>0.25</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

26 cases were processed
### Analysis of Variance

Mean mean general info over study - IDDM mother

<table>
<thead>
<tr>
<th>Time since diagnosis band</th>
<th>Unique sums of squares. All effects entered simultaneously</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Source of variation</td>
</tr>
<tr>
<td>Main Effects</td>
<td>time since diagnosis band</td>
</tr>
<tr>
<td></td>
<td>ageband</td>
</tr>
<tr>
<td>Explained</td>
<td>time since diagnosis band</td>
</tr>
<tr>
<td></td>
<td>ageband</td>
</tr>
<tr>
<td>Residual</td>
<td>time since diagnosis band</td>
</tr>
<tr>
<td></td>
<td>ageband</td>
</tr>
<tr>
<td>Total</td>
<td>time since diagnosis band</td>
</tr>
<tr>
<td></td>
<td>ageband</td>
</tr>
</tbody>
</table>

23 cases were processed. 5 cases (21.7%) were missing due to empty cells or a singular matrix, higher order interactions have been suppressed.

### Post hoc analysis (p 178) One Way Analysis Of Variance

Mean mean general info over study - IDDM mother

<table>
<thead>
<tr>
<th>Variable MMGINFOM mean mean general info over study mother by Variable TDIADBAN time since diagnosis band</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
</tr>
<tr>
<td>Between Groups</td>
</tr>
<tr>
<td>Within groups</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Post hoc test

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

\[
\text{MEAN}(j)-\text{MEAN}(l) \geq 3.5162 \times \text{RANGE} \times \sqrt{\frac{1}{N(l)} + \frac{1}{N(j)}}
\]

(*) indicates significant differences which are shown in the lower triangle.
Analysis of Variance

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>0.08</td>
<td>1</td>
<td>0.08</td>
<td>0.41</td>
<td>0.53</td>
</tr>
<tr>
<td>Careband</td>
<td>0.04</td>
<td>1</td>
<td>0.04</td>
<td>0.18</td>
<td>0.67</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>0.09</td>
<td>1</td>
<td>0.09</td>
<td>0.46</td>
<td>0.50</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>0.08</td>
<td>3</td>
<td>0.03</td>
<td>0.14</td>
<td>0.94</td>
</tr>
<tr>
<td>group / careband</td>
<td>0.03</td>
<td>1</td>
<td>0.34</td>
<td>0.17</td>
<td>0.68</td>
</tr>
<tr>
<td>group / sex of parent</td>
<td>0.01</td>
<td>1</td>
<td>0.01</td>
<td>0.01</td>
<td>0.99</td>
</tr>
<tr>
<td>careband / sex of parent</td>
<td>0.04</td>
<td>1</td>
<td>0.04</td>
<td>0.20</td>
<td>0.66</td>
</tr>
<tr>
<td>3-way interactions</td>
<td>0.08</td>
<td>1</td>
<td>0.08</td>
<td>0.42</td>
<td>0.52</td>
</tr>
<tr>
<td>group / careband / sex of parent</td>
<td>0.08</td>
<td>1</td>
<td>0.08</td>
<td>0.42</td>
<td>0.52</td>
</tr>
<tr>
<td>Explained</td>
<td>0.37</td>
<td>7</td>
<td>0.05</td>
<td>0.27</td>
<td>0.96</td>
</tr>
<tr>
<td>Residual</td>
<td>12.39</td>
<td>63</td>
<td>0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>12.76</td>
<td>70</td>
<td>0.18</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed 27 cases (27.6%) were missing
Appendix J

Complete ANOVA tables for results discussed in Chapter Six. Tables are arranged in the order of the results section and each is preceded by the number of the page where the results were reported.
### Analysis of Variance

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>136.63</td>
<td>3</td>
<td>45.54</td>
<td>0.89</td>
<td>0.45</td>
</tr>
<tr>
<td>Sex</td>
<td>60.27</td>
<td>2</td>
<td>30.14</td>
<td>0.59</td>
<td>0.56</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>64.92</td>
<td>1</td>
<td>64.92</td>
<td>1.27</td>
<td>0.26</td>
</tr>
<tr>
<td>Group / Sex</td>
<td>16.47</td>
<td>2</td>
<td>8.23</td>
<td>0.16</td>
<td>0.85</td>
</tr>
<tr>
<td>Explained</td>
<td>213.36</td>
<td>5</td>
<td>42.67</td>
<td>0.83</td>
<td>0.53</td>
</tr>
<tr>
<td>Residual</td>
<td>10256.87</td>
<td>200</td>
<td>51.28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10470.23</td>
<td>205</td>
<td>51.07</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

206 cases were processed 0 cases (0%) were missing

### Analysis of Variance

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>252.23</td>
<td>3</td>
<td>84.07</td>
<td>1.14</td>
<td>0.33</td>
</tr>
<tr>
<td>Sex</td>
<td>128.72</td>
<td>2</td>
<td>64.37</td>
<td>0.874</td>
<td>0.42</td>
</tr>
<tr>
<td>2-way interactions</td>
<td>110.78</td>
<td>1</td>
<td>110.78</td>
<td>1.50</td>
<td>0.22</td>
</tr>
<tr>
<td>Group / Sex</td>
<td>42.34</td>
<td>2</td>
<td>21.17</td>
<td>0.287</td>
<td>0.75</td>
</tr>
<tr>
<td>Explained</td>
<td>387.54</td>
<td>5</td>
<td>77.51</td>
<td>1.05</td>
<td>0.39</td>
</tr>
<tr>
<td>Residual</td>
<td>14804.64</td>
<td>201</td>
<td>73.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>15192.18</td>
<td>206</td>
<td>73.75</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

208 cases were processed 1 case (0.5%) was missing
### Analysis of Variance

**Anxiety**

*by Group and Sex*

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>347.69</td>
<td>3</td>
<td>115.90</td>
<td>9.09</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Group</td>
<td>99.54</td>
<td>2</td>
<td>49.77</td>
<td>3.91</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td>241.61</td>
<td>1</td>
<td>241.61</td>
<td>18.96</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>16.43</td>
<td>2</td>
<td>8.22</td>
<td>.645</td>
<td>0.53</td>
</tr>
<tr>
<td>Group Sex</td>
<td>16.43</td>
<td>2</td>
<td>8.22</td>
<td>.645</td>
<td>0.53</td>
</tr>
<tr>
<td>Explained</td>
<td>379.46</td>
<td>5</td>
<td>75.89</td>
<td>5.96</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Residual</td>
<td>1835.13</td>
<td>144</td>
<td>12.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2214.59</td>
<td>149</td>
<td>14.86</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

152 cases were processed 2 cases were missing (1.3%) were missing

(For post hoc analysis, p249)

### One Way Analysis Of Variance

**Anxiety**

*by Group*

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of squares</th>
<th>Mean Squares</th>
<th>F Ratio</th>
<th>F probability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>104.23</td>
<td>52.12</td>
<td>3.63</td>
<td>0.03</td>
</tr>
<tr>
<td>Within groups</td>
<td>147</td>
<td>2110.36</td>
<td>14.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>149</td>
<td>2214.59</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Post hoc test**

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

\[ \text{MEAN}(j) - \text{MEAN}(l) \geq 3.5162 \times \text{RANGE} \times \sqrt{\frac{1}{N(l)} + \frac{1}{N(j)}} \]

(*) indicates significant differences which are shown in the lower triangle

<table>
<thead>
<tr>
<th>Mean</th>
<th>Group</th>
<th>Control</th>
<th>Renal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.35</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.10</td>
<td>Diabetic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.35</td>
<td>Renal</td>
<td></td>
<td></td>
<td>*</td>
</tr>
</tbody>
</table>
## Analysis of Variance

### Depression by Group Sex

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>102.50</td>
<td>3</td>
<td>34.17</td>
<td>4.46</td>
<td>0.005</td>
</tr>
<tr>
<td>Group</td>
<td>81.61</td>
<td>2</td>
<td>40.80</td>
<td>5.33</td>
<td>0.006</td>
</tr>
<tr>
<td>Sex</td>
<td>19.34</td>
<td>1</td>
<td>19.34</td>
<td>2.52</td>
<td>0.11</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>3.27</td>
<td>2</td>
<td>1.63</td>
<td>0.21</td>
<td>0.81</td>
</tr>
<tr>
<td>Group / Sex</td>
<td>3.27</td>
<td>2</td>
<td>1.63</td>
<td>0.21</td>
<td>0.81</td>
</tr>
<tr>
<td>Explained</td>
<td>108.23</td>
<td>5</td>
<td>21.66</td>
<td>2.83</td>
<td>0.02</td>
</tr>
<tr>
<td>Residual</td>
<td>1103.23</td>
<td>144</td>
<td>7.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1211.50</td>
<td>149</td>
<td>8.13</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

152 cases were processed 2 cases (1.3%) were missing

(For post hoc analysis) One Way Analysis Of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Sum of squares</th>
<th>Mean Squares</th>
<th>F Ratio</th>
<th>F Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>87.33</td>
<td>43.66</td>
<td>5.71</td>
<td>0.004</td>
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<tr>
<td>Within groups</td>
<td>147</td>
<td>1124.17</td>
<td>7.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>149</td>
<td>1211.50</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Post hoc test

Multiple range tests: LSD test with significance level 0.05, the difference between two means is significant if

\[
\text{MEAN}(j) - \text{MEAN}(i) \geq 3.5162 \times \sqrt{\frac{1}{N(i)} + \frac{1}{N(j)}}
\]

(*) indicates significant differences which are shown in the lower triangle

<table>
<thead>
<tr>
<th>Mean</th>
<th>Group</th>
<th>Control</th>
<th>Renal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.52</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.49</td>
<td>Diabetic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.33</td>
<td>Renal</td>
<td>*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Analysis of Variance

### Mean PSSI0 score over study by Group Sex of Parent

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>48.90</td>
<td>2</td>
<td>24.45</td>
<td>0.90</td>
<td>0.41</td>
</tr>
<tr>
<td>Sex of Parent</td>
<td>10.48</td>
<td>1</td>
<td>10.48</td>
<td>0.38</td>
<td>0.54</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>37.03</td>
<td>1</td>
<td>37.03</td>
<td>1.36</td>
<td>0.25</td>
</tr>
<tr>
<td>Group Sex of parent</td>
<td>2.48</td>
<td>1</td>
<td>2.48</td>
<td>0.09</td>
<td>0.76</td>
</tr>
<tr>
<td>Explained</td>
<td>53.51</td>
<td>3</td>
<td>17.84</td>
<td>0.65</td>
<td>0.58</td>
</tr>
<tr>
<td>Residual</td>
<td>2154.43</td>
<td>79</td>
<td>27.27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2207.94</td>
<td>82</td>
<td>26.93</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed 15 cases (15.3%) were missing

## Analysis of Variance

### Mean Anxiety score over study by Group Sex of Parent

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>91.08</td>
<td>2</td>
<td>45.54</td>
<td>4.01</td>
<td>0.02</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>5.22</td>
<td>1</td>
<td>5.22</td>
<td>0.46</td>
<td>0.5</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>84.32</td>
<td>1</td>
<td>84.32</td>
<td>7.42</td>
<td>0.008</td>
</tr>
<tr>
<td>Group Sex of parent</td>
<td>11.52</td>
<td>1</td>
<td>11.52</td>
<td>1.01</td>
<td>0.32</td>
</tr>
<tr>
<td>Explained</td>
<td>105.96</td>
<td>3</td>
<td>35.32</td>
<td>3.11</td>
<td>0.03</td>
</tr>
<tr>
<td>Residual</td>
<td>898.13</td>
<td>79</td>
<td>11.37</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
<td>10004.08</td>
<td>82</td>
<td>12.25</td>
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<td></td>
</tr>
</tbody>
</table>

98 cases were processed 15 cases (15.3%) were missing
### Analysis of Variance

Mean depression score over study by Group and Sex of Parent

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>12.40</td>
<td>2</td>
<td>6.20</td>
<td>0.8</td>
<td>0.46</td>
</tr>
<tr>
<td>Group</td>
<td>3.79</td>
<td>1</td>
<td>3.79</td>
<td>0.49</td>
<td>0.49</td>
</tr>
<tr>
<td>Sex of Parent</td>
<td>8.22</td>
<td>1</td>
<td>8.22</td>
<td>1.05</td>
<td>0.31</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>1.39</td>
<td>1</td>
<td>1.39</td>
<td>0.18</td>
<td>0.67</td>
</tr>
<tr>
<td>Group</td>
<td>1.39</td>
<td>1</td>
<td>1.39</td>
<td>0.18</td>
<td>0.67</td>
</tr>
<tr>
<td>Explained</td>
<td>13.15</td>
<td>3</td>
<td>4.38</td>
<td>0.56</td>
<td>0.64</td>
</tr>
<tr>
<td>Residual</td>
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<td>79</td>
<td>7.80</td>
<td>7.67</td>
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</tr>
<tr>
<td>Total</td>
<td>628.94</td>
<td>82</td>
<td>7.67</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed 15 cases (15.3%) were missing

---

### Analysis of Variance

Mean PSSI0 score over study by Careband and Group

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>73.08</td>
<td>3</td>
<td>24.36</td>
<td>1.09</td>
<td>0.36</td>
</tr>
<tr>
<td>Careband</td>
<td>5.59</td>
<td>1</td>
<td>5.59</td>
<td>0.25</td>
<td>0.62</td>
</tr>
<tr>
<td>Group</td>
<td>1.51</td>
<td>1</td>
<td>1.51</td>
<td>0.07</td>
<td>0.79</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>62.61</td>
<td>1</td>
<td>62.61</td>
<td>2.79</td>
<td>0.1</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>10.21</td>
<td>3</td>
<td>3.40</td>
<td>0.15</td>
<td>0.93</td>
</tr>
<tr>
<td>Careband / Group</td>
<td>9.54</td>
<td>1</td>
<td>9.54</td>
<td>0.43</td>
<td>0.52</td>
</tr>
<tr>
<td>Careband / Sex of parent</td>
<td>0.13</td>
<td>1</td>
<td>.131</td>
<td>0.006</td>
<td>0.94</td>
</tr>
<tr>
<td>Group / Sex of parent</td>
<td>0.05</td>
<td>1</td>
<td>.051</td>
<td>0.002</td>
<td>0.96</td>
</tr>
<tr>
<td>3-way interaction</td>
<td>10.68</td>
<td>1</td>
<td>10.68</td>
<td>0.48</td>
<td>0.49</td>
</tr>
<tr>
<td>Careband / Group / Sex of parent</td>
<td>10.68</td>
<td>1</td>
<td>10.68</td>
<td>0.48</td>
<td>0.49</td>
</tr>
<tr>
<td>Explained</td>
<td>106.71</td>
<td>7</td>
<td>15.24</td>
<td>0.68</td>
<td>0.69</td>
</tr>
<tr>
<td>Residual</td>
<td>1414.39</td>
<td>63</td>
<td>22.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1521.10</td>
<td>70</td>
<td>21.73</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

98 cases were processed 27 cases (27.6%) were missing

---

Appendix J, page 6 of 7
### Analysis of Variance

#### Mean Anxiety score over study by Careband Group Sex of parent

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>147.57</td>
<td>3</td>
<td>49.19</td>
<td>4.38</td>
<td>0.007</td>
</tr>
<tr>
<td>Careband</td>
<td>50.14</td>
<td>1</td>
<td>50.14</td>
<td>4.46</td>
<td>0.04</td>
</tr>
<tr>
<td>Group</td>
<td>0.028</td>
<td>1</td>
<td>0.03</td>
<td>0</td>
<td>0.96</td>
</tr>
<tr>
<td>Sex of parent</td>
<td>83.02</td>
<td>1</td>
<td>83.02</td>
<td>7.38</td>
<td>0.008</td>
</tr>
<tr>
<td>2-way interaction</td>
<td>22.99</td>
<td>3</td>
<td>0.77</td>
<td>0.68</td>
<td>0.57</td>
</tr>
<tr>
<td>Careband / Group</td>
<td>12.56</td>
<td>1</td>
<td>12.56</td>
<td>1.12</td>
<td>0.29</td>
</tr>
<tr>
<td>Careband / Sex of parent</td>
<td>0.13</td>
<td>1</td>
<td>0.13</td>
<td>0.01</td>
<td>0.92</td>
</tr>
<tr>
<td>Group / Sex of parent</td>
<td>11.97</td>
<td>1</td>
<td>11.97</td>
<td>1.07</td>
<td>0.31</td>
</tr>
<tr>
<td>3-way interactions</td>
<td>12.77</td>
<td>1</td>
<td>12.77</td>
<td>1.14</td>
<td>0.29</td>
</tr>
<tr>
<td>Careband / Group / Sex of parent</td>
<td>12.77</td>
<td>1</td>
<td>12.77</td>
<td>1.14</td>
<td>0.29</td>
</tr>
</tbody>
</table>

Explained                    | 185.63         | 7  | 26.52       | 2.40 | 0.03     |
Residual                     | 708.28         | 63 | 11.24       |      |          |
Total                        | 893.90         | 70 | 12.77       |      |          |

98 cases were processed

### Analysis of Variance

#### Mean Depression score over study by Careband Group Sex of parent

Unique sums of squares. All effects entered simultaneously

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main Effects</td>
<td>22.47</td>
<td>3</td>
<td>7.49</td>
<td>0.87</td>
<td>0.46</td>
</tr>
<tr>
<td>Careband</td>
<td>3.19</td>
<td>1</td>
<td>3.19</td>
<td>0.37</td>
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<td>0.78</td>
</tr>
<tr>
<td>Careband / Group</td>
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<td>1.54</td>
<td>0.18</td>
<td>0.67</td>
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<tr>
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</tr>
<tr>
<td>3-way interaction</td>
<td>1.62</td>
<td>1</td>
<td>1.62</td>
<td>0.19</td>
<td>0.67</td>
</tr>
<tr>
<td>Careband / Group / Sex of parent</td>
<td>1.62</td>
<td>1</td>
<td>1.62</td>
<td>0.19</td>
<td>0.67</td>
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</table>

Explained                    | 29.08          | 7  | 4.15        |      |          |
Residual                     | 541.28         | 63 | 8.60        |      |          |
Total                        | 570.35         | 70 | 8.15        |      |          |

98 cases were processed
Appendix K

Mann-Whitney U test of socioeconomic data for high and low response groups.
### Mothers age at June 1992 by mothers response band

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th>Low response band (&lt;66%)</th>
<th>High response band (&gt;66%)</th>
<th>Total</th>
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</thead>
<tbody>
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<td></td>
<td></td>
</tr>
<tr>
<td>U</td>
<td>W</td>
<td>Exact 2-tailed p</td>
<td>Z</td>
<td>2-tailed p</td>
</tr>
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<td>164.0</td>
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### Subject child’s age at June 1992 by mothers response band

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<td>U</td>
<td>W</td>
<td>Z</td>
<td>2-tailed p</td>
<td></td>
</tr>
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<td>230.5</td>
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### Number of children in the family by mothers response band

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<th>High response band (&gt;66%)</th>
<th>Total</th>
</tr>
</thead>
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<tr>
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<tr>
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## Level of highest education by mothers response band

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<th>High response band (&gt;66%)</th>
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<tr>
<td>21.38</td>
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Corrected for ties

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<th>2-tailed p</th>
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## Family finances by mothers response band

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## Highest family occupation by mothers response band

<table>
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<th>High response band (&gt;66%)</th>
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<tr>
<td>19.38</td>
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Corrected for ties

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### Mann-Whitney U - Wilcoxon Rank Sum W Test

#### Fathers age at June 1992 by fathers response band

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<td>High response band (&gt;66%)</td>
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Corrected for ties

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<th>2-tailed p</th>
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<td>196.0</td>
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#### Subject child's age at June 1992 by fathers response band

<table>
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<th>Cases</th>
<th>Description</th>
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</thead>
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Corrected for ties

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#### Number of children in the family by fathers response band

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<th>Description</th>
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</thead>
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<tr>
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Corrected for ties

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<th>Exact 2-tailed p</th>
<th>Z</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>101.0</td>
<td>393.0</td>
<td>0.79</td>
<td>-0.32</td>
<td>0.75</td>
</tr>
</tbody>
</table>
### Mann-Whitney U - Wilcoxon Rank Sum W Test

**Level of highest education by fathers response band**

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th>Low response band (&lt;66%)</th>
<th>High response band (&gt;66%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
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<td>16.77</td>
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Corrected for ties

<table>
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<th>2-tailed p</th>
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### Family finances by fathers response band

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<tr>
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Corrected for ties

<table>
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<th>W</th>
<th>Z</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>95.0</td>
<td>230.0</td>
<td>0.39</td>
<td>0.23</td>
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</table>

### Highest family occupation by fathers response band

<table>
<thead>
<tr>
<th>Mean Rank</th>
<th>Cases</th>
<th>Low response band (&lt;66%)</th>
<th>High response band (&gt;66%)</th>
<th>Total</th>
</tr>
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<tr>
<td>14.29</td>
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Corrected for ties

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<th>Z</th>
<th>2-tailed p</th>
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</thead>
<tbody>
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<td>93.5</td>
<td>171.5</td>
<td>0.90</td>
<td>0.90</td>
</tr>
</tbody>
</table>
Appendix L

Leaflets developed to address some of the issues revealed by the information needs questionnaire and the parents support group transcripts. These four leaflets are now available locally in clinic and nationally from the British Kidney Patient Association.
school teacher or school nurse may be willing to give them. Members of the Renal Team will visit your child’s school to discuss any special requirements or arrangements with the teachers.

d) Clinic Appointments — Clinic appointments while on dialysis will usually take up one day a month if travelling long distances. Clinic appointments before dialysis will be less frequent but after a transplant can be quite often for a while depending upon how well the kidney functions. Appointments should not affect the overall education level attained.

Q How much time is my child likely to need off school?

School attendance will be affected by the time needed for starting dialysis and operations such as kidney transplants. If your child needs to be at home for a while (for example if they are on a lot of medications following transplant), a home tutor can often be arranged through your local education authority. All children who are well enough during a hospital admission receive education from the teachers of the hospital school.

Q How can I help my child cope with any teasing they might experience?

Children who have anything different about them are often teased. Those children who are smaller or are showing side effects of medications (such as weight gain or extra hair growth) may be subjected to teasing or even bullying. The best way to reduce this is by good communication. Encourage your child to tell you how their day at school has been. This gives them a chance to tell you if they are having problems. If there are difficulties, you could go together to talk with the teacher. They often have effective ways to reduce bullying. The teacher, parent, child or member of the Renal Team could even talk to the class as a whole and explain about renal failure and its effects. Teasing often occurs because the other children simply do not understand enough.

If the problems persist, talk it over with the Clinical Psychologist or social worker at the hospital who may have some further suggestions on how the problems may be tackled.

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SCHOOL AND SPORT FOR CHILDREN ON CHRONIC DIALYSIS AND FOLLOWING TRANSPLANTATION

common questions

Most questions require answering on an individual basis, but some of the general issues are mentioned and discussed in this leaflet.

Always go to your Nephrologist (Kidney Specialist) with further questions or worries.

Other team members will also be able to help.
Families often have questions about sport for children with renal failure. Here we mention the most common ones and try to provide a little information that may help. Remember that this is general advice and does not overrule anything specific told to you by the doctors.

**Q Can my child go swimming?**

Swimming is not recommended for children who have a dialysis catheter in place (either peritoneal or haemodialysis). This is because of an increased risk of infection when the exit site is damp. However, please discuss this with your primary nurse as swimming may be allowed on special occasions such as holidays. After a transplant, swimming is encouraged once the wound has fully healed and all tubes have been removed.

If your child does not want to be left out of school, they can paddle in shallow water during swimming lessons.

**Q Are there any sports to avoid?**

Sport and participation in P.E. and games at school is to be encouraged. It helps keep children fit and also provides a lot of fun and friends. The sports which we discourage are those which may dislodge a dialysis catheter or put a transplanted kidney at risk of a direct blow. Such sports include karate/martial arts and rugby.

**Q What if my child is too small or too tired to really succeed at sport?**

Some children are smaller and may be a little tired when they have renal failure. These children can become disheartened or upset if they never seem to win. It is important that you emphasise the other things that your child is good at and also that they are encouraged to do sport that is less physically demanding. Children themselves know their own capabilities.

**Q How will Chronic Renal Failure affect my child’s education?**

Very little we hope since once dialysis begins your child may have more energy and be able to concentrate better. This should help them to cope with full time education.

Today many children receive home peritoneal dialysis. This type of dialysis should have minimal affects upon the school day. Haemodialysis involves your child attending hospital for three whole mornings or afternoons each week until transplant. If this type of dialysis is required your child can do school work whilst on dialysis. On non-dialysis days your child will attend their own school.

**Q How will treatments interrupt my child’s schooling?**

There are 4 main areas to consider:

a) **Dialysis** – CCPD (continuous cycling peritoneal dialysis) is done overnight so your child can attend school as normal. If your child is on CAPD (continuous ambulatory peritoneal dialysis) then in some cases, you may need to carry out a bag change in the lunch break. Most schools will provide a clean, private room for this if it is easier than your child returning home. However this may shorten their playtime with friends. After school activities also coincide with CAPD time, but older children can often do their own bag changes to fit in with their social activities.

b) **Diet** – A healthy eating diet is usually recommended. Some children may require a modified diet but restrictions are kept to a minimum whenever possible. Most schools are happy to cater for individual needs or packed lunches prepared at home may be a good idea. Talk to the dietitian if you would like some advice.

c) **Medication** – If your child is too young to take his or her own medicines, the
Give the doses as prescribed and at fairly even intervals over 24 hours.
Always finish the course as prescribed even if the infection appears to clear up quickly.

All antibiotics can have side-effects but they rarely occur. These can include: rash, diarrhoea, nausea, sickness. If these problems occur please contact the doctor.

Please note that certain antibiotics are prescribed with caution in patients on Ciclosporin after a renal transplant. eg.

Erythromycin
Trimethoprim
Acyclovir – this is given to patients on immunosuppressive drugs who are in close contact with chickenpox.

WHAT IF MY CHILD VOMITS BACK MEDICATIONS?

If your child vomits within an hour of taking the medications, then these need to be repeated.

If your child has vomiting diarrhoea while taking immunosuppressives for the kidney transplant, the family need to INFORM the hospital. The medications may need to be given through a vein until the vomiting and diarrhoea stops.

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MEDICINES TO IMPROVE NUTRITION AND GROWTH

Alfacalcidol (1 Alpha) – the active form of vitamin D – needed for good bone growth.
Calcichew, Titanalac or Settlers Tums (calcium carbonate) – medicines used to reduce the uptake of phosphate from food. Ferrous sulphate (oral paediatric solution) or Sytron – iron supplements to treat anaemia.
Ketovite and Forceval – vitamin and/or mineral supplements.
Sodium Bicarbonate (solution or tablets) – used to treat acidosis.

BLOOD PRESSURE MEDICINES

These medications are used to lower/raise blood pressure. They work either on the kidneys or on the blood vessels.
Frusemide, Spironolactone and Metolazone – are diuretics which increase urine output. Enalapril and Captopril – known as ACE inhibitors (act on hormone from the kidney) Nifedipine – a vasodilator (dilates blood vessels).
Atenolol and Propanolol – known as beta blockers (these slow heart rate down and reduce blood pressure).

IMMUNOSUPPRESSIVES

Immunosuppressives are used to treat severe inflammation (swelling) of the kidney but mainly to prevent rejection of a transplanted kidney. They are very powerful drugs and are given in large doses at first and then gradually reduced with time.

Following a kidney transplant, immunosuppressive medicines are taken for as long as the kidney functions, but the dose is usually reduced with time.

Prednisolone is a corticosteroid (not an anabolic steroid such as those abused by some athletes). It may cause some initial weight gain at first and some fattening of the face. This should improve after the steroid drugs are reduced with time.

Azathioprine – usually taken as a single evening dose. It may also decrease resistance to infection.

Cyclosporin – may cause an increase in hair growth and some enlargement of the gums. If hair growth is of concern, please discuss with your primary nurse or doctor as various treatments are available. The blood levels of Cyclosporin will be measured at clinic visits.

MISSED DOSES OF IMMUNOSUPPRESSIVES PUT THE DONOR KIDNEY AT RISK, although a few hours delay to the dose is not crucial.

IMMUNISATIONS/VACCINES

If immunosuppressives are being taken then all live vaccines such as BCG (for tuberculosis), live polio and rubella should NOT be given. Vaccines made from dead bacteria or viruses may be acceptable but always check with the Nephrologist first.

ANTIBIOTICS

Antibiotics are a group of medicines which are used either to fight an infection or to stop one developing.

Some infections are more sensitive to one antibiotic than another. Often the doctor will choose an antibiotic most likely to be effective against the suspected infection, but may change the antibiotic when further information is available.

There are certain guidelines to follow when taking antibiotics.
The transplant co-ordinator is always available if you wish to discuss aspects of the donor side of transplantation.

The Future for Children with Chronic Renal Failure

Common Questions

There are many areas of concern for families of children with Chronic Renal Failure. Some of these are concerned with what the future might hold.

Most questions require answering on an individual basis, but some of the general concerns are mentioned and discussed in this leaflet.

Always go to your Nephrologist with further questions or worries.

Other members of the Renal Team such as the Social Worker will also be able to help.
Q How will my child develop physically?
Children treated for renal failure nowadays have generally better nutrition and growth. Effective dialysis and successful transplantation now mean that children stand a very good chance of reaching a reasonable adult height.

Q What about sexual development?
Puberty may be delayed and longer in older children with Chronic Renal Failure.

Q Will renal failure effect whether my child will be able to have their own children?
Women who have had a successful transplant have gone on to have healthy babies. Men have become fathers.

Q Contraception. Can my daughter take the pill when it is appropriate?
The pill can have complications with blood pressure and clotting, and each patient needs to be carefully assessed. The pill is NOT generally advised, but it is possible to prescribe it for some patients.

Q Are there long term complications of renal failure?
The answer to this must be that there can be. It is difficult to predict the very long term outcome of children with renal failure.

In the past many complications reported in renal patients came about when their treatment had been inadequate, but now that it has advanced, it is likely that complications will be greatly reduced.

There can be some effects from long term use of some of the drugs, especially the powerful immunosuppressives. For example skin can be more sensitive to the harmful rays of the sun. This can be reduced by the use of a sun block which can be obtained on prescription. A sun hat is also recommended in very hot weather.

Q How long will a kidney transplant work for my child?
It is impossible to predict accurately how long any one transplanted kidney is likely to continue working. Some patients still have kidney transplants working after 20 years.

The figures today suggest that around 80% of cadaveric kidneys transplanted are working after two years. If the kidney was from a live related donor then the figures are even better with 90% after 2 years.

Certain factors effect the survival of the kidney and some important rules for increasing the life of a transplanted kidney include:
- Give the immunosuppressive drugs as prescribed. NEVER miss doses as this puts the kidney at risk.
- Always attend clinic. The routine blood tests of immunosuppressive drug levels and of the kidney function are vital. The Nephrologist often needs to alter the treatment to prevent a rejection episode.

The older child should remember:
- Attend clinic.
- Take your medicines. If you don’t you might risk losing your kidney.
- Do NOT smoke. Smoking effects the small blood vessels in the kidney.
- Alcohol intake in adults should always be no more than moderate.

Parents worry how to answer their child’s question “Where does the kidney come from?”

If you are uncertain how to answer this then please discuss it with the team social worker, psychologist or other team members.
USES OF TESTS

The Nephrologist uses the results of examination in the clinic along with urine and blood tests to see how well the kidneys are working.

If you are not receiving the amount of information that you would like about test results, then please discuss this with your nephrologist or clinic nurse.

CHRONIC RENAL FAILURE

Children with Chronic Renal Failure often undergo tests to check their kidney function. This leaflet explains a little about each test.

Always go to your Nephrologist (Kidney Specialist) if you have further questions or worries.

Other members of the Renal Team will also be able to help.
CLINICAL TESTS

**Height and weight** are checked regularly to check growth.

**Blood pressure** is checked regularly as it may be raised in kidney failure. Drug treatments may be used to help control blood pressure.

URINALYSIS

Testing the urine for blood, protein and other substances can tell us a great deal about your child’s kidney function. A sample of urine may be required for culture to see if your child has a urine infection.

BLOOD TESTS

**Urea and Electrolyte levels (U and E’s)**

**Urea and Creatinine** are both waste products of the body. They are usually removed from the blood by the kidneys and passed into the urine. By looking at the level of urea and creatinine in the blood the Nephrologist gains more information about how well the kidneys are working.

**Electrolytes** such as potassium and sodium are excreted and balanced by the kidneys. In renal failure these electrolytes may become imbalanced, which can sometimes be a serious problem.

Adjustments to diet or dialysis (if your child is receiving this treatment) may be made if the levels are too high or too low.

**Calcium and Phosphate** are measured as they are involved in the growth of bones and affected by diet and drug treatments.

**Haemoglobin Levels (Hb)** are monitored to detect anaemia. Anaemia is common in renal failure as the kidneys release hormones involved in the production of red cells that carry the haemoglobin and oxygen around the body.

**Iron and vitamin levels** may also be monitored.

**Fat levels** in the blood may be tested in children who have problems with nephrotic syndrome. Your child needs to come to the clinic FASTED for this test (i.e. not having eaten for 12 hours and no breakfast). You will be told when this test is to be done.

HORMONE TESTS

**Parathyroid hormone (PTH)** is the one involved with good bone growth and may be measured 3 monthly prior to and whilst on dialysis.

**VIRAL TESTS**

Children with Chronic Renal Failure are usually tested for Hepatitis virus and others such as Cytomegalovirus (CMV) and chickenpox.

X-RAYS AND SCANS

**Bone X-rays** are carried out every 6 months to a year to monitor bone growth. It usually involves an x-ray of the wrist and hand.

**Ultrasound scans (US)** are carried out both in the x-ray department and on the ward. They require no needles and cause no pain. An ultrasound shows the outline and shape of the kidneys.

Some jelly like cream is placed on the front and back (over the kidneys) for this test. It may feel cold and is easily removed.

Special x-ray tests such as DMSA and Mag 3 are discussed in a separate leaflet.

**Micturating Cystourethrogram (MCUG)** is also discussed in a separate leaflet.
Appendix M

Checklist developed by Hulstijn-Dirkmaat and Damhuis (1994) to identify a selection of parents' concerns, information needs and the impact of illness.

Items

- Concern about the future
- Unexpected medical complications
- Distance home—hospital
- Family recreation
- Eating/feeding problems
- Admissions to hospital
- Uncertainty result transplantation
- Hygienic limitations
- Problems growth retardation
- Physical handicaps/limitations
- Uncertainty transplantation time
- Fear of peritonitis
- Visits outpatient clinic
- Late dialysis at 23:00
- Financial problems
- School absenteeism
- Waiting period transplantation
- To be available for transplantation
- Social isolation
- Frequency of changing the dialysate
- Behavioural problems
- Fixation on the disease
- Work absenteeism
- Changing rules, habits
- Problems with siblings
- Sustaining the treatment
- Lack of social contacts peers
- Problems household activities
- Coming to terms, acceptance
- Administering diet and medication
- Counselling and education
- Fluid restriction
- Drain into the abdomen
- Talks with the doctor
- Lack of information
- Responsibility for the treatment
- Responsibility diet and medication

*Concern about the future
  Medical 66.7
  Educational
  Social 25.6
  Occupational